Evaluating the effectiveness of innovations involving nurses for people in the community with chronic obstructive airways disease

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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Abbreviations used in this document

ACTRITE	Acute Chest Triage Rapid Intervention Team
ADL	activities of daily living
ARAS	Acute Respiratory Assessment Service
CDM	chronic disease management
CI	confidence interval
COPD	chronic obstructive pulmonary disease
DH	Department of Health
ED	early discharge scheme
FEV1	forced expiratory volume at 1 second
FVC	forced vital capacity
FEV1/FVC	ratio of forced expiratory volume at 1 second: forced vital capacity
GHQ	General Health Questionnaire
GP	General Practitioner
HaH	Hospital at Home scheme
HRQOL	Health related quality of life
ITT	intention-to-treat analysis
LOS	length of stay
LTOT	long term oxygen therapy
MRC	Medical Research Council
Mthly	monthly
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NIV	non-invasive ventilation
PCT	Primary care trust
QOL	quality of life
RCT	randomized controlled trial
RNS	Respiratory Nurse Specialist
SR	systematic review
SGRQ	St George's Respiratory Questionnaire
WTE	whole time equivalent

Executive Summary

This report describes an 'extended' systematic review of nurse innovations for patients with COPD normally living in the community and a survey of the current provision of respiratory nurse specialists (RNS) services for patients with Chronic Obstructive Pulmonary Disease (COPD) in England and Wales in April 2003.

The aim of the literature review was to locate and review systematically relevant quantitative and qualitative studies involving nurse services for people with COPD who normally live in the community. The aims of the survey were to map the current provision of specialist nurse service for patients living in the community with COPD in England and Wales, and to identify the type of provision.

We conducted a comprehensive literature search for English and Dutch language published articles including 19 electronic bibliographic databases. The methodological quality of the published reports of the included randomised controlled trials (RCTs) was assessed in two different ways, both of which record risk of bias, and these assessments were used to allocate a level of evidence score to each outcome reported by the individual studies.

The literature search identified nearly 7,000 citations including 168 potentially relevant articles. Following full text retrieval 40 papers remained eligible; of these 13 were randomised controlled trials and two were systematic reviews. For data extraction and synthesis we divided the studies into two distinct groups: chronic disease management type interventions for patients with COPD and interventions for acute exacerbations of COPD. No evaluations of specialist nurse led clinic interventions were identified.

We identified one Cochrane systematic review and seven published randomised controlled trials (RCTs) of chronic disease management nursing interventions for patients with COPD. All the RCT studies of chronic disease management nursing interventions had some methodological limitations. The chronic disease management interventions could be divided into brief (one month) and long term (one year). Most involved home visits by a respiratory nurse but in two studies it was not clear where follow up was carried out. The content of the home visits varied.

There is some evidence that for patients with moderate to severe COPD chronic disease management nursing interventions may not: reduce mortality; improve health related quality of life as determined by disease specific instruments; improve psychological well-being; reduce impairment and disability as determined by total Sickness Impact Profile scores; improve pulmonary function; or reduce all cause hospital admissions.

However, there is limited evidence arising from a single RCT that a nurse led home care programme involving quarterly home visits and monthly telephone calls may reduce hospital admissions and hospital costs at 12 months follow up among patients on long term oxygen therapy.

We identified several potential outcomes of the chronic disease management nurse interventions on which there is currently no, or very little, evidence; including patient self management skills, and coping with their disease.

We identified one Cochrane systematic review and six RCTs of nursing interventions for acute exacerbations of COPD. The aim of these studies was generally to explore the feasibility and safety of transferring hospital care to the community. All the RCTs had some methodological limitations, most of the studies had small sample sizes and none were designed to show true equivalence between the intervention and control groups. No study involved more than two centres so it is not certain that the benefits seen can be rolled out to the whole population. Some of the interventions for acute exacerbations involved early supported hospital discharge while in others patients could avoid hospital admission altogether. For all studies only around a quarter of patients presenting with an acute exacerbation of COPD were eligible and consented to participate. Generally the components and the intensity of the different interventions for acute exacerbations were similar. In all the interventions a respiratory nurse was the main health care provider. Most services operated on weekdays only and the number of whole time equivalent nurses in the team when reported was two or three.

There is reasonable evidence that among the selective patient populations that have been included in trials to date domiciliary interventions for acute care in COPD do not influence: mortality; pulmonary function; or hospital readmissions within the following three months.

There is very little, or no, evidence available on the effect on patients or their carers of domiciliary interventions for acute care in COPD around: health related quality of life; satisfaction with care; and psychological well-being.

Other non RCT quantitative studies were scarce and contributed very little to the review's findings. Only two qualitative studies were identified, both around chronic disease management, these appeared to be of poor quality and their results could not be confidently transferred to other situations. The additional search of Dutch language literature yielded only one relevant, published paper although we did identify three studies from The Netherlands which were in progress or awaiting publication. Some of which were evaluating interventions that have not previously been evaluated – clinic interventions

There is very little information in the published, 'grey' and unpublished literature on how to implement nurse innovations for COPD in the community.

We identified 234 specialist nurse led services in England and Wales for patients with COPD in the community from the survey. Current provision of specialist respiratory nurse services is scattered over England and Wales. There appears to be inequality in the provision of these services and many Primary Care Trusts do not have a nurse led service for patients with COPD in the community.

Most existing services are based in secondary care and are funded by recurrent monies form primary and/or secondary care. 14 per cent of services have some funding from non-recurrent or charitable monies.

The current provision of respiratory nurse specialist services for patients with COPD in the community in England and Wales appears to be dynamic with new services developing or changing while others are discontinued.

The type and content of the services identified in the survey varied greatly, but the majority involved chronic disease management schemes. It was notable that the types of service provided, and their components, were often very different from the services evaluated in the research literature. In particular there were many hybrid schemes (schemes providing both acute interventions and chronic disease management) and many schemes providing clinic care only.

Many of the chronic disease management type services currently available in England and Wales offer models of care which have not been robustly evaluated in COPD (i.e. have not been the subject of RCTs). However, unlike the chronic disease management type models which have been the subject of RCTs, many current services contain components which are evidence based such as the provision of pulmonary rehabilitation.

Consumers who gave feedback on an interim report of the review were generally supportive of the research reported in the RCTs. Most respondents felt that the studies were evaluating appropriate outcomes but several felt that it was also important to look at;

- the psychological benefits of treatment

- the effect on self management

- the effect on quality of life and

- the effect on carers.

Many of the consumers who responded were not happy about basing decisions on service provision on this sort of research. Among other things some felt that each individual patient's needs should be taken into account and that they needed better information and education about their disease.

Recommendations

Recommendations for service providers

Nurse led hospital at home or early discharge schemes for patients with COPD living in the community should be prioritised over the type of nurse led chronic disease management models that have been studied to date.

Hospital at home or early discharge schemes should include the following components common to most of the interventions which have been subjected to evaluation in RCTs;

- a package of care on discharge home including drugs, nebulisers and oxygen concentrators, as indicated

- patients to be seen at home within 24 hours of discharge

- home visits to include assessment of the patient

- the use of explicit care pathways

- arrangements for out-of-hours care (usually provided by existing services) and

- follow up under the scheme lasting at least seven days and probably longer.

Service providers should be aware that five of the six hospital at home or early discharge schemes that have been subjected to evaluation in randomised controlled trials

only operated on weekdays. Hospital at home or early discharge schemes that operate over weekends must be robustly evaluated.

There is very little evidence available at present to support the continuation of the *type* of chronic disease management models *that have been evaluated to date*. Existing services providing this sort of care should be robustly evaluated against the aims of the particular service. Alternatively, these services should consider adopting the characteristics of generic disease management programmes, or disease management programmes for other chronic conditions, which have been shown to be effective in well designed evaluations.

If any new, nurse led chronic disease management services for COPD patients living in the community are established they should be robustly evaluated against the aims of the particular service.

Novel service developments should be explored for the type of patients presenting with an acute exacerbation of COPD who were not considered eligible for, or did not wish to participate in, the early discharge or hospital at home schemes evaluated to date. (From our national survey we identified two, at present, unevaluated schemes for such patients.

1)supported discharge schemes that discharge patients home to nurse support later than a conventional 'early discharge' but discharge earlier than a conventional hospital stay for an acute exacerbation

2) community nurse unit schemes where a patient is admitted whose exacerbation does not require hospital admission but requires more monitoring than domiciliary nurse visits.)

Information on the successful implementation of new services for patients with COPD in the community should be disseminated. Keeping details on the implementation of new services for patients with COPD in the community should be standard practice and this information should be made easily available and actively disseminated to other health professionals and policy makers.

Recommendations for future research around COPD care

Multi-centre implementation research rolling out hospital at home/early discharge schemes to see if the benefits

demonstrated in single centres can be seen across many centres and in different populations is required.

The potential benefits in terms of reduced hospital admissions and emergency department visits with chronic disease management schemes in COPD patients receiving long term oxygen therapy should be explored further.

Studies should look at the effect of domiciliary interventions on other community health care services and on social services.

Health economic studies of hospital at home/early discharge schemes which include the costs carried by patients and carers are needed.

Researchers should consider including patients' health related quality of life and carers' quality of life as outcomes and should explore the effects of interventions on patients' and carers' psychological well being and coping. Wherever possible validated instruments suitable for patients with COPD and their carers should be used.

Researchers should use robust techniques to explore patient and carer satisfaction with services.

There is a need for qualitative research of high quality around these interventions.

For the benefit of future readers, researchers should document the components of interventions clearly in published reports on their work or in linked documents stored on the world wide web.

Recommendations for systematic reviewers

Conducting a survey of the existing provision of services in tandem with a systematic review of the effectiveness of different service models can be a very useful exercise and, where appropriate, should always be considered.

Methods need to be developed to identify the best ways of involving consumers in systematic reviews and consulting them about the findings. In particular, techniques should be developed to explain systematic reviews and communicate their findings to consumers or other lay audiences.

This review demonstrated the potential benefits of drawing on a broader range of evidence than conventional systematic reviews, however in practice in extending the review this way contributed little to our overall findings. Further work should be undertaken to determine whether the benefits of this approach outweigh the resources required to extend the scope of a review in this way.

Recommendations for research funders

Research comparing the effectiveness of generic verses single condition interventions in chronic disease management should be commissioned.

Research which unpicks whether generic interventions and/ or interventions which have been found to be effective in one chronic disease can be transferred with similar benefit to another chronic disease should be commissioned.

The Report

Section 1 Background and structure of review

1.1 Chronic disease as a driver for service development

Globally by 2020 chronic diseases will comprise four of the five leading causes of burden of disease (Lopez 1998). In England alone, there are now nearly 10 million people with a chronic disease (Donaldson, 2003). The steady increase in the prevalence and burden of chronic disease is challenging health services, whose focus has primarily been on providing acute management. The UK Department of Health (DH) estimates that 60 per cent of hospital bed days involve patients with chronic disease or its complications and that two thirds of patients admitted to hospital as a medical emergency are suffereing from a chronic disease or an exacerbation of a chronic disease (DH 2004a).

The increasing burden of chronic disease has provided the impetus to develop innovations in care. These have often involved a breakdown of the historic demarcations between health professionals' roles and/ or the division of services between primary and secondary care. Notable examples from North America include Evercare, the intensive case management of high risk older patients by nurse practitioners, and the Kaiser Permanente, a long established, non-profit making health maintainance organisation in California. The Evercare Demonstration Program was an intensive intervention involving nurse practitioners working with relatively small caseloads of frail, older people nursing home residents (Kane 2002). Evaluation suggested that the programme suceeded in substituting nursing home care for hospital care with resultant cost savings and no reduction in either the quality of care or patient satisfaction. The Evercare programme is currently being evaluated in several PCTs in the UK by the National Primary Care Research and Development Centre: (www.npcrdc.man.ac.uk/ResearchDetail.cfm?ID=131). The Kaiser Permanente appears to provide better care at a similar cost to the National Health Service (NHS) largely through a reduction in costly hospital bed days (Feachem 2002). This reduction in hospital bed days appears to be achieved, at least in part, through disease management

programmes and more home care. Again, key features of the Kaiser Permanente approach are being trialed in the UK (Modernisation Agency 2004).

In the UK the management of chronic disease, including innovations in the care of chronic disease, is now firmly on the national policy agenda and is a priority of the NHS Improvement Plan (DH 2004). The Plan embraces a series of DH/NHS initiatives including;

- the National Service Frameworks (DoH, 2002a), several of which aim to improve the management of selected chronic diseases

- intermediate care services which aim to build a bridge between hospital and home by helping people to recover and resume independent living more quickly (Secretary of State (SoS) for Health 2000)

- schemes to support patient self management, such as the Expert Patient Programme (SoS for Health 2000; 2001)

- the new General Medical Services (GMS) contract, many of the quality indicators relate to chronic disease management (NHS Confederation 2003)

- the redesign of roles and processes in primary care including the development of: practitioners with special interests (DH 2003); primary care nurses (DH 2002b); and community matrons; together with changes in prescribing regulations (Modernisation Agency 2004).

1.2 COPD

Chronic obstructive airways disease (COPD) is a common, slowly progressive respiratory disorder associated with high morbidity and mortality. The World Health Organisation (WHO) estimates that COPD is the fourth leading cause of death worldwide (National Heart Lung and Blood Institute 2001). The Global Burden of Disease Study estimated the fraction of mortality and disability attributable to major disease or injury. According to these projections, by 2020 COPD will be the fifth leading cause of life years lost from premature disability and mortality worldwide (in 1990 it ranked 12th) (Murray 1996).

In the UK more than 730,000 people are known to have COPD (Pauwels 2000), but this is likely to be an underestimate as patients are often not diagnosed until their condition has reached an advanced stage. In 1996-7 the NHS spent more that £818 million on COPD (NHLBI 2003). Exacerbations account for 40 per cent of total

spending on COPD (Davies 1998), and such exacerbations are one of the principal contributors to the winter pressure on hospital beds (Damiani 2002). In the UK, hospital admissions for COPD have increased steadily from 0.5 per cent of all admissions in 1991 to 1 per cent in 2001 - accounting for nearly a million hospital bed days per year (Lung & Asthma Information Agency 2003).

COPD is characterised by airways obstruction. In the National Institute for Clinical Excellence (NICE) Clinical Guidelines (2004) airway obstruction is defined as a reduced FEV1 (forced expiratory volume in 1 second) of less than 80 per cent of the predicted value for that individual and a reduced FEV1/FVC (forced vital capacity) ratio of less than 0.7. Most of the lung impairment is fixed, although some reversibility can be produced by bronchodilators or other therapy. Patients with COPD experience frequent sustained worsening of their COPD symptoms (in particular breathlessness, cough and sputum production) that require a change in usual treatment; these episodes are termed exacerbations (Rodriguez-Roisin 2000). The majority of exacerbations are treated at home or in primary care while patients with more severe COPD and more severe exacerbations are treated in hospital. Typically patients with moderate to severe COPD, as defined by the GOLD guidelines, experience between 2 to 4 exacerbations per year (Wilkinson, in press). Exacerbations may affect morbidity and mortality; recovery from them may be prolonged, for some beyond three months (Seemungal 2000), they contribute to the long term decline in lung function (Donaldson 2002) and are associated with worse health related quality of life (Seemungal 1998).

1.2.1 What helps?

There are no immediate prospects for the pharmacological reversal of lung impairment (Morgan 2003). Smoking cessation remains the most important intervention in modifying the course of the disease (Paggiaro 1998, NICE 2004). Bronchodilators are the main pharmacological treatment for the control of symptoms and pulmonary rehabilitation is effective in improving dyspnoea and fatigue and enhances patients' sense of control over their condition (Lacasse 2004).

The recent NICE guidelines on the management of patients with COPD in primary and secondary care (2004) identify

key priorities to implement in the management of COPD. These are;

- diagnosis

- smoking cessation

- effective inhaled therapy

- pulmonary rehabilitation

- use of non-invasive ventilation (NIV)

- the management of exacerbations (including reducing frequency and 'hospital at home' schemes) and

- that care should be delivered by multidisciplinary teams involving Respiratory Nurse Specialists (RNSs).

Programmes of care have been developed that incorporate some or all of these elements and while these are often multi-professional, nurses commonly co-ordinate or lead such services. However the evidence supporting the recommendation that care should be delivered by multidisciplinary teams involving an RNS is graded as 'D' (expert opinion and/or experience of respected authorities or arising from extrapolation of more robust evidence).

1.3 Innovations involving nurses for the management of patients in the community with COPD

In 1981 a report by the Royal College of Physicians drew attention to the condition of patients with chronic respiratory disease and called for the introduction of respiratory health workers. This call was taken up by the Royal College of Nurses (RCN) and led to the development of the Respiratory Nurses Forum. Since 1989 the British Thoracic Society has recommended that RNSs should be attached to all departments of respiratory medicine to act as links between hospital and community (Margereson 1997). The original respiratory nurse posts were generic but over time respiratory nurses have tended to become more specialised. However, there are no set UK standards or training for respiratory nurse specialists and their remit is often broad (Wilson-Barnett 1994). Specialist respiratory nurses are generally distinguished from other nurses giving support to patients with chronic lung disease by their extensive experience and by having undertaken additional education in the specialty.

Broadly, two types of nurses practice the care of COPD patients in the community: generalist community nurses (such as practice nurses, nurse practitioners and district nurses); and RNSs. While the generalist nurses have had innovations within their practice, it is the specialist respiratory nurses who have co-ordinated/led many innovations of service for patients in the community with COPD. Such nurses, while often based in hospital, serve as a bridge between primary and secondary care and act as co-ordinators of patients overall respiratory care. These specialist services are supported by consistent evidence that specialists are more knowledgeable about the management of conditions associated with their speciality and more likely to practice in accordance with guidelines (Donohoe 1998, Harold 1999).

An important driver for the recent development of nursing innovations around COPD in the UK has been winter pressure monies (funds dedicated to 'unblocking' hospital beds in winter) which pumped primed many of the initiatives, many of which have subsequently been maintained on non-recurrent funding. This has promoted ad hoc development of the services and many different variations on a theme (Jane Scullion: personal communication). Two different models of specialist respiratory nurse interventions in COPD have emerged in the literature: chronic disease management type schemes for a caseload of patients in the community (e.g. Littlejohns 1991, Smith 1999); and schemes which attempt to divert patients away from unplanned COPD related admissions to secondary care, or to reduce the duration of unplanned acute admissions, by providing care in the patient's home ('hospital at home') (e.g. Davies 2000).

1.4 The importance of consulting with patients and their carers on management of their illness

In chronic diseases like COPD there are specific reasons why it is important to consult patients, and carers on the management of their condition. Firstly, chronic diseases can have an impact on the patient beyond physical morbidity, for example FEV1 does not predict quality of life in patients with COPD (Wijkstra 1998). Secondly, in chronic diseases the emphasis is often on the patient and their carer to manage their disease on a daily basis. Where hospital treatment is replaced by home based treatment it is particularly important to ensure that patients' rights and

well-being are maintained, and that there is no increase on the burden on informal carers (Corrado 2001). The DH has prioritised the importance of patient consultation and patient involvement as experts in their conditions and management (Expert Patient DoH 2001). There are also several initiatives to involve patients in research (INVOLVE, Cochrane patient and Communication Group).

1.5 Effective implementation

Specialist nurse respiratory services for patients with COPD in the community are new forms of care, and may have distinct characteristics that may impede their successful implementation. For instance, some are transferring acute care away from the hospital into the home and the wider community this may place extra burden on existing community services (such as out-of-hours reliance on community nurses and general practitioners, requiring the existing staff to learn new referral and care pathways). Some elements of these services involve a transfer of care from the hospital respiratory clinical specialist and from the general practitioner and practice nurse. These changes in professional boundaries may be difficult to overcome. Overall these types of services, which are now supported by recommendations in NICE guidelines, may require specialist skills that are in short supply.

1.6 Structure of the review

This project is an 'extended' systematic review concerning innovations involving nurses in the organisation or delivery of health services to people with chronic obstructive pulmonary disease (COPD) living in the community. The review is described as 'extended' because it aimed to provide evidence on a wider range of outcomes than a conventional systematic review. This involved the systematic retrieval of unpublished literature, 'grey' literature and Dutch language literature. The SDO's brief specified the retrieval of grey literature from outside the UK. We chose to concentrate our efforts on The Netherlands because the research team's prior knowledge suggests that the Dutch have considerable experience of different innovations involving nurses for COPD and because primary care in Holland has many similarities with that in the UK.

The main aim of the review was;

To examine the evidence concerning the effectiveness of innovations involving nurses for the care of people with COPD living in the community.

Five further aims were intended to provide additional information to further inform and guide the findings and recommendations of the review;

- to determine which patients are most likely to benefit, and in what ways, from the different interventions examined

- to examine to what extent, and with what success, these innovations have been implemented within the NHS

- to understand the views of users and carers, and of service providers on the implications of this review

- to discuss the policy implications for the NHS of this review and to make recommendations which incorporate the views of users, carers and service providers

- to compare the findings of this review with the findings of existing reviews of community based innovations involving nurses in four other common chronic conditions: Parkinson's disease, renal failure, congestive heart failure and diabetes mellitus.

Objectives

The specific objectives of the review were as follows;

- to review systematically the relevant published quantitative and qualitative studies and grey literature concerning innovations involving nurses for people with COPD normally living in the community

- to identify relevant grey literature and potential case examples by conducting a postal survey in England and Wales of all respiratory medicine consultants, of members of the General Practice Airways Group, of members of the Royal College of Nursing Respiratory Nurses' Forum, delegates at the most recent International Respiratory Nursing Conference and key informants at primary care organisations

- to map the current provision of these innovative services for people with COPD in England and Wales and enabled us to invite service providers to contribute feedback and participate in debate on the implications and policy recommendations arising from the review

- to collect grey literature, and other existing local information, on a number of case examples of interventions

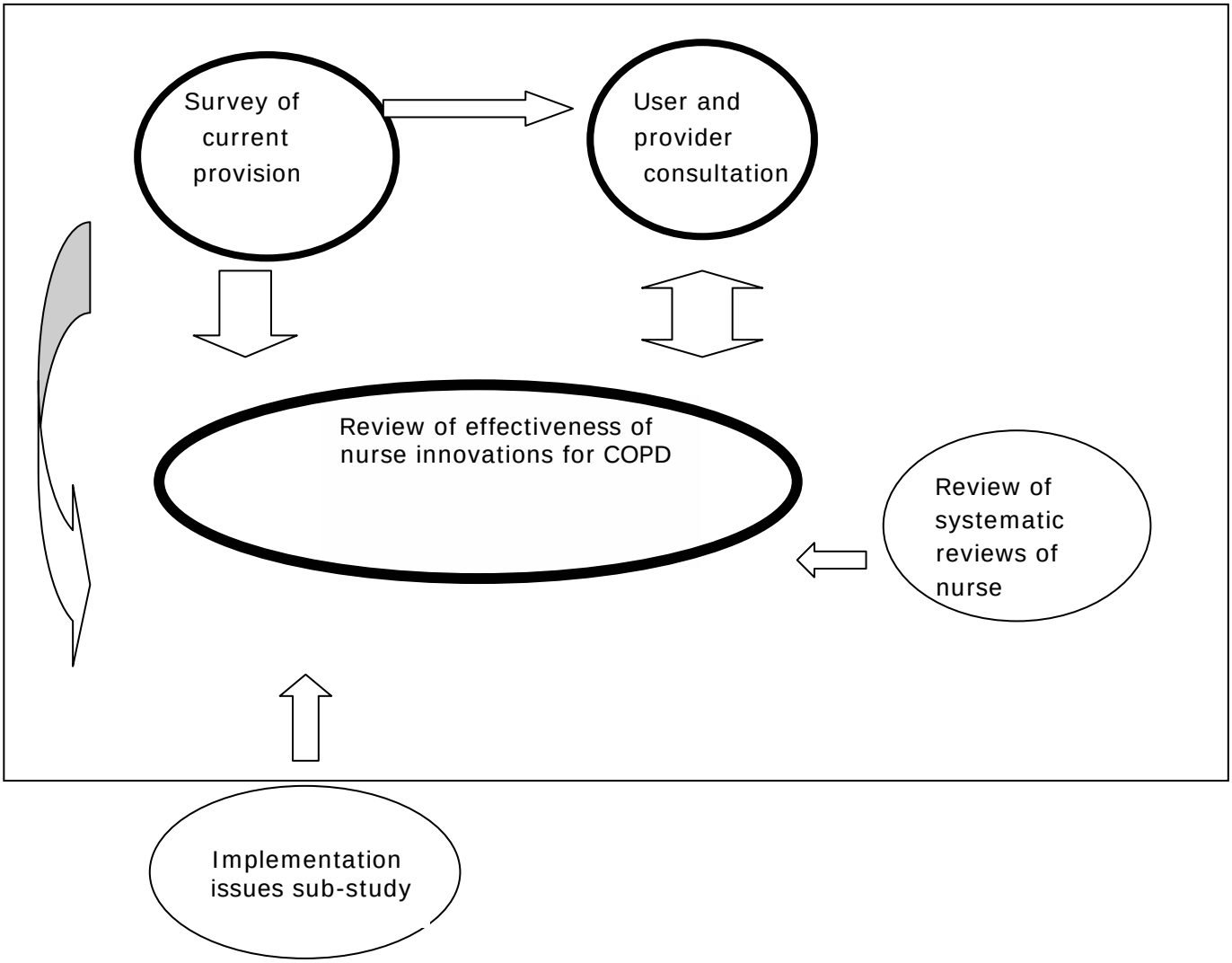
involving nurses for COPD patients living in the community in England and Wales

- to contact respiratory specialists and general practitioners in The Netherlands for information and grey literature concerning nursing innovations for people with COPD living in the community

- to conduct a rapid consultation exercise which involves users, carers and service providers in discussion of the implications and the recommendations arising from the findings of the whole study.

Figure 1 (overleaf) displays the reviews elements. The block arrows indicate the main direction of information.

Figure 1 Flow chart describing components of the review



Section 2 The extended literature review and consultation on the provisional findings

2.1 Introduction

This chapter has several components.

Section 2.3 to 2.4 describes the methods and findings of the main review, this is an 'extended' literature review of the effectiveness of nursing innovations for people with COPD normally living in the community. We have described this review as 'extended' because it included the systematic retrieval of unpublished literature, 'grey' literature and Dutch language literature.

Section 2.5 describes the results of our attempts to systematically identify implementation issues from the material identified in both the main review and the survey (Chapter 3).

The section 2.6 describes the results of a rapid review of existing systematic reviews of nurse innovations for patients with other chronic diseases.

Section 2.7 to 2.8 describes the methods and results of two consultation exercises, one involving health care providers (Section 2.6), and one involving users and carers (Section 2.7), on the findings and recommendations from our preliminary report on the review of the published randomised controlled trials (RCTs).

2.2 Objectives

2.2.1 Objectives of the main review

1) To review systematically the relevant published quantitative and qualitative studies and grey literature concerning innovations involving nurses for people with COPD in the community. Specific questions to be addressed in the review include;

- what nurse-orientated innovations have been developed for patients with COPD living in the community?

- what is the evidence to support the effectiveness of the different interventions?

- what characterises the patients who appear to benefit/do not benefit from particular innovations (e.g. objective severity of the COPD as determined by FEV1, associated co-morbidity, and social circumstances)?

2) To contact respiratory specialists and general practitioners in Holland for information and grey literature concerning nursing innovations for people with COPD living in the community.

2.2.2 Objectives of the review of implementation issues in published, unpublished and grey literature retrieved in the main review and survey

3) To describe what has been documented about the implementation of innovations involving nurses for the care of people with COPD from the published and grey literature identified in this review.

2.2.3 Objectives of the rapid review of other systematic reviews of chronic conditions

4) To compare the findings of this review with the findings of existing reviews of community based innovations involving nurses for four other common chronic conditions: Parkinson's Disease, congestive heart failure, renal failure and diabetes mellitus identified from a rapid review.

2.2.4 Objectives of the consultation exercises

5) To conduct a rapid consultation exercise involving users, carers and service providers to discuss the implications and the recommendations arising from the findings of the whole study.

6) To draw conclusions and make recommendations based on our findings.

2.3 Methods of the main review – the extended systematic review of nurse innovations for COPD

2.3.1 Types of innovations included in the review

For the purposes of this review *innovations* were defined as services that are not provided as standard care throughout England and Wales. Innovations *involving nurses* were defined as inpatient, outpatient or community based interventions, or packages of care, which were nurse-led, nurse co-ordinated or largely delivered by nurses. The 'nurses' delivering these innovations did not necessarily have to be Respiratory Nurse Specialists (RNSs). The review was concerned with innovations involving nurses which were applied to people with COPD in the community and/or their relatives or carers. Examples of such innovations include;

- nurse-led clinic based services

- schemes delivered by nurses to avert unplanned hospital admissions for patients who would conventionally be admitted for an acute exacerbation of COPD. These are often called 'hospital at home' schemes

- schemes that aim to shorten hospital inpatient stay for patients experiencing an acute exacerbation of COPD. (These are often called 'early discharge schemes')

- pro-active home visits delivered by nurses;

- specialised discharge planning or co-ordination delivered by nursing staff.

Nurse led or delivered educational innovations that consisted solely of education directed at health professionals or that were applied to a sample of patients with various diseases were not included in the review.

2.3.2 Types of Studies

The review included published English language quantitative, qualitative and purely descriptive studies, unpublished quantitative, qualitative and purely descriptive studies from England and Wales and Dutch language published and unpublished controlled trials. Because of earlier confusion and blurring of the definitions for asthma

and COPD we limited our search to studies published in or after 1980.

Please note the handling of the purely descriptive studies or papers is not discussed further in this section (see Section 2.5 and Appendix 7 on implementation issues).

2.3.3 Types of outcome measures

The outcomes of interest included deaths (all cause and COPD related), hospital admissions, event free survival, patients' quality of life (QOL), patients' perceptions of the services, carers' QOL and perceptions of the services, opinions and perceptions of service providers or other health professionals and costs and performance statistics describing these services.

2.3.4 Search strategy

The review team developed the search strategy in consultation with a local librarian with expertise in searching electronic databases. The search terms used and the search strategy were based on;

- a list of terms provided by the review's advisory groups

- the British Thoracic Society's definition of COPD

- the Cochrane Airways Group search strategy for COPD

- analysis of terms used in papers cited by Cochrane systematic reviews of related areas.

Search terms were divided into four main groups:

Disease terms

Terms used to describe chronic obstructive pulmonary disease and its synonyms were COPD, chronic obstructive pulmonary disease, pulmonary emphysema, COAD, chronic obstructive airways disease, irreversible airways disease, chronic obstructive lung disease, airflow obstruction, chronic bronchitis, chronic airflow obstruction, and emphysema.

Nursing terms

The primary focus of the review is nurse-led interventions, so a set of nursing-related terms were generated. No distinction was made in this set of terms of setting, therefore hospital-based care was included here.

Care terms

These were the terms that tried to identify community-based interventions but were not restricted to nurses.

Patient-related terms

These were terms used to identify patients' perception of care. Searches were undertaken within each database that combined the disease terms with each of the other groups of terms to produce three sets of results in the first instance;

- care results

- nursing results and

- patient results.

Additional search terms: 'chronic respiratory failure' and 'long-term oxygen therapy', suggested after the initial searches resulted in the generation of additional sets of references. See Appendix 1 for details on search terms used and for the full Medline search strategy.

Electronic databases searched

We searched 19 electronic bibliographic databases of published papers and grey literature for English and Dutch language studies.

All databases were searched for the period January 1980 to January 2003. English language and international databases were;

- Allied and Complementary Medicine Database (AMED)

- Applied Social Sciences Index and Abstracts (ASSIA)

- British Nursing Index, (BNI)

- Cumulative Index to Nursing & Allied Health Literature (CINHAL)

- Cochrane library: the Cochrane database of systematic reviews; database of abstracts of reviews (DARE) and the Cochrane central register of reviews (CENTRAL)

- Embase

- Health Management Information Consortium Database (HMIC)

- Medline

- National Research Register (NRR)

- System for Information on Grey Literature in Europe (SIGLE)

- Psych-info

- ISI Web of Science: Science Citation Index 1981-2002, Social Science
Citation Index 1981-2002 and Arts and Humanities Citation Index 1981-2002 and

- The Steinberg Collection of Nursing (theses collection)

We attempted to contact all the authors of eligible entries of studies in progress found in the NRR, SIGLE, and the Steinberg collection to establish whether the study was ongoing or whether the study existed as a full paper.

Conference proceedings

Abstracts of conference proceedings from January 1993 to September 2003 were searched online if available. If they were not available online, library copies of the conference proceedings held within the University of London library network and the British Library were screened. Where conference proceedings were not available online or as hard copies we contacted conference organisers to request if available copies of conference proceedings. Conference proceedings of the following organisations were searched;

- American Thoracic Society

- British Thoracic Society, winter meetings

- European Thoracic Society

- Australian and New Zealand Thoracic Society

- Royal College of Nursing (RCN) Research Society

- RCN Respiratory forum

- Association of Respiratory Nurses

We attempted to contact all the authors of potentially eligible conference abstracts to establish whether the study was ongoing or whether the study existed as a full length paper (published or unpublished).

Identifying unpublished studies and grey literature

In the survey (described in Chapter 3) we wrote to key informants of all identified specialist nurse services for patients with COPD in England and Wales. We asked them if there were unpublished or published evaluations or audits of their services and requested that they send us, using our freepost envelope, a copy of these reports (or a reference if the reports had been published). We also placed a call for literature in the newsletters of the Association of Respiratory Nurses and in Inspiration (the

journal of the RCN respiratory forum), and on the websites of these two organisations. The study was presented while it was in progress at three conferences (International Conference in Community Health Care Nursing Research, September 2003; RCN Respiratory Nurses Forum, September 2003; British Thoracic Society, December 2003) and at each conference we undertook a call for published and unpublished studies.

Additional searches for qualitative studies

We envisaged that locating qualitative research might be difficult because it is published in a large number of journals, some of which are not referenced in electronic bibliographic databases. We undertook additional searches for qualitative material based on advice from members of the Cochrane Qualitative Research Methodology Group. This involved;

- approaching authors of identified eligible trials and qualitative studies

- approaching authors identified in our search of studies on the illness experiences of patients with COPD identified in the review

- a call for relevant qualitative material was circulated on the web by the Association of Respiratory Nurses discussion forum and

- citation tracking of any identified qualitative research.

Identification of additional published and unpublished studies from the Netherlands

Six organisations were contacted to ask for relevant Dutch literature or names of key contacts, these were;

- The International Primary Care Respiratory Group

- Dutch Thoracic Society

- Dutch Association of Lung Nurses

- Dutch Asthma Foundation

- The Health Management Forum

- The Quality Institute for Adjusted Home-care Renewal (KITTZ).

Eight Dutch bibliographic citation databases were searched in Dutch, these were;

- Database of the National Expert Centre Nursing and Care (www.levv.nl Landelijk Expertisecentrum Verpleging en Verzorging).

- Website General Association of Nurses and Caretakers (www.avvv.nl Algemene Vereniging Verpleegkundigen en Verzorgenden).

- Dutch Institute for Scientific Information Services (www.niwi.nl Nederlands Instituut voor Wetenschappelijke Informatiediensten)

- Datafile Foundation Research and Development Public Health (www.xs4all.nl/~stoom/ Stichting Onderzoek en Ontwikkeling Maatschappelijke Gezondheidszorg)

- Datafile Dutch Institute for Research of Health Care (www.nivel.nl Nederlands Instituut voor Onderzoek van de Gezondheidszorg)

- Dutch Central Catalogue (http://picarta.pica.nl)

A complex search strategy was not developed because the databases were relatively small. The following search terms in Dutch were used to search the databases: 'Respiratory nurse', 'Respiratory nursing', 'COPD', 'Chronic bronchitis', 'Lung emphysema', 'Airway obstruction' and 'CARA' (chronische aspecifieke respiratoire aandoeningen, a term used to differentiate COPD from asthma)

Additional searches involved a call for studies sent to and circulated among delegates of a Dutch national nursing conference; 'The role of the nurse in COPD' (De rol van de longverpleegkundige bij COPD, Amsterdam November 2003) (http://www.verenigingnvl.nl), and a call in a national journal for respiratory nurses, (Inspiratie Nieuwsblad voor Longverpleegkundigen 2003; 12(4): 11-12).

2.3.5 Screening of titles and abstracts

Using a standardised eligibility form all identified English language titles, key words, and abstracts (if available) were screened for eligibility by two reviewers working independently (see Appendix 2). Dutch language titles and abstracts were screened by one reviewer. Comparison between the reviewers' independent results was made throughout the screening process to ensure consistency. Full texts of all papers and grey publications which might be eligible for the review, or where there was any doubt, were obtained and assessed for eligibility by the project researcher and one other member of the review group

working independently. Any disagreements were resolved either by discussing eligibility with a third reviewer with expertise in the area of dispute or by bringing the full text of the paper to a meeting of the full review group for discussion.

2.3.6 Data extraction

Data extraction and quality assessment were based solely on the published reports (or, for unpublished studies, on the unpublished reports made). The key characteristics and outcomes were extracted in a standardised way from the full text of the studies for potential inclusion. The data extraction sheet was based on recommendations in the Cochrane Collaboration handbook (Alderson 2004), in the Centre for Research and Dissemination handbook on systematic review (CRD, Report Number 4, 2001) and on advice from the review's advisory groups.

Extracted characteristics of services were based on common components identified in descriptive and evaluative papers and from the advice given by the Nurse Reference Group (see Box 2.1 for details of components). A statistician acted as a consultant to the project and commented on the statistical analysis of each included quantitative study. (See Appendix 6, for a full copy of the data extraction form).

Additional extraction

A health economist employed as a consultant to the project provided expert advice on economic analyses in retrieved papers. Economic analyses were abstracted in to a special data collection form (CRD, Report Number 6, 2001). A highly experienced qualitative researcher independently extracted data from the eligible qualitative papers**.**

Box 2.1 Details of intervention components extracted

Duration of intervention
How were patients referred to the service?
Which patients were eligible and how were they assessed?
Details of discharge home* (when, how, provided a standard discharge package)
Home visits (frequency, by whom, details of content)
Out-of-hours cover
Exacerbation care pathways employed?
Clinical support to nurses
Additional support services (whether the intervention offered other support services such as physiotherapy)
* if applicable

2.3.7 Quality evaluation

Quality of the randomised control trials

The methodological quality of the RCTs was assessed using the Delphi list (Verhagen 1998) and the Jadad score (Jadad 1996). These consider specific sources of bias that may influence the validity of a study's results.

The Delphi list quality items considered were;

- treatment allocation

- was a method of randomisation performed?

- was the treatment allocation concealed?

- were the groups similar at baseline regarding the most important prognostic indicators? `

- were the eligibility criteria specified?

- was the outcome assessor blinded?

- was the care provider blinded?

- were point estimates and measures of variability presented for the primary outcome measures? and

- did the analysis include an intention to treat analysis?

We excluded one item, 'was the patient blinded', from the original Delphi list for our quality assessment. We considered that for most of the interventions examined in this review, particularly if the comparison is 'usual care', it is highly unlikely that a properly consented, individually

randomised study participant would be unaware of the care to which she/he had been allocated.

We incorporated two different items from Jadad's quality assessment scale (The Delphi list 1a and 1b are common to both scales);

- is the study described as double blind? (For the reasons described above we effectively excluded this criterion when assessing study quality as these interventions are extremely unlikely to be double blind) and

- was patient attrition described for both groups including the number of patients lost or excluded along with reasons?

We used the explanation and elaboration of the CONSORT statement (Altman 2001) and the Delphi list (Verhagen: personal communication) to operationalise the Delphi list quality criterion, as follows;

- a random (unpredictable) assignment sequence is performed, and the authors specify the method of sequence generation such as random number table or computerised random number generator

- a concealed treatment allocation means that a random assignment sequence is generated by an independent third party not responsible for determining the eligibility of patients. The person enrolling patients and assessing eligibility should have no influence on the assignment sequence

- a precise description of which prognostic indicators are regarded as important should be specified, either in the text or in tabular form, by the authors. The reviewer determines when the groups are regarded as similar

Score 'yes' if the inclusion and exclusion criteria are clearly defined.

- the reviewer determines when enough information about the blinding is given in order to score a 'yes'

- the reviewer determines when enough information about the blinding is given in order to score a 'yes'

- authors must state their primary endpoints or outcome measures. Both point estimates and measures of variability should be presented. (Reviewers' note: studies which do not clearly identify their primary endpoints or primary outcomes can not score a 'yes' on 6)

- 'Intention-to-treat' means analysing all randomised patients for the most important outcome measures, and on the most important moments of effect measurement irrespective of non-compliance and co-interventions.

Statistical power and generalisability refer to the external validity of studies and we comment on these in the data abstraction tables. All included studies were examined independently by a medical statistician and we have noted in the data abstraction tables where there were concerns about the suitability or clarity of the particular statistical tests reported in the papers.

Quality of other types of quantitative studies

We used the same quality criteria, apart from the questions regarding randomisation and allocation concealment, to judge the quality of any non-RCTs.

Quality of audit studies

We intended to use the checklist of the Principles of Best Practice in Clinical Audit (2002, National Institute of Excellence) to assess the methodological quality of any published audit studies**.**

Quality of qualitative studies

The quality of the included qualitative studies was assessed in two ways:

The experienced qualitative researcher who extracted data from the eligible qualitative papers commented on their overall quality

We attempted to apply the Critical Appraisal Skills Programme (CASP) checklist to the papers.

2.3.8 Level of evidence and grades of recommendation

We used our assessments of the risk of bias in the quantitative studies (from our quality assessments) to allocate an evidence score, using the Oxford Centre for Evidence-based Medicine Levels of Evidence and Grades of Recommendation (www.infopoems.com/resources/levels.html), to each study and outcome examined. This system gives a score for studies of therapy, prevention, aetiolgy and harm running from 1a (best evidence) to 5 (‘expert opinion without critical appraisal, or based on physiology, bench research or ‘first principles’ ’) depending on the study design, conduct of the study and the study findings. Systematic

reviews (SRs) of RCTs score a 1a, individual RCTs score either 1b or 2b and 'weaker' designs, such as cohort studies and case series, score on a range from 2 to 5. A minus sign is added after the 'a' (e.g. 1a-, 1b-) to indicate SRs 'displaying worrisome heterogeneity' or RCTs 'with a wide confidence interval'. In this review we also used this notation when we were unsure whether the evidence really satisfied requirements to reach a particular evidence level. (further details on these levels of evidence can be found in Appendix 3)

2.3.9 Summarising and synthesising the results

Summarising and synthesising the quantitative studies

Findings of each individual study were summarised in the data extraction forms, grouped by type of intervention and synthesised;

- by potential outcome variables with Level of Evidence ratings where possible and

- in meta-analyses, if both feasible and appropriate.

Summarising and synthesising other types of evidence

Findings of economic and qualitative studies were synthesised narratively.

2.4 Results of the Literature Review

2.4.1 Database search results for published and grey literature

Our main search (using English and international bibliographic citation databases) identified 6,931 citations. The number of citations identified for each database is shown in Table 2.1. There were 254 references where the two reviewers disagreed about screening. Fewer disagreements occurred as the screening progressed. Most disagreements were resolved by discussing the paper with a third reviewer with expertise in the field, and in a few cases if eligibility remained unclear, the papers were discussed at the next peer management and review group meeting. After screening titles and abstract 168 potentially relevant articles were identified. Following retrieval of the full text 128 papers correct were excluded; see Appendix 4 for list of excluded studies.

Following full text retrieval and assessment 40 papers remained eligible these were;

- systematic reviews n=2

- controlled trials, RCTs n= 13 (15 papers)

- non-RCT studies with some quantitative evaluation n = 4

- other qualitative studies (separately reported) n=1

- descriptive studies n= 16

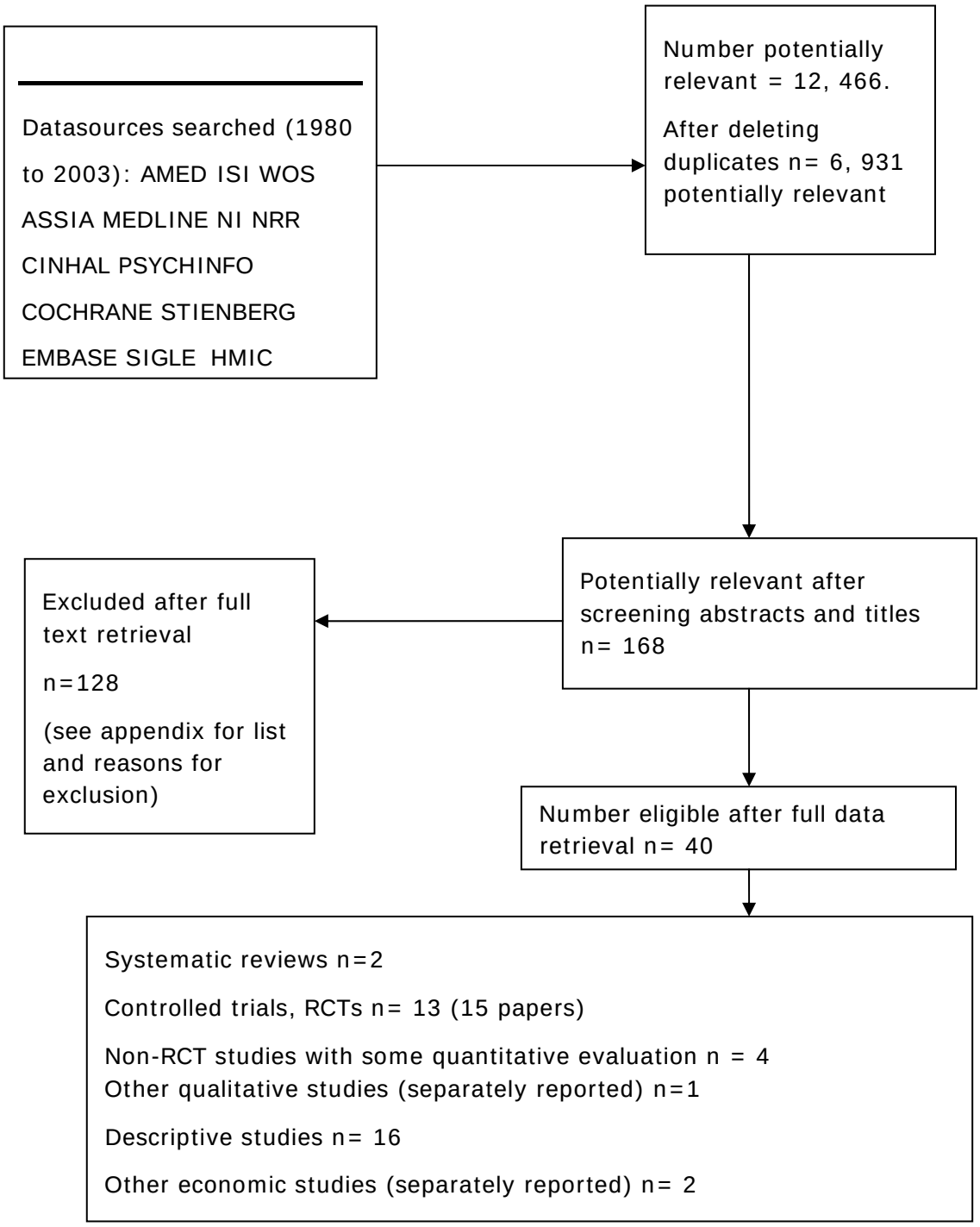
- other economic studies (separately reported) n= 2 (see study flow chart).

Table 2.1 Number of citations identified by database

Database	Number of citations identified
AMED	344
ASSIA	185
BNI	102
CINHAL	1539
COCHRANE Library databases	1283
EMBASE	3452
HMIC	57
MEDLINE	3116
NNR	60
PSYCHI-INFO	173
SIGLE	26
STEINBERG collection (on 'respiratory' only)	500
WOS	1814
TOTAL (including duplicate identification)	12466

A flow chart for the review is shown in Figure 2.1 overleaf.

Figure 2.1 Review flow chart



We were unable to obtain a copy of all the abstracts of conference proceedings for all the years we planned to search. The only complete search was for the RCN Research Society (see Table 2.2). One reviewer undertook screening for eligibility of conference abstracts. 34 abstracts were eligible. Comparing the citation details of included abstracts with the details of eligible full text published or unpublished papers, five abstracts were found to have been subsequently published in full text, and for ten abstracts we had received grey literature on the study from survey respondents. We were unable to contact the authors of eight abstracts (see Appendix 5 for details of these studies). 11 authors replied to our request for details of their studies, seven reported that their studies were on going, details are in Section 2.4 and Table 2.7, and four authors sent unpublished reports on their study.

Table 2.2 Record of conference proceeding abstracts searched

Conference	Numbers identified	Years searched
Australian and New Zealand Thoracic society	2	2001
British Thoracic Society (BTS)	13	1995-2003
European Respiratory Society (ERS)	6	1997-2003
American Thoracic Society (ATS)	1	2001-2003
Royal College of Nursing Respiratory Nurses Forum (and newsletter)	4	2001-2003
International Primary Care Respiratory Group	5	2002-2003
RCN-Research Society Conference	1	1993-2003
Association of Respiratory Nurses	3	2002-2003
Total	35	

2.4.2 Search results of the Dutch language literature review

Four additional studies were identified in our search for Dutch literature using databases not internationally available (Kloosterziel, in progress; Van Alphen 2003; Vrijhoef, paper in preparation; Vrijhoef, in progress). Although this additional Dutch language search was restricted to RCTs, two non-trial evaluative studies were also identified (Vrijoef, in progress; Van Alphen 2003). Results were available for two studies, Kloosterziel (in progress) and Van Alphen 2003) and these were extracted, the other two studies are discussed in Section 2.4.

2.4.3 Type of intervention

After scrutiny of the eligible papers it was apparent that there were two distinct types of interventions being evaluated and we divided the studies for synthesis, as follows;

- chronic disease management type interventions for COPD

- interventions for acute exacerbations of COPD.

The findings of these two types of studies are discussed separately below.

2.4.4 Chronic disease management interventions

We identified one Cochrane systematic review (Smith 2004) and seven published RCTs of respiratory nurse chronic disease management interventions for patients with COPD (Cockcroft 1987; Bergner 1988; Littlejohns 1991; Smith 1999; Farrero 2000; Egan 2002; Hermiz 2002). Two RCTs involved an economic evaluation (Bergner 1988; Farrero 2000) and one included a qualitative evaluation (Egan 2002). We also identified one non-randomised controlled study (Ketelaars 1998), one small mixed before and after/ non-randomised control group study (Poole 2001), one before and after evaluation with economic analysis (Campbell Haggerty 1991), and one qualitative study looking at shared care for COPD and diabetes mellitus (Eijkelberg 2002). The studies were undertaken in Europe, Australasia and the United States (see Table 2.3 for characteristics of each trial and Appendix 6 for full details of data extracted from each paper). All except one (Hermiz 2002) were single centre studies.

Table 2.3 Characteristics of RCTs of chronic disease management type interventions for patients in the community with COPD

Study	Location and study length	Number (n) in trial arms, comments on design	Inclusion criteria	(1) Name (if given) and description of intervention, (2) main aim/question of trial	Outcomes/Evaluation measures. If reported given as main outcomes and other outcomes
Cockcroft 1987	UK Single centre. 9 months	Two groups:1-control n=33 (usual treatment), 2-intervention n=42.	Patients with COPD admitted to hospital at least twice in preceding 3 years or new patients seen within past year.	Respiratory health worker (nurse) visiting patients monthly, model followed to identify problems of daily living and set goals to increase independence. Patients encouraged to recognise signs of health deterioration and to take appropriate action. Sessions tailored to individual. Aim/question: to evaluate the role of the respiratory health worker.	Mortality, number and duration of admissions, quality of life (General Household Questionnaire 28 question version), patient questionnaire about mobility, knowledge of condition and medicines designed for the study, questionnaire on physical and psychological aspects of patients' lives designed for study. Patients' disability and distress rated by independent assessors
Berger 1988	USA. Single centre. 12 months	Three groups: 1-Standard homecare n=102, 2. Outpatient care n=100, 3-Intervention n=99.	FEV1 <60%, FEV1:FVC < 60%, age 40-75, 'housebound', able to administer aerolized metaproterenol.	Specialised respiratory home care program delivered by trained respiratory nurses visits including assessment at least monthly. Aim/question cost effectiveness of the three trial arms.	Primary outcome: Costs Other outcomes: Sickness Impact Profile, the General Well-Being Schedule and a walking tolerance test developed by investigators, survival rates, pulmonary function.
Littlejohns 1991	UK Single centre. 12 months.	Two groups: 1-Control n=79 (usual treatment), 2-intervention n=73.	Patients aged 30-75, no other major disease, FEV1 < 60% predicted, in stable COPD and had no change or perceived need for change in medication for last 6 weeks.	Respiratory health worker (nurse) Patients received normal care at clinic plus education, monitoring compliance and optimising of treatment, assessment, and liaison with physiotherapy and social services from a respiratory health worker. Not clear if respiratory health worker saw	Primary outcomes: FEV1, Hospital Anxiety and Depression Scale (HADS) Sickness Impact Profile, six minute walking test Other outcomes: MRC chronic Bronchitis questionnaire; satisfaction questionnaire; patient diary record of prescriptions and health service

				patients at clinic or home. Aim/question whether a respiratory health worker was effective in reducing respiratory impairment, disability and handicap experienced by patients with chronic airflow.	use.
Smith 1999	Australia Single centre. 12 months.	Two groups: 1-control n=48 (usual treatment), 2-intervention n=48.	Patients with severe COPD: attending hospital as inpatients/outpatients, or referred by GP. Aged over 40, with FEV1:FVC < 60%, in stable state, had a carer involved in their management.	'Outreach service'. After discharge patients visited 2/4 weekly over a year. Visits included assessment, education, medication compliance, counselling for smoking and fitness advice. Aim/question: Does intervention result in reduction of health service use, mortality, and an improvement in HRQL and FEV1?	Main outcome: Health service use, survival. Other outcomes only measured n intervention group: Dartmouth Primary Care CO-OP quality of life questionnaire for patients and carers. FEV1,
Farrero 2000	Spain. Single centre. 12 months	Two groups: 1-control n=62 (usual treatment) 2-intervention= 60. Included cost-effectiveness analysis	Using LTOT for 6 months or more.	Hospital-based home-care program Respiratory nurse made quarterly home visits and monthly calls to patient. Visits included assessment. Aim/Question: To evaluate the effects of a hospital based home care program for severe COPD patients receiving LTOT.	Blood gases, pulmonary function tests, number of hospital admissions; emergency department visits; hospital LOS; and quality of life in the first 40 consecutive patients using Spanish version of the Chronic Respiratory Questionnaire.
Egan 2002	Australia Single centre. 3 months.	Two groups 1-control n=33 (usual treatment), 2-intervention n=33. Plus subgroup qualitative	Aged >18 yrs, admission to a respiratory bed for COPD, within 72 hours of hospital admission, cognitive function adequate.	Nursing-based case management. In hospital nurse co-ordinated care, education and discharge planning. At discharge nurse gave support and acted as referral point for services. Nurse follow up at 1 and 6 weeks post discharge (not clear if at home or clinic), and phoned	St Georges Respiratory Questionnaire (SGRQ); Social Support Survey; Hospital Anxiety and Depression Scale (HADS); Subjective Well-Being Scale. Unscheduled hospital re-admissions.

		analysis of 18 patients and carers		patient. Aim/question To compare the effect of a brief nursing based case management intervention with that of normal care for patients hospitalised with COPD.	
Hermiz 2002	Australia Two centres 3 months.	Two groups: 1-control n=93 (usual treatment), 2-intervention n=84.	Aged 30-80, attended A&E or admitted for COPD.	Home based care/brief intervention after acute care. Two home visits by community nurse, one within week of discharge, second a month later. Visit involved assessment, education, advice on smoking, and acted as a referral point to other services. Aim/question: Hypothesis: Home visiting could improve patient knowledge about disease, improve QOL and decrease hospital utilisation.	Main outcome Presentation to hospital Other outcomes St Georges respiratory Questionnaire (SGRQ), knowledge, self-management and satisfaction. GP and nurse visits, care provided and GPs satisfaction with care

Abbreviations used in table: FEV1=forced expiratory volume at 1 second,. FVC=forced vital capacity, GP=General Practitioner, HADS=Hospital and Depression Scale, HRQOL=Health related quality of life, QOL=Quality of life, SGRQ=St. George's Respiratory Questionnaire

Chronic disease management interventions: the Cochrane systematic review

The systematic review (Smith 2004) reviewed studies of 'supervised, home based intervention in patients with COPD using a parallel group RCT design'. The most recent substantive update was in May 2001 and the review included four of the RCTs we identified (Cockcroft 1987; Bergner 1988; Littlejohns 1991; Smith 1999). The reviewers noted important methodological limitations in all studies. They concluded; 'Meta-analysis demonstrated that mortality was not significantly reduced by the intervention (Peto OR 0.72, 95 per cent CI 0.43 to 1.21). Post hoc subgroup analysis suggested that mortality was reduced by the outreach nursing programme in patients with less severe disease.' However we consider that there was not always enough information provided to categorise a study's patients as having moderate or severe COPD. This meta-analysis involved only two studies. The numbers used for deaths in one study (Cockcroft 1987) for the intervention group were those dying after randomisation but before they had been visited by the study nurse while all deaths arising in the control group were included (see data abstraction sheet in Appendix 6). Repeating this meta-analysis on an intention to treat basis resulted in a Peto OR which, although still tending towards favouring treatment, had 95 per cent confidence intervals which embraced the line of no effect (Peto OR 0.429, 95 per cent CI 0.183 to 1.005).

The Cochrane systematic review also found no overall effects on lung function, exercise performance or hospital admissions, where these were reported. Improvement in health related quality of life was reported in one study in moderate COPD but not in another in severe COPD.

Chronic disease management interventions: patient groups in the identified RCTs

The mean age of the subjects in the RCTs was very similar (between 65 and 70 years, apart from Littlejohns 1991- mean age 62 years). There were similar proportions of male subjects (60 to 70 per cent) apart from two studies (Egan, 2002 – 36 per cent males in intervention group, 60 per cent in control; Hermiz 2002 47 per cent male). (This information was not supplied for one study, Farrero 2000).

One study included patients with different types of chronic respiratory disability, although this was mainly caused by COPD (Cockcroft 1987). The information provided on the severity of COPD at baseline differed between the studies but all studies

appear to have included patients with moderate or severe COPD (BTS guideline definitions). A previous hospital admission for COPD was not a prerequisite for entry into all the studies. One study (Farrero 2000) was specifically targeted at patients receiving long term oxygen therapy (LTOT).

Chronic disease management interventions: components of the interventions

The interventions could be divided in to brief or long-term interventions: the duration of the interventions studied varied from around one month (Hermiz 2002; Egan 2002) to one year (Bergner 1988; Smith 1999; Farrero 2000; Poole 2001) in three studies the duration of the intervention was unclear.

Home visits by a nurse with respiratory training (or a community nurse - Hermiz 2002) appear to be the main component of all but two of the interventions. For two RCTs it is not clear if the studies also involved home visits (Littlejohns 1991; Egan 2002). Specialised discharge planning was the main component of only one RCT (Egan 2002). One study described additional telephone follow up (Farrero 2000). None of the English language reports appeared to involve follow up at a specialised clinic as part of the intervention under study (although some studies mentioned usual outpatient follow up for both intervention and control groups). None of the studies mentioned a specific pulmonary rehabilitation component. None of the studies mentioned providing cover outside normal working hours.

Content of the home visits/ follow up

The studies included a variable amount of information on the content of the home visits/ follow up. In some studies regular spirometry and pulse oximetry were a component of the home visits/ follow up (Littlejohns 1991; Smith 1999; Farrero 2000), other interventions did not include clinical examination during follow up (Cockcroft 1987; Ketelaars 1998). Only one study mentioned providing some patients with a supply of drugs to be kept at home and taken in the event of an acute exacerbation (Poole 2001). None of the studies mentioned managing patients at home according to written protocols, care pathways or treatment algorithms. Liaison with the general practitioner was mentioned in two studies (Littlejohns 1991; Smith 1999), in another study the nurses did not contact the GPs but encouraged patients to do so (Cockcroft 1987). Patient education appears to have been a major component of most of the home visits. This covered medication and smoking cessation advice, fitness advice and advice on the early identification of acute exacerbations.

Chronic disease management interventions: control groups in the RCTs

In five of the RCTs the control groups received usual care. In one RCT the control treatment is not specified (Cockcroft 1987) and in Bergner's study (1988) there are two control groups. One group received a standard home care programme with general nurses and the other received an office care programme with no home care. (We used the standard home care programme as the control group in the meta-analysis).

Chronic disease management interventions: quality of the included RCTs

The published reports of all the RCT studies suggested potential methodological limitations that could have affected the validity or generalisability of their findings**.** In particular;

- in five studies they either did not provide a sample size calculation, or the sample size calculation was unclear, or the researchers did not achieve the intended sample size (Cockcroft 1987; Smith 1999; Farrero 2000; Egan 2002; Hermiz 2002).

- three of the studies were rather small with less than 50 patients in each arm (Cockcroft 1987; Smith 1999; Egan 2002).

- only one study reported both adequate randomisation and adequate allocation concealment (Littlejohns 1991).

- in six of the studies it was not possible to ascertain the generalisability of the results to other populations of COPD patients (Cockcroft 1987; Bergner 1988; Littlejohns 1991; Smith 1999; Farrero 2000; Hermiz 2002).

Table 2.4 Methodological quality assessment of RCTs of nurse interventions for chronic disease management of patients with COPD.

	Described as randomised *#	Sequence generation *#	Allocation concealment#	Described as double-blind#[1]	Describe withdrawal and dropouts#	Baseline Similarity *	Eligibility Criteria*	Assessor Blinded*	Point estimate and variability#	Intention-to- treat analysis*	Lev evi sco
Bergner 1988	Y	U	U	N	N	Y	Y	U	Y	Y	2b
Cockcroft 1987	Y	U	U	N	Y	Y	Y	U	N	U	2b
Egan 2002	Y	Y	U	N	N	N	Y	U	N	U	2b
Farrero 2000	Y	U	Y	N	Y	Y	Y	U	N	U	2b
Hermiz 2002	Y	U	U	N	Y	Y	Y	U	N	U	2b
Littlejohns 1991	Y	Y	Y	N	Y	Y	Y	U	Y	U	1b
Smith 1999	Y	Y	N	N	Y	Y	Y	U	N	Y	2b

N=NO, U=Unclear, Y=Yes.

**items from Delphi criteria: Verhagen AP, de Vet HC, de Bie RA, Kessels AG, Boers M, Bouter LM, et al. The Delphi list a criteria list for quality assessment of randomized clinical trials for conducting systematic reviews developed by Delphi consensus. J Clin Epidemiol. 1998;51:1235-1241.*

 # items from Jadad Score. Jadad AR, Moore RA, Carrol D, et al. Assessing the quality of reports of randomized clinical trials: is blinding necessary? Control Clin Trials 1996; 17:1-12.

[1] This criterion was not used in our assessment of study quality since it is not be feasible for these types of trials to be double blind.

Level of evidence score from Oxford Centre for Evidence-based Medicine Levels of Evidence (May 2001) www.infopoems.com/resources/levels.

The quality of the RCTs is summarised in the Table 2.4. Taking these criteria into account we assessed the level of evidence for each of the RCTs to be 2b except for Littlejohns (1b).

Chronic disease management interventions: findings of the RCTS

Patient Outcomes

Health related quality of life (HRQL)

Change in St George's Respiratory Questionnaire (SGRQ) scores between baseline and follow up at three months: no significant differences between the intervention and control groups in the two RCTs that examined this outcome (Egan 2002; Hermiz 2002). (It was not technically possible to meta-analyse these results and produce a combined odds ratio as they were presented in two different ways). No significant differences in The Spanish version of the Chronic Respiratory Questionnaire were noted between baseline and 12 months follow up in one small sub-study in an RCT of patients on LTOT (Farrero 2000). Two RCTs looked at different generic measures of HRQL. One only looked at the intervention group (Smith 1999) while Cockcroft (1987) found no significant difference in the 28 question version General Household Questionnaire Score (GHQ) between the intervention and control groups at nine months follow up.

Psychological well being

No significant difference in Hospital Anxiety and Depression (HADS) scores were seen at three months follow up (Egan 2002) or at 12 months follow up (Littlejohns 1991), although, as noted above, these two interventions were very different. Egan also noted no difference between intervention and control patients in the Subjective Well-Being Scale at three months follow up. Bergner (1988) found no significant differences in General Well Being scale scores between intervention and control groups at six or 12 months follow up. There was no significant difference in the results of assessments of distress made by outside assessors at baseline and follow up (nine months) between intervention and control patients in Cockcroft's study (1987).

Social Support

There was no difference between intervention and control patients in the Social Support Survey (used to measure social support in chronically ill populations across four

dimensions; tangible support, affectionate support, positive social interaction and emotional/informational support) at three months follow up in Egan's study (2002).

Impairment and disability

Two RCTs found no difference in the total Sickness Impact Profile (SIP) scores at 12 months between intervention and control groups (Bergner 1988; Littlejohns 1991), although there was a statistically significant difference in the physical component of the SIP score in favour of the intervention group in Littlejohns's study. Cockcroft (1987) noted no significant differences in outside assessors' assessments of disability between intervention and control groups

Patient satisfaction and patient preferences

Patient satisfaction was explored in one RCT which found no difference between intervention and control patients in the level of satisfaction with the service using an unvalidated instrument designed for the study (Littlejohns 1991). Another RCT collected information during a face to face or telephone interview on a different aspect of satisfaction. This was patients' satisfaction with the treatment they received from their GPs (Hermiz 2002). No difference in satisfaction between intervention and control patients was noted. No studies reported on patient preferences for care (i.e. whether they preferred usual care or the model in the intervention).

Patient knowledge about COPD and patient self management skills

How effective were the educational components of the interventions? Patients' self-management skills were not assessed in any of the RCTs. Two RCTs looked at patient knowledge about their condition. Cockcroft used a questionnaire designed for his study and found more people improved their knowledge about their condition in the intervention group compared to the control group (relative risk, RR 1.39, 95 per cent confidence intervals 1.1 to 1.9). There was also a tendency for better knowledge about medications (RR 1.9, 95 per cent confidence intervals 0.99 to 1.42) in the intervention group. Hermiz assessed patients' knowledge and understanding at baseline and three months follow during an interview. She found intervention patients were significantly more likely to know the name of their disease, the role of vaccination (for influenza or pneumococcal pneumonia) and the factors that prevent COPD worsening but not when to seek help,

compared to control patients. It is not clear what instrument was used to determine this.

Health related behaviour

Health related patient behaviour was reported in two studies. Hermiz found no significant differences in the proportion of patients who were still smoking, or had received influenza or pneumococcal vaccinations between intervention and control patients at three months follow up. Cockcroft found intervention group patients were more likely to give up smoking but it is not clear if these data were validated.

Mortality

(Since the clinical interventions are somewhat heterogeneous we report the findings of the following statistical meta-analyses with caution and suggest that our findings are interpreted in the same light.)

Four of the RCTS reported on mortality at 12 months (Bergner 1988; Littlejohns 1991; Smith 1999; Farrero 2000) and one reported on mortality at 9 months (Cockcroft 1987). None of these studies found deaths significantly reduced in intervention or control patients, although Littlejohns found significantly reduced odds of death in the intervention group (odds ratio, OR 5.5, 95 per cent confidence intervals 1.2 to 24.5) after controlling for age and FEV1 in what appears to be a post hoc analysis. Meta-analyses of results of the five studies shows a Peto OR effect size of 0.91 favouring intervention, 95 per cent confidence intervals 0.59 to 1.39, P = 0.66). Since the patient population in the RCT by Farrero might be considered to be very different from the other patient populations the meta-analysis was repeated excluding this study as a sensitivity analysis, the OR was little altered (0.79, 95 per cent confidence intervals 0.47 to 1.33, P = 0.37). Forest plots are shown in Appendix 7.

Pulmonary function

Given the nature of COPD, it is perhaps not surprising that at 12 months follow up no differences were seen between intervention and control groups in terms of: the per cent predicted forced expiratory volume in one second (FEV1 per cent predicted) (Bergner 1988; Farrero 2000); forced expiratory volume (Smith 1999), or forced vital capacity (Farrero 2000). Farrero (whose RCT included only patients on LTOT) also found no significant differences in arterial blood gases between intervention and control.

Health care use – hospital admissions

Five RCTs reported on all cause (or total) hospital admissions during follow up (Cockcroft 1987; Littlejohns 1991; Smith 1999; Farrero 2000; Hermiz 2002). One RCT reported on unscheduled hospital admissions only, although it is not clear how these were determined (Egan 2002) and Hermiz and Cockcroft also reported on respiratory admissions. Unfortunately the findings of the RCTs around admissions were all reported in several different ways and it was not possible to perform meta-analyses on these results.

Only one study (Farrero 2000) found a highly significant difference in hospital admissions between intervention and control (mean admissions per intervention patient 0.5 (SD 0.9) vs. 1.3 (SD 1.7) in the control patients, P = 0.001 (please see data abstraction sheet, Appendix 6, for statistical comment)). As stated prior, this study was the only one to target a very particular patient population.

Heath care use – days spent in hospital

Three RCTs reported on days spent in hospital for all causes during follow up (Littlejohns 1991; Smith 1999; Farrero 2000), again only Farrero found a significant reduction in the intervention group. Cockcroft found that days spent in hospital for respiratory causes were significantly greater in the intervention group.

Heath care use – emergency department attendances

Smith (1999) found no significant differences in emergency department attendance during follow up between intervention and control patients while Farrero (2000) found attendance significantly reduced.

Heath care use – outpatient visits

Two RCTs reported no difference in the number of outpatient attendance during follow up between intervention and control groups (Littlejohns 1991; Smith 1999).

Heath care use – the general practitioner

What effect do these home care interventions have on general practitioners' work? Two studies examined this: Hermiz found no differences in the proportion of patients visiting their GP or in the number of visits to the GP between intervention and control groups. Littlejohns found no more home visits by GPs to patients between the groups but a significant tendency for more visits surgery visits to

see a GP in the intervention group. No RCTs explored what GPs or other members of the primary care team thought of the interventions.

Carer quality of life, carer satisfaction and carer treatment preference

None of these outcomes were reported by the RCTs.

Chronic disease management interventions: other quantitative studies

Ketelaars (1998) examined the effect of home visits by RNSs after discharge from a pulmonary rehabilitation centre among patients with COPD. Comparison group patients received home visits from general community nurses. Poole conducted a pilot study of regular home visits by a RNS (data abstraction sheets for these two non-randomised quantitative studies are found in Appendix 6). Ketelaars's cohort study may be subject to bias because of the large and unequal attrition experienced at nine months follow up in the intervention and comparison groups (19 per cent and 42 per cent respectively), although the researchers explored the effect of imputing missing values and found it had little effect on their results. Poole's mixed methodology study was extremely small (16 subjects in each of two arms).

Since the strength of the evidence from these studies was lower than that from the included RCTs (both were considered to be level of evidence 4), we only present evidence from these studies on outcomes not included by the RCT studies.

Patient coping

Ketelaars (1998) used the COPD Coping Questionnaire (CCQ), derived from the Asthma Coping Questionnaire, to assess patient coping strategies. No difference was seen in scores between intervention and comparison groups at nine months follow up (level of evidence: 4).

Patient compliance (adherence)

In Ketelaar's study (1998) compliance was defined as follow through on recommendations and therapy prescribed by a pulmonary rehabilitation centre and was measured using patient self-report. No differences in scores between intervention and comparison groups were noted at 9 months follow up (level of evidence: 4).

Chronic disease management interventions: economic analyses

Systematic data abstraction of economic studies is included in the data abstraction sheets in Appendix 6. Bergner's (1988) cost effectiveness analysis from a societal perspective compared respiratory home care with standard home care and with office care (office care patients did not receive any home nursing services) and found no statistically significant differences in annual costs across the three groups, although the respiratory home care did have the highest annual costs and incurred the highest home care nursing and inpatient costs.

Farrero's (2001) cost effectiveness study (also reviewed on the Centre for Reviews and Dissemination website http://144.32.228.3/scripts/WEBC.EXE/nhscrd/expand?saan=0000270712) focussed on hospital resource use and found lower costs in the intervention group. Campbell Haggerty (1991) looked at the Respi-Care programme, which was co-ordinated by a hospital based RNS. Typical care involved weekly nurse visits to the patient's home, and respiratory therapy and social services visits every two weeks, other services and 24 hour on call cover. The very small (17 patients) before and after study involved retrospective data collection of pre-programme data which may have led to bias (Campbell Haggerty 1991). After implementation of the programme there was a reduction in the number of hospital days, visits to the emergency department and hospital costs.

Chronic disease management interventions: qualitative evidence

The two published qualitative studies that we identified (Egan 2002; Eijkelberg 2002) are described and appraised against the Critical Appraisal Skills Programme (CASP) criteria in Appendix 6. Both studies were assessed to be of poor quality and it is doubtful whether their results could be transferred to other situations.

Chronic disease management interventions: Dutch language literature

We identified one eligible, unpublished, Dutch language study (Van Alphen 2003). The data were abstracted by a native Dutch speaking reviewer, see Appendix 6. The report described substituting RNS-led out patient care for physician-led outpatient care. The intervention does not appear to have included home visits. The evaluation involved a pre-test post-test design involving two cohorts of patients: a newly diagnosed group and a group with a

longer history of COPD. The primary outcome was HRQOL measured by the SGRQ. Unfortunately the study was assessed to be of low quality and the results did not include any quantitative data, nor evidence of any statistical analysis. We were therefore unable to derive any generalisable results from this study.

Chronic disease management interventions: conclusions with level of evidence rating on outcomes

There is some evidence that COPD chronic disease management interventions;

- may not reduce mortality among patients with moderate or severe COPD in general (level of evidence: 1a-).

- may not improve patients' health related quality of life as determined by disease specific (level of evidence: 1a-), or generic instruments (level of evidence: 2b).

- may not improve patients' psychological well being (level of evidence: 1a-).

- may not reduce impairment and disability as determined by total SIP scores (level of evidence: 1a-) or outside assessors (level of evidence: 2b).

- may not improve pulmonary function (level of evidence: 1a-).

- may not reduce the number of all cause hospital admissions in patients with moderate to severe COPD (level of evidence 1a), except possibly among those receiving LTOT (level of evidence 2b).

- may not reduce the days spent in hospital in patients with moderate to severe COPD (level of evidence: 1a-), except possibly among those receiving LTOT (level of evidence: 2b).

- may not influence the frequency of outpatient visits (level of evidence: 1a-).

- may increase patients' knowledge about COPD (level of evidence:1a-)

(Note level of evidence given as 1a- rather than 1a because of heterogeneity among the interventions.)

There is a little evidence from one RCT with methodological limitations to suggest that COPD chronic disease management interventions;

- do not reduce respiratory re-admissions and unscheduled re-admissions (level of evidence 2b).

- do not improve social support as measured by the Social Support survey (level of evidence: 2b).

- do not effect attendance at emergency departments among patients with COPD in general (level of evidence: 2b), but may reduce attendance among those receiving LTOT (level of evidence: 2b).

There is no evidence, or the available evidence is very weak, or equivocal on the following areas;

- patients' satisfaction with disease management interventions.

- patients' preferences for care around disease management services.

- patients' self management skills.

- patients' adherence with treatment recommendations.

- patients' coping with their disease.

- their effect on promoting smoking cessation among patients.

- their effect on general practitioner services.

- what members of the primary care team think of these interventions.

- what carers think of these interventions or on how they might influence carers' quality of life.

2.4.5 Interventions for acute exacerbations of COPD

We identified one systematic review (Ram 2003) which was published towards the end of the project, and seven recently published trials, six RCTs (Cotton 2000; Davies 2000; Skwarska 2000; Nicholson 2001; Ojoo 2002; Hernandez 2003) and one parallel group study (Sala 2001), involving patients presenting with an acute exacerbation of COPD. The Nicholson trial (2001) was a pilot study. These papers compared hospital at home (HaH) or early discharge (ED) schemes with usual hospital care. Three trials included cost analyses (Skwarska 2000; Nicholson 2001; Hernandez 2003). We also identified: a cost-analysis using a cohort study with no comparison group (Gordois 2002); a pre-test post-test (before and after) study (Gibbons 2001); and two descriptive studies with an uncontrolled subgroup satisfaction survey (Gravil 1998; Flanigan 1999). All but one of the trials was undertaken in Europe: four in the UK; two in Spain; and one in Australia. No audit or qualitative studies were identified (see Table

2.5 for characteristics of each trial and Appendix 6 for full details of the data extracted).

Table 2.5 Characteristics of controlled trials of nurse interventions for patients in the community with acute COPD

Study	Location and study length	Number (n) in trial arms, comments on design	Inclusion criteria	(1) Name (if given) and description of intervention, (2) main aim/question of trial	Outcomes/Evaluation measures. If reported main outcomes and oth outcomes
Cotton 2000	UK 2 months	Two groups:1-control n=40 (usual treatment-conventional hospital management) 2-intervention n=41.	Emergency admission with an exacerbation of COPD and that formed part of the diagnosis admitted to medical ward.	'Early discharge'. Assessed on ward the following day after emergency admission for COPD. Discharge home on next working day (ideally within 3 days). Visited on first morning after discharge by nurse and thereafter as needed, median duration of f/up 24 days and median number of visits 11. Visit for assessment/management followed the Acute Respiratory Assessment Service (ARAS) model. Out-of-hours care by GP. Aim/question: Hypothesis that patients currently treated throughout the course of their illness at hospital could be treated successfully at home after a brief period in hospital.	1-Health care utilisation-readmission rate or durat stay on readmission, days readmission 2-Survival.
Davies 2000	UK 3 months. Single centre	Two groups: 1-control n=50 (usual treatment-conventional hospital management), 2- intervention. n=100.	A diagnosis of COPD based on standard criteria.	'Hospital at home'/ACTRITE (3 whole time equivalent Respiratory Nurse Specialists (RNS). Patient presenting with an exacerbation of COPD assessed by RNS in A&E, discharged with no overnight stay, patients escorted home by RNS, social support available if needed. Discharge medication package given, nurse visits twice daily for 3 days and thereafter as needed. Out-of-hours cover by existing district nurse care. Aim/question: Hypothesis that selected patients currently admitted with exacerbations of COPD could be safely cared for at home with sufficient support.	Main outcome 1-Health s use-Readmission rate, 2-Pulmonary function FEV1, Survival. Other outcomes QOL- Subgroup SGRQ

Skwar-ska, 2000	UK single centre 2 months	Two groups: 1-control n=62 (usual treatment), 2-intervention n=122. Cost effectiveness analysis	Patients presenting to A&E with a diagnosis of an exacerbation of COPD as the main reason for admission.	Acute Respiratory Assessment Service/home support discharge. Team of nursing and medical staff. Weekday office hours, Patients discharged home (with? no overnight stay) with treatment package. Nurse visit day after hospital discharge and then 2/3 days until recovery is sufficient to no longer require support. Visit for assessment. Out-of-hours cover not specified. Aim/question: to assess the potential of reducing emergency admission.	1-Health service use Rea rates time to discharge, 2 Pulmonary function, 3-QC Satisfaction 5-cost effectiveness.
Nichols on 2001	Australia, 2 centre. Duration of f/up unclear	Two groups: 1-Control n=12, 2-Intervention n=13. Cost minimalisation	Aged>45 yrs, COPD-FEV1 <60%, admitted	Early discharge Mandatory nurse visits day 1, 2, 3, 7 and optional visits 4, 5, 6. GPs reviewed patients in own home. Supportive services involved (i.e. occupational therapy, physiotherapy). Out-of-hours: hospital staff provided 24hr phone support. Aim/question: To compare the resource use and costs of acute care at home, hospital at home, with inpatient care for acute COPD patients.	Main outcome Costs. Other outcomes Lung fun satisfaction, psychologica morbidity
Sala 2001	Spain, single centre. Duration unclear	Parallel controlled trial. N=105 in intervention, 100 in control.	Admission to respiratory ward with diagnosis of exacerbation of COPD.	'Supported discharge'. After first few days in hospital patients discharged home, days after discharge hospital based RNS home visit and thereafter visit as needed. Discharge package included O2 and nebuliser if needed. At visit assessment. Patient could reach nurse via mobile phone during regular working hours. Out-of-hours cover not specified. At end of home support programme lung specialist visited patient. Aim/question:1-To assess feasibility and safety of supported discharge program, 2-Its impact on length of stay, 3-its effects on hospital resources	Hospital service utilisation Length of stay, number o patients hospitalised duri supported discharge and hospitalised during first 2 following discharge and a weeks, mean number of h beds utilised daily by resp patients. Also looked at: visits at home/ patient ar mobile calls

Ojoo, 2002	UK Single centre. 3 months	Two groups: control n=30 (usual treatment-conventional hospital management) or intervention n=30.	over 18, FEV1/FVC ratio <70%, FEV1 reversibility to salbutamol <15% worsening of symptoms with any combination of: increased purulence and/or volume and worsening dyspnoea.	'Hospital at home'. 2 outreach nurses. Referral at hospital for exacerbation of COPD, discharge within 48 hours of admission with a discharge package including medication and 02 if needed. Assessed daily and gave education and support. Out-of-hours support via chest clinic. Out-of-hours: dirt phone line to chest clinic support (no other out-of-hours support specified). Aim/question: To determine patient and carer preferred site of management and satisfaction with care received in patients randomised to either hospital at home or inpatient management.	1-Patient preference-retrospective preference gain via structured interview and questionnaire administered by blinded observer 2 weeks after discharge. 2-Satisfaction, 3-Pulmonary function, 4-Health service use 5-Survival
Hernandez, 2003[1]	Spain, 2 centres, 2 months	Two groups n=101 (usual treatment-conventional hospital management)	COPD exacerbation as a major cause of referral to A&E and	'Home hospitalisation'. Assessed by specialised team (1 chest physician and 1 nurse) at Emergency Room admission for exacerbation of COPD on weekdays office hours. - Decision on ER or after short period of hospitalisation. At discharge home pharmacological therapy, and 2 hrs tailored education including recognition/ prevention of exacerbations, ADL, socialisation. Pt	Main outcomes; 1-Health service use-readmission, A&E visits, 2-survival, 3-QOL-(SGRQ, SF-12), Other outcomes 1-self-

		or intervention. n=121. Cost effectiveness analysis.	absence of any criteria for imperative hospitalisation as stated by the BTS guidelines	visited within 24hrs discharge for 1 hr visit for assessment and education, up to 5 visits in next 2 months and free phone access, with nurse calls to ensure compliance. Aim/question: Hypothesis: That home hospitalisation with free phone access to RNS would generate a better outcome at lower costs than inpatient hospitalisation.	management, 2-satisfaction. 3-Knowledge Cost considered on length of stay, A&E visits, outpatient visits, GP visits, social support visits, nurse home visits, prescriptions, and calls and transportation services. Values inferred from average tariffs for COPD patients in a public insurance company.

Abbreviations used in table: FEV-=forced expiratory volume at 1 second,. FVC=forced vital capacity, GP=General Practitioner, HADS=Hospital and Depression Scale, HRQOL=Health related quality of life, QOL=Quality of life, SRGQ=St. Georges Respiratory Questionnaire.

Interventions for acute exacerbations of COPD: the Cochrane systematic review

The systematic review by Ram (2003) reviewed RCTs of hospital at home schemes for the management of acute exacerbations of COPD and included the six RCTs we identified (Cotton 2000; Davies 2000; Skwarska 2000; Nicholson 2001; Ojoo 2002; Hernandez 2003). It also included a study that did not meet our eligibility criteria as it included a sample of patients with a variety of diseases (Shepperd 1998). The reviewers considered that all studies were of high methodological quality. The RCTs provided data on hospital readmission and mortality both of which were not significantly different when the two groups were compared (RR 0.89; 95 per cent CI 0.72 to 1.12 and RR 0.61; CI 0.36 to 1.05, respectively). Both patients and the carers preferred hospital at home schemes to inpatient care (RR 1.53; 95 per cent CI 1.23 to 1.90). Ram (2003) concluded that; 'One in four carefully selected patients presenting to hospital emergency departments with acute exacerbations of chronic obstructive pulmonary disease can be safely and successfully treated at home with support from respiratory nurses.' The review found no evidence of significant differences between 'hospital at home' patients and hospital inpatients for readmission rates and mortality at two to three months after the initial exacerbation.

Interventions for acute exacerbations of COPD: patient groups in the identified in controlled studies

A total of 927 participants were included in the seven trials. The individual sample size ranged from 25 to 222. Participants' gender was approximately distributed equally in three trials, one trial had fewer males in the control group (Skawarska 2000), and in one trial 97 per cent of patients were male (Hernandez 2003). The gender distribution was not reported in two trials (Nicholson 2001; Sala 2001). The mean age of patients ranged from 65 to 71 years and was similar in both arms in all the RCTs, in the parallel group study the patients in the comparison group were younger (although this difference was not statistically significant), mean 65 years versus 70 in the intervention group (Sala 2001). One trial did not report participants' age (Nicholson 2001).

In all studies patients had presented to health services with an acute exacerbation of COPD. The percentage of predicted

forced expiratory volume in one second (FEV1) was recorded at recruitment in four studies, with the average ranging from 35 per cent to 46 per cent (Davies 2000; Cotton 2000; Sala 2001; Hernandez 2003), not all studies stated whether this was tested post bronchodilator (Cotton 2000). Mean FEV1 was reported in four trials (Cotton 2000; Davies 2000; Skwarska 2000; Ojoo 2002) and values ranged from 0.66 l Skwarska 2000) to 1.0 l (Ojoo 2002).

The studies all excluded patients with severe co-morbidity. Other exclusions included patients who had no phone access, were not living in the locality, lived alone or had poor social conditions (criteria for entry into the individual studies are outlined in Table 2.5 and in more detail in Appendix 6). The total number of patients who presented to health services with an acute exacerbation of COPD and who took part in the studies was 697/2613 (27 per cent). (Two studies did not provide this information). The main reason for exclusion from the studies was a complicated exacerbation of COPD.

Discharge arrangements

The time between the patient presenting with an acute exacerbation and hospital discharge varied according to the type of scheme being evaluated. In the hospital at home schemes a patient could enter the scheme without an overnight hospital stay (Davies 2000; Skwarska 2000). In the two trials on early discharge patients were assessed for eligibility the day after admission (Cotton 2000; Ojoo 2002). The Hernandez trial evaluated both a hospital at home scheme and an early discharge scheme (2003). In the trial on supported discharge they were assessed for eligibility after receiving a few days standardised hospital care (Sala 2001). Discharge arrangements were not reported in Nicholson's trial.

Interventions for acute exacerbations of COPD: components of the interventions

All the reports gave detailed descriptions of their interventions (Nicholson (2001) provided most detail on a website (http://www.health.gov.au/hsdd/acc/ndhp/pdfs/hsr12.pdf). On the whole the components and the intensity of the interventions studied were similar. In all the interventions the respiratory nurse was the main health care provider. Five trials stated that their service operated on weekdays only (Cotton 2000; Nicholson 2001; Ojoo 2002; Skwarska 2000; Hernandez 2003). All trials were undertaken from

secondary health care, apart from Cotton (2000). Not all reported the number of whole time equivalent nurses in the team; those that did had two (Ojoo 2002) or three (Davies 2000).

Discharge package

Four trials documented a discharge package of pharmacological therapy and equipment, including antibiotics, corticosteroids, nebulised bronchodilators and oxygen concentrator (Davies 2000; Skwarska 2000; Sala 2001; Ojoo 2002). In the trial by Hernandez (2003), in addition to pharmacological therapy, before discharge patients were given two hours tailored to their needs on education and training on adherence and recognition/ prevention of triggers of exacerbations, training on using drug therapy, smoking cessation, daily activity advice and dietary advice. In two trials no details on a discharge package of care were given (Cotton 2000; Nicholson 2001).

It was reported that patients were escorted home after discharge by the respiratory nurse in one trial (Davies 2000). In four trials the patient was seen at home within 24 hours of discharge home (Cotton 2000; Swarska 2000; Sala 2001; Hernandez 2003). One trial did not detail time from hospital discharge to the patient's first home visit (Ojoo 2002).

Home care

The duration of the schemes and the number of nurse visits varied. The average length of time on the scheme ranged from seven days (Skawarska 2000; Sala 2001) to 24 days (Cotton 2000). Hernandez (2003) reported that patients could remain on the scheme for up to eight weeks but did not report the average time actually spent on the scheme. Three trials did not report the duration (Davies 2000; Nicholson 2001; Ojoo 2002). The average number of nurse home visits ranged from two to 11, in Ojoo's trial this was not reported.

Five trials gave details on the content of home visits. In Cotton's trial the home management followed the Acute Respiratory Assessment Service (ARAS) model which involved the nurse assessing the patient's progress based on subjective feelings and clinical observations. The other trials also stated that the nurse assessed the patient (Nicholson 2001; Sala 2001; Ojoo 2002; Hernandez 2003), and two also stated that education was provided (Ojoo 2002; Hernandez 2003).

24 hour cover

Not all trials specified if 24 hour cover was provided (Skwarska 2000; Sala 2001; Hernandez 2003). Out-of-hours cover, when specified, was either undertaken within primary and community care (Cotton 2000; Davis 2000) or within secondary care (Nicholson 2001; Ojoo 2002).

Care pathway

A care pathway for the exacerbation was mentioned in four studies (Skwarska 2000; Cotton 2000; Davies 2000; Nicholson 2001; Sala 2001). Not all specified who provided clinical support to the nurses but when specified it was the hospital respiratory medical team (Skwarska 2000; Davies 2000; Sala 2001; Nicholson 2001; Hernandez 2003).

Length of follow-up

Length of follow-up varied. In two trials it was two weeks, (Nicholson 2001; Ojoo 2002). The other trials followed patients up to two or three months.

Trial aims

The stated main aims of the trials varied and some had several aims. Three explored the safety of services (Davies 2000; Skwarska 2000; Nicholson 2001), four effectiveness (Cotton 2000; Skwarska 2000; Hernandez 2003), two patient satisfaction (Skwarska 2000; Ojoo 2002), two quality of life (Skwarska 2000; Hernandez 2003) and two costs (Skwarska 2000; Nicholson 2001).

Interventions for acute exacerbations of COPD: comparison or control groups

All trials used standard hospital care as treatment for the comparison group.

Interventions for acute exacerbations of COPD: quality of included controlled trials

The published reports of all controlled trials suggested potential methodological limitations that could have affected the validity or generalisability of their findings. In particular:

A potential major limitation of all the studies was their small sample sizes: four studies had less than 100 patients in each arm (Skwarska 2000; Ojoo 2002; Nicholson 2001; Cotton 2002). Only two studies gave power calculations (Davies 2000; Skwarska 2000). None of the studies were designed

to show true equivalence between the intervention and usual care (Jones 1996).

All were single centre studies.

Only two studies adequately described the method of randomisation (Cotton 2002; Hermandez 2003).

Several studies reported methodological characteristics that may have biased their findings (see Table 2.6 and Appendix 6)

The quality criteria for these studies is summarised in Table 2.6. Based on these findings we assessed the level of evidence for these studies ranged from 2b to 1b.

Table 2.6 Methodological quality assessment of RCTs of nurse interventions for acute management of patients with COPD.

	Described as randomised *#	Sequence generation *#	Allocation concealment #	Described as double-blind#[1]	Describe withdrawals and dropouts#	Baseline Similarity *	Eligibility Criteria*	Assessor Blinded*	Point estimate and variability#	Intention-to- treat analysis*
Cotton, 2002	Y	Y	Y	N	Y	Y	Y	U	Y	Y
Davies, 2000	Y	N	Y	N	Y	Y	Y	U	N	Y
Hermande , 2003	Y	Y	Y	N	U	Y	Y	U	Y	U
Nicholson, 2001	Y	U	U	N	N	N	Y	U	Y	U
Ojoo, 2002	Y	U	Y	N	Y	Y	Y	U	N	U
Skwarska, 2000	Y	Y	U	N	Y	Y	Y	N	N	U

N=NO, U=Unclear, Y=Yes.

**items from: Delphi criteria (Verhagen 1998), # items from Jadad Score (Jadad 1996)*

Level of evidence score from Oxford Centre for Evidence-based Medicine Levels of Evidence (May 2001)
www.infopoems.com/resources/levels.

[1] This criterion was not used in our assessment of study quality since it is not be feasible for these types of trials to be double blind.

Interventions for acute exacerbations of COPD: findings of RCTs

(See Appendix 6 for data extraction sheets for each study.)

Patient outcomes

Health related quality of life (HRQL)

Three RCTs (Davies 2000; Skwarska 2000; Hernandez 2003) evaluated patients' HRQL. In one trial (Hernandez) this was a primary outcome and the mean improvement in total SGRQ score between baseline and follow up was significantly greater in the intervention group compared to the control group (mean improvement -6.9 intervention vs. 2.4 controls, p=0.05). A difference of this magnitude is likely to be clinically significant. In the Davies trial, in a subgroup analysis of 50 patients there was no significant difference in SGRQ score between baseline and follow up in intervention or control patients, but these results may have been affected by high attrition in both arms of the trial. Skwarska's trial reported no significant differences between the groups on any dimension of the Chronic Respiratory Questionnaire. One study used the Short Form-12, they found no significant difference in scores (Hernandez 2003).

Patient satisfaction with service and service preference

Three RCTs evaluated patient satisfaction with the service (Nicholson 2001; Ojoo 2002; Hernandez 2003). In one trial, satisfaction was measured two weeks after discharge from the acute scheme by a blinded observer using an unvalidated questionnaire developed specifically for the project (Ojoo 2002). The authors found no statistically significant difference in satisfaction between the trial arms. Neither the Hernandez trial or the Nicholson trial provided details on what instrument was used or how it was measured.

Ojoo (2000) also assessed patient service preference two weeks after discharge. Preference was based on a single question. Patients in the intervention arm were significantly more likely to prefer domiciliary care 26/27 (96.3 per cent) compared with the control group 16/27 (59.3 per cent) (p=0.001).

Patient knowledge about COPD and patient self management skills

One RCT evaluated patients' knowledge of their illness (Hernandez 2003). No details are provided of how they assessed knowledge. They found significantly more patients who had domiciliary care improved their level of knowledge compared to those who had

been treated in hospital, 58 per cent versus 27 per cent p= <0.01. The same trial found significantly better compliance with inhaler technique in the intervention group compared to the control group, 81 per cent versus 48 per cent p=<0.001. However, they did not provide details of how they measured compliance or specified if the observer was blinded.

Mortality to three months

Five RCTs evaluated mortality (Cotton 2000; Davies 2000; Ojoo 2002; Skwarska 2002; Hernandez 2003); in three studies it was identified as a primary outcome (Davies 2000; Cotton 2000; Hernandez 2003). All studies found mortality to be similar in both groups, with trials reporting 2.4 per cent to 9 per cent of patients dying up to three months post recruitment onto the study (Peto odds ratio 0.63, 95 per cent CI 0.30 to 1.32) (Forrest plot in Appendix 7B). A second meta-analysis excluding Hernandez (as this trial had not reported loss to follow-up) found very similar results (Peto odds ratio 0.66, 95 per cent CI 0.26 to 1.72).

Pulmonary function

Four RCTs evaluated pulmonary function (Davies 2000; Nicholson 2001; Ojoo 2002; Skwarska 2002), one identified it as a primary outcome (Davies 2000). All reported FEV1. In three studies, overall no significant differences were observed in pulmonary function (Davies 2000; Ojoo 2002; Skwarska 2002). The fourth, a small pilot study, reports a significant improvement in FEV1 in the hospital group, only the p value was reported (p=<0.05) (Nicholson 2001).

The Ojoo group also evaluated mean improvement in FVC (per cent predicted) they found no statistically significant difference. In one trial they undertook other lung function tests (Skwarska 2002), both arms of the trial showed similar significant improvements in respiratory rate and peak expiratory flow rate.

Oxygen saturation

One RCT assessed mean change of oxygen saturation (Skwarska 2002), it found a statistically significant improvement in both groups.

Symptoms

One RCT evaluated symptoms. It used a 3 to 10 point scoring system for seven COPD symptoms (not reported as a validated measure), scores were not statistically significantly different between groups (Ojoo 2002).

Carer satisfaction with service and service preference

One RCT (Ojoo 2002) evaluated carers' satisfaction, it asked 12 questions on aspects of care: two were open-ended and the rest used a likert scale. No significant differences were seen between the groups. The same trial evaluated carer service preference two weeks after discharge based on one question. They found significantly more carers in the intervention group preferred domiciliary care: 17/20 (85.7 per cent) versus 6/14 (42.9 per cent), p=0.01.

Health care use: days in hospital at initial presentation

Two trials measured days spent in hospital at the initial presentation with an acute exacerbation (Cotton 2000; Hernandez 2003). In the Hernandez trial those in the intervention group spent an average 1.71 days in hospital (SD 2.33) compared to 4.15 (SD 4.1) days in the controls p=<0.001. In Cotton's trial the early discharge group's mean length of stay was 3.2 days (range 1-16) compared to 6.1 (range 1-13) with conventional management.

Health care use: days under hospital/domiciliary care

Three trials compared days spent under domiciliary care for the intervention group compared to days spent under hospital care for patients in the control group (Ojoo 2000; Skwarska 2000; Hernandez 2003). All found patients in the domiciliary group spent longer under care: 7.4 vs. 5.9 (NS) (Ojoo 2000); 7 vs. 5 (median) (p=0.01) (Skwarska 2000); and 7 vs 5 (p=<0.01) (Hernandez 2003).

Health care use: hospital readmission before discharge from nurse scheme

Two trials reported the proportion of intervention patients that were readmitted before discharge from the home nursing scheme: 7 per cent (n=9) (Skwarska 2000); 9 per cent (n=9) (Davies 2000).

Health care use: hospital readmission to three months

Five trials reported hospital readmission data (Davies 2000; Cotton 2000; Skwarska 2000; Ojoo 2002; Hernandez 2003). In two trials it was the primary outcome (Cotton 2000; Davies 2000), and two trials differentiated between respiratory and all cause readmissions (Davies 2000; Skwarska 2000). No statistically significant difference in the proportion of patients readmitted in the intervention or control groups was found (Skwarska 2000; Ojoo 2002; Hernandez 2003) or per group (Davies 2000; Ojoo 2002) was found (Peto OR 0.76; 95 per cent

CI 0.54 to 1.06) (see Appendix 7B for Forrest plot). Meta-analysis of the two trials that evaluated respiratory readmission during follow up was not significant (Peto OR for readmission 0.70; 95 per cent CI 0.42 to 1.16).

Health care use: emergency department attendance

One RCT trial evaluated the number of emergency department visits (Hernandez 2003). They found significantly fewer patients in the intervention group visited the emergency department; 11(9.6) vs. 21(22.3) (p=0.02). The mean number of emergency department visits per patient was also fewer in the intervention group 0.13 (SD 0.43) vs. 0.31 (0.62) (p=0.01).

Additional social services for home care group

Only one trial documented overall social service use in the home care group, they found 24/100 required social referral with a median of 20 hours care (Davies 2000).

GP visits

One trial assessed the number of GP home visits (Skwarska 2000). No significant difference was found between the study arms.

GP satisfaction with service

One trial assessed GP satisfaction with the care of the patients in the intervention group using a postal questionnaire (Skwarska 2000). The results were affected by a high non response rate. All respondents were satisfied with the decision to provide domiciliary support.

Interventions for acute exacerbations: other quantitative studies

Gravil (1998), Flanigan (1999), Sala (2001) and Gibbons (2001) examined the effect of an acute respiratory assessment service for patients with an exacerbation of COPD. Sala's study is a parallel group controlled trial that assessed the length of hospital stay and readmission rates. Gravil's paper and Flanigan's paper were mainly descriptive but undertook a survey of patient satisfaction with the service. The Gibbon group used a pre-test, post test design and evaluated the effect on length of hospital stay and cost on 218 patients referred to the service over a seven month period.

Since the strength of the evidence from these studies was lower than that from the included RCTs, and none of the outcomes examined in these studies differed from those examined in the

RCT studies, their results are not presented here. Key descriptive data has been extracted in the appendices. The trial by Cotton used the intervention described by Gravil in their evaluation, this description has been combined with the extraction for the Cotton trial (see Appendix 6 for data abstraction sheets).

Interventions for acute exacerbations of COPD: economic analyses

Health service cost

Three RCTs (Skawarska 2000; Nicholson 2001; Hernandez 2003) and one cohort study (Gordois 2002) assessed cost. Costs considered were only health care costs including length of inpatient stay, number of emergency department attendances, drug use and GP costs. In the Nicholson trial, cost was identified as a primary outcome. All trials report the delivery of the intervention as being less costly. In the Skwarska trial the mean health service cost per patient was £877 for home support group and £1753 for patients admitted to hospital. The mean cost of GP care between discharge and final assessment was slightly greater for the hospitalised patients than for the ARAS patients. In the Hernandez trial the average direct costs per patient home hospitalisation were €1233.12 (95 per cent CI 978.54-1568.04) and for conventional care €2033.51 (95 per cent CI 1547 to 2556.81).

In Nicholson's trial the average cost per episode was $2534 (95 per cent CI 1766-3321) in the control group and $745 (95 per cent CI 595-895) in the intervention. The other study that assessed cost, Gordois 2002, was of a weaker methodological design (uncontrolled cohort study). It assessed cost by number of bed days and therapy use, and estimated that 1437 bed days were saved, 427 months of long term nebuliser therapy and 63 courses of antibiotics.

Interventions for acute care: qualitative evidence

No studies were identified.

Interventions for acute care: Dutch language literature

No studies were identified.

Interventions for acute care: conclusions with level of evidence rating on outcomes

There is reasonable evidence that among the selective patient populations that have been included in trials to date domiciliary interventions for acute care in COPD;

- do not increase mortality (level of evidence 1a).

- do not affect pulmonary function (level of evidence 1a).

- reduce the length of hospital stay at initial presentation (level of evidence 1a).

- do not affect hospital readmission to three months (level of evidence 1a).

- result in the patient remaining under the care of the specialist health professional for a longer duration than conventional hospital care (level of evidence 1a).

There is some evidence to suggest that domiciliary interventions for acute care in COPD;

- is the preferred care option for patients and carers (Level of evidence 2b)

- improves patients' knowledge and their self management skills (level of evidence 2b)

- does not reduce patient's oxygen saturation (level of evidence 2b)

- does not increase GP home visits (level of evidence 2b)

- early discharge schemes and schemes that avoid hospital admission altogether appear to be equally safe (level of evidence 1a-).

There is no evidence or the available evidence is very weak or equivocal on the effect of the se interventions on the following areas;

- patients' and carers' health related quality of life

- patients' and carers' satisfaction with care

- patients' and carers' psychological well-being

- their effect on symptoms

- their effect on community, general practice and social support services

- what members of the primary care and secondary care team think of these interventions.

Ongoing and unpublished evaluations

We identified 21 ongoing evaluative studies and for 13 of these we were able to contact one of the authors (see Table 2.7 for details of these studies). Four further studies have been completed and are awaiting publication (see Table 2.8)

Table 2.7 Evaluative studies in progress

Author, name of study	Study design, country	Intervention	Comment
Fowler, A quantitative and qualitative evaluation of a respiratory specialist nurse service for patients with moderate or severe chronic obstructive airways disease Source: NRR	Observational cohort study and qualitative study, UK	RNS chronic disease management model with clinic and home visit follow up.	Report in preparation
Griffiths, Multidisciplinary support for patients with COPD following hospital discharge Source: NRR	RCT, two centres, UK	Home support visits for 2 months at discharge following an acute exacerbation of COPD	Due to be completed in 2004
Kinn, Patient preferences for COPD exacerbations and accident and emergency attendance. Source: Annual International Nursing Research Conference, UMIST 2003	Survey, UK	Hospital at home	Due to be completed in 2004
Kloosterziel, The respiratory nurse as disease specific nurse for patients with COPD Source: H Vrijoef	RCT, The Netherlands	Respiratory nurse clinic versus pulmonologist clinic	Due to be completed end of 2004 or early 2005
Mair, Acute chest triage rapid intervention guided by home care or telecare Source: NRR	RCT, UK	To compare nurse home care with nurse telecare for the treatment of acute exacerbations in patients with COPD	Study in progress
Morrison, The effect of a respiratory	Before and after study,	Respiratory outreach and	Report in

nursing outreach and pulmonary rehabilitation scheme on hospital admissions with COPD Source: Thorax 2000; 55 (supple 3).	UK	pulmonary rehabilitation for patients presenting with an exacerbation of COPD	preparation
Tolson An exploration of patient and family experiences and care preferences during the treatment of acute uncomplicated COPD exacerbations. Source: Personal communication	Not known, UK	Home care for acute exacerbation of COPD	No results reported yet.
Vrijhoef Specialist nurse-led clinics Source: Personal communication	Non-equivalent control group design, Netherlands	Specialist-nurse led clinics vs. general practitioner clinics in primary care	Study in progress.

Table 2.8 Studies completed but unpublished

Author, name of study	Study design, country	Intervention	Comment
Crewes Role of Respiratory Nurse Specialist. Source: NRR	Multicentre RCT, UK	RNS home visits to patients with COPD and on LTOT	Unpublished report: (insufficient information for data abstraction and inclusion in main review)
Vrijhoef Specialist nurse led clinics Source: Personal communication	RCT, The Netherlands	Specialist-nurse led clinics vs. respiratory consultant clinics in secondary care	Study completed, paper submitted for publication.
White Home based rehabilitation study of patients with COPD Source: NRR	RCT, UK	Home support and education by nurses and physiotherapists following discharge from hospital.	Study completed, paper submitted for publication
Jones A survey of community based pulmonary rehabilitation Source: Personal communication	Qualitative Study, UK	Nurse co-ordinated pulmonary rehabilitation service	Unpublished report.

2.5 Systematic search for evidence on implementation of nurse innovations for COPD form the material in the review and from the survey

One of the original aims of this project was to examine with what success innovations involving nurses for the care of people with COPD living in the community have been implemented within the NHS. We specifically wanted to identify factors promoting or impeding the implementation of the innovations reviewed in Sections 2.3 and 2.4. Our original hypothesis was that information on implementation issues might be a particular feature of the grey or unpublished literature (a full report of this exercise is presented in Appendix 8).

2.5.1 Methods

Two researchers working independently reviewed all the published and unpublished literature eligible for inclusion in the main review together with the service literature sent at our request in by respondents to our survey of health providers (see Chapter 3 for details on retrieval). Papers that described factors or arrangements that facilitated the delivery of the intervention, or that mentioned organisational problems during the set up or delivery were included in this exercise.

The reviewers abstracted all the information on implementation and attempted to grade the evidence for quality as described in Section 2.3. For non-evaluative studies we intended to test the application of a framework, TAPUPAS, developed by the UK Centre for Evidence Based Policy and Practice, Queen Mary, University of London (Pawson, 2003). This framework has seven main themes: transparency; accuracy; purposivity; utility; propriety; accessibility; and specificity.

To provide information on the scope of implementation information provided, the implementation issues arising were considered in relation to the overarching 'generic' themes arising from work by Griffith and Bryar (2003). Their themes for the successful development of community nursing practice were drawn from examination of a large number of practice development activities in community nursing and from the practice development literature

2.5.2 Results

Many papers mentioned implementation issues but provided very little information. There was so little information in the included papers that it was not possible to assess the quality of the evidence for the statements on implementation. Most of the information on implementation concerned innovations for acute exacerbations. Despite this we did identify several statements on implementation - these most commonly related to helping the service become part of main stream health services by ensuring a good communication network is established between services. Examples of this included allowing sufficient lead time to introduce the service, setting up communication pathways and employing support staff. Another common implementation theme was the necessity of gaining support from healthcare management and the clinical respiratory team in order to establish recognition of the service, provide ease of referrals to and from the service and for clinical and medical legal support.

The implementation issues arising were plotted against the themes proposed by Griffiths and Bryar (2003) (see Appendix 8), but several of the themes were overlapping and allocation of different implementation issues to particular themes involved was a subjective decision. The information on implementation abstracted was characterised by lack of detail.

2.6 Rapid review of other systematic reviews of specialist nurse innovations for patients living in the community with chronic diseases

We compared the findings of this review with the findings of SRs of specialist nurse innovations for patients living in the community with four other chronic diseases: congestive heart failure (CHF), Parkinson's disease, renal failure and diabetes mellitus (DM) identified in a rapid and pragmatic search for RCTs. The aim was to explore the components of the interventions, the outcomes measured and any evidence on their effectiveness, and to compare these findings with those of the COPD review.

2.6.1 Methods

Databases searched

The four databases searched were: the Cochrane database of systematic reviews, DARE, the Health Technology Assessment (HTA) database and CINHAL. We also had access to the extensive literature retrieved during a recently completed Cochrane

systematic review of disease management programs for patients with CHF which had been led by one of the reviewers (Taylor, 2003). Search strategies, eligibility criteria and screening for eligibility and data extraction, quality evaluation and synthesis are reported in Appendix 9.

2.6.2 Results

All reviews provided documentation on the review process but, apart from the Cochrane SR (Loveman 2003), this was very brief. Since less reliance could be placed on these SRs because of the under reporting of key methodological processes, we excluded all except Loveman. This SR explored the effectiveness of nurse specialist nurse interventions for patients in the community with diabetes mellitus. After in depth data extraction it was found that this SR did not inform the COPD review. The interventions were different and the main outcome measured in all trials were diabetes specific process outcomes, (e.g. glycaemic control) only one measured quality of life (further details on methods and findings are in Appendix 9)

2.7 Consumer consultation on interim report

After synthesising the RCT studies, completing the survey of service provision (Chapter 3) and developing some draft recommendations we consulted the members of four British Lung Foundation patient self-help 'Breathe Easy' groups for feedback.

2.7.1 Consultation exercise methods

There is no gold standard method of lay consultation (Ryan 2001). We devised our approach to consumer consultation after seeking advice from INVOLVE (formerly Consumers in NHS Research), the Cochrane Consumer and Communications group and in consultation with the review's advisory groups. Having gained permission form the British Lung Foundation, we approached four groups located in geographically and socio-economic diverse areas of England and Wales. We choose groups known to be with and without access to a COPD nurse specialist service. The groups had a combined membership of 1,053. Members were mostly chronic respiratory patients and their carers. COPD was one of the most common respiratory disorders afflicting members. All four of the groups approached were willing to participate in the consultation.

In the spring of 2003 we presented the proposed project to each group at one of their regular meetings. The presentation was supported by a leaflet. Each branch also wrote a small piece on our research in their newsletter. At each presentation we asked

the members how they would like us to capture and reflect their views on the preliminary report. Three of the groups wanted to be sent a copy of the report and to respond by post and two wanted a follow-up presentation and discussion (one group wanted both). We also made it possible for consumers to read and respond to the report via our website.

A lay version of the preliminary report was developed for users and carers (see Appendix 10). After discussion with the Steering Group three questions were formulated and a feedback form developed (see Box 2.2 for a summary of the form and see Appendix 11 for a copy of the feedback form). Prior to presenting to the groups the material was piloted on several consumers.

Box 2.2 Summary of feedback form.

Our questions to you:

Overall, the study results suggest to us that (A) specialist nurse services to patients in the community with stable COPD do not work, and that (B) some patients with an attack of COPD can be treated as well at home as in hospital

1. Is this sort of research important to you?
2. Are the researchers, in the studies we found, testing for the right sorts of thing?
3. Should decisions on whether or not to provide services be based on this sort of evidence, or should decisions be based on, or take into account other things?

We posted 998 copies of the preliminary report and feedback form to members of three of the Breathe Easy groups. In each group's newsletter there was another brief, supportive article on the consultation exercise. We also met with around 80 users and carers in person when we presented the findings and recommendations to two Breathe Easy Groups. At these meetings Breath Easy members working in small groups discussed the questions and completed feedback forms.

Two reviewers working independently read all the consumer responses. Each reviewer identified themes and these were compared.

Please note: we did not intend to conduct a piece of in depth, rigorous qualitative research around the consumer consultation exercise. We have simply borrowed some of the techniques commonly used in the analysis and presentation of qualitative data (identification of recurrent themes, presentation of quotes) to help us collate and summarise the consumer responses.

2.7.2 Results

84 completed feedback sheets were returned – this represents a response from many more than 84 individuals as these include the responses of patient-carer couples and responses arising from the small group discussions.

Responses were frequently very detailed and contained a wealth of information about patients' and carers' individual experiences of care for their lung disorder. Many of the comments received, although valuable accounts of patients' and carers' experiences, did not address our questions.

Question 1: Is this sort of research important to Breathe Easy members?

The vast majority of respondents felt that the sort of research described in the RCTs was important and many felt it was very important. Both those who had experienced a respiratory nurse specialist service, and those who had not, believed the research was important. Respondents often spontaneously said that this sort of research was important for both patients and carers. See Box 2.3 for examples of some of their responses.

Box 2.3 Example of some of the responses to the question 'Is this sort of research important to you?'

'Any sort of research into COPD and the way patients can be treated quickly and at home…it can only be for the better'.

'[The research] is very important but would appreciate that carer's comments be sought.'

'It is very important to me. At the moment I do receive some visits from the respiratory nurse instead of having to attend the clinic and I benefit from her expert advice and help.'

'Yes [the research is important], but we need to be better informed exactly what is happening all too often we are told at the end of a study when it is too late to make an impression.'

Question 2: Are the studies looking at the right outcomes?

Respondents were shown/provided with a table of all the outcomes that the RCTs had examined. Most respondents felt that these studies were looking at appropriate outcomes but several mentioned the need to look at;

- the psychological benefits of treatment
- the effect on self management
- the effect on quality of life and
- the impact on the carer.

Some respondents mentioned the importance of considering patient satisfaction (see Box 2.4 for examples of some responses)

Box: 2.4 Example of some of the responses to the question 'Are the researchers, in the studies we found, testing for the right sort of thing?'

'We consider more research should be done into the non-professional carers – spouses and partners- and lines of communication between professional and non-professional carers and on lines of communication between hospitals and GP on discharge of patient.'

'I honestly think not, quality of life means more than a survey showing in about 80% of the people only the nursing specialist can help in this field.'

'Broadly yes, but as I only receive one visit per year from the specialist nurse it is impossible to judge the efficacy of such a service – probably a waste of money'.

Question 3: Basing decisions around provision of services on this sort of evidence

Responses to the first two questions were generally affirmative but the responses to our third question on using RCT evidence to make decisions on service provision were split. Around half of the feedback sheets said that decisions should be based on this sort of evidence while the remainder said that decisions should take other things into account.

Whether or not respondents felt that service planning should be based on the type of trial evidence presented, a number of the things respondents felt should be taken into account emerged repeatedly;

- the individual nature of each patient and their particular needs
- the need to ask patients
- the need for better information for patients about COPD
- the need for better education of patients about COPD
- the importance of patient choice about care
- negative experiences of previous hospital care for COPD
- negative experiences of GP care for COPD
- benefit from their existing respiratory nurse specialist
- the belief that a respiratory nurse specialist would help them.

Respondents also frequently called for more funds for COPD services. Some of the responses (Box 2.5) illustrate the respondents' strong desire for the voices of patients to be heard and the potential difficulties of applying RCT evidence to individuals with their own opinions, beliefs and experiences.

Box 2.5 Example of some of the responses to the question 'Should decisions on whether or not to provide services be based on this sort of evidence, or should decisions be based on, or take into account other things?'

'These decisions should not just depend on this sort of evidence. A lot more notice should be and I am glad to say, appears to be taken of patients' viewpoints. The NHS should involve COPD patients much more in their decision-making, especially those decisions where full medication is concerned.'

'I have been in hospital six times in the last 18 months so I seem to have the Acute Attack but after each time, I'm learning more and more about COPD. So the more research that goes into this disease the more people like me can learn how to deal with their illness and get the most out of life.'

'If all the criteria listed are taken into account it could be a good basis for decisions. However, patient's knowledge of the disease and detailed self-management of their condition would also allay anxiety / depression and naturally improve quality of life.'

'Yes. Services should be based on patient needs rather than dictate and patient consultation is imperative. Personal interviews would probably yield a much better understanding of what is ideally required.'

' [Decisions] should be based on individual cases as everyone suffers different degrees of COPD to get a full picture of the situation.'

'Other things must be taken into consideration, most elderly people rely on a nurse calling for comfort, information, help and friendship, for most it is their only lifeline to civilisation.'

'All aspects must be taken into account home conditions play a big part in success of any treatment. My own nurse is excellent but visits are a bit far apart due to overwork load.'

'Yes, but as NHS funding is finite the priority given must be based the overall perceived good weighed against the many other perhaps more important demands on the service. We need a 'Solomon' minister of health.'

'Decisions should be made by asking the patients where they prefer to be treated not assume if your send a nurse once a week all will be well.'

'I think decisions on not to or to provide services should always be based on the evidence no matter what they find the patient always comes first, this service helps people very much. In my case I'm very grateful. I've been lucky up until now that I have always been treated at the surgery.'

'I think that as services are provided, experience will show what changes or modifications would be beneficial.'

2.8 Provider consultation on interim report

1063 respondents (61 per cent) from our survey of current service provision (described in Chapter 3) said they would be interested in providing feedback on a preliminary version of our report.

2.8.1 Methods

After synthesising the RCTs we drafted a preliminary report with conclusions and recommendations for heath care providers. The findings, conclusions and recommendations did not differ substantially from those in this report. The document was placed on a password protected website together with an electronic feedback form. The feedback form asked five questions (see Box 2.6 and Appendix 12)

In November 2003 we wrote to all those who said they would be interested in providing feedback with the website address and password. We also offered to send out a hard copy of the report if requested. A month later we emailed a reminder to all those who had originally supplied us with an email address and sent letters to a random sample of respondents who had not provided an email address.

Box 2.6 Summary of the feedback form

Please indicate whether or not you agree with the following statements by clicking on the appropriate option:

1-Summarising the research evidence around innovations for COPD in this way is important?

Strongly agree Agree No opinion/unsure Disagree Strongly disagree

2-I was surprised by the findings of the survey and/or the preliminary summary of published evidence?

Strongly agree Agree No opinion/unsure Disagree Strongly disagree

3-The researchers involved in the individual studies included in this report looked at the right sort of outcomes?

Strongly agree Agree No opinion/unsure Disagree Strongly disagree

4-I concur with the recommendations in this preliminary report?

Strongly agree Agree No opinion/unsure Disagree Strongly disagree

5-Decisions on whether or not to provide services should be based on this sort of evidence?

Strongly agree Agree No opinion/unsure Disagree Strongly disagree

Provider responses were read by two reviewers independently, each identified themes within the responses.

2.8.2 Results of provider consultation exercise

Although we cannot state how many individual respondents viewed our results online, in November and December 2003 the password protected webpages were visited as follows;

- preliminary report 655 times

- executive summary 522 times

- feedback form 105 times.

Only 65 respondents (6 per cent of those we wrote to) sent feedback, respondents represented all the types of health professional originally surveyed but most respondents were nurse consultants or specialists (see Appendix 13). Their responses were often very brief. Two respondents did not answer the questions we set but gave overall comments.

The majority (59/62) agreed or strongly agreed that summarising the research evidence around innovations for COPD in this way was important. A few said that it was important to use other research methodologies as well. Around half stated that they were

surprised by the findings. Those that commented were invariably surprised by the lack of research evidence to support chronic disease management models. Several commented on the limited number of outcomes evaluated and on the limitations of the studies. Most respondents felt that the individual studies had looked at the right outcomes. A few outcomes that were not extensively evaluated in the studies were repeatedly suggested by respondents, these were: health related quality of life; carer outcomes; and self-management skills. Several of those who suggested the need for quality of life outcomes went on to state that this measurement was more appropriate than any other outcomes.

Most of the respondents (90 per cent) agreed with the recommendations of the preliminary report but, paradoxically, only half of the respondents agreed with the statement that decisions on whether or not to provide services should be based on this sort of evidence. Respondents commonly said that other factors should be taken into account, two were repeatedly mentioned:

- the need to take local factors, such as population and level of clinical expertise, into account and

- the need for more research.

Section 3 Specialist nurse services for patients in the community with COPD - A survey of current provision of services in England and Wales

3.1 Introduction

This chapter presents the methods and findings of the two-stage survey of respiratory health providers in England and Wales to investigate the extent, and characteristics, of *specialist* nurse services for patients in the community with COPD. It also presents conclusions, discussion and recommendations for policy and research in light of the evidence on effectiveness found in the main review.

3.2 Objectives

To conduct a postal survey of respiratory medicine consultants and members of: the Royal College of Nursing Respiratory Nurses Forum; the General Practice Airways Group; and primary care organisations in England and Wales. The survey aimed to;

- map current provision of specialist nurse services for people with COPD in England and Wales.

- identify relevant grey literature and ongoing or unpublished evaluations (the findings of this exercise are reported in Chapter 2).

- identify case examples of services from written material submitted by the services in the survey.

- draw conclusions and make recommendations based on the findings of the survey and the main literature review.

3.3 Methods

The survey was undertaken in two stages. The first stage identified key informants for each service and the second provided details on the identified services. Survey questionnaires and supporting letters were developed in consultation with the review advisory groups and piloted with prospective recipients (see Figure 3.1 for a flow chart describing the survey).

3.3.1. Stage 1 survey

The aim of the first survey was to provide an address and a named key contact for respiratory nurse specialist services. In addition, the questionnaire asked if the respondent knew of any local physiotherapy or respiratory technician-led service for patients in the community with COPD. The aim of this extra information was to provide some indication of whether these services provided similar coverage or were present in areas that appear to be without a nurse service. The questionnaire also asked whether the respondent would be interested in commenting on the preliminary findings and recommendations of the review (see Appendix 13 for a copy of the questionnaire and accompanying letter).

In consultation with the review's advisory groups a list was compiled of potential contacts in England and Wales who might either provide specialist nurse services for patients in the community with COPD, or have local knowledge of the existence of such services (Table 3.1 lists the organisations and numbers of members)

This approach allowed a wide range of health providers in primary and secondary health care to be surveyed and enabled us to triangulate responses. However we anticipated that this approach would affect the proportion of questionnaires returned since a single organisation would often receive several copies of the survey questionnaire and these might all be passed on to the same individual. In addition, questionnaires to members of the RCN Respiratory Forum were sent out by the Forum on our behalf. This prevented us from cross checking names of RCN Respiratory Forum members against the membership of the other organisations surveyed leading to some Forum members receiving the questionnaire more than once. No reminders were sent for the first stage questionnaire.

Table 3.1 Organisations and groups surveyed in England and Wales

	Number of members
Royal College of Nursing Respiratory Nurses Forum	3,967
General Practice Airways Group	937
Respiratory medicine consultants	516
Primary care trust nursing leads	304
Primary care trust chief executives	304
Primary care trust commissioning leads	304
Total	6,332

We mapped the respondent's postcodes against PCT boundaries and followed up with phone calls PCTs where no one had returned a questionnaire. Names, addresses and postcodes of identified service providers were cross checked throughout and duplicate information was removed. Whenever necessary we contacted local health providers for clarification.

3.3.2 Stage 2 survey

The second questionnaire was posted to the key informants of the respiratory nurse services identified by the first survey. This questionnaire aimed to collect details on service provision. The review's advisory groups identified key service components to be included in the survey questions. These included;

- the type of respiratory patients the service catered for and any eligibility criteria

- the source of funding for the service

- whether the scheme was based in primary or secondary care.

- the number of whole time equivalent (WTE) specialist nurses delivering the service and

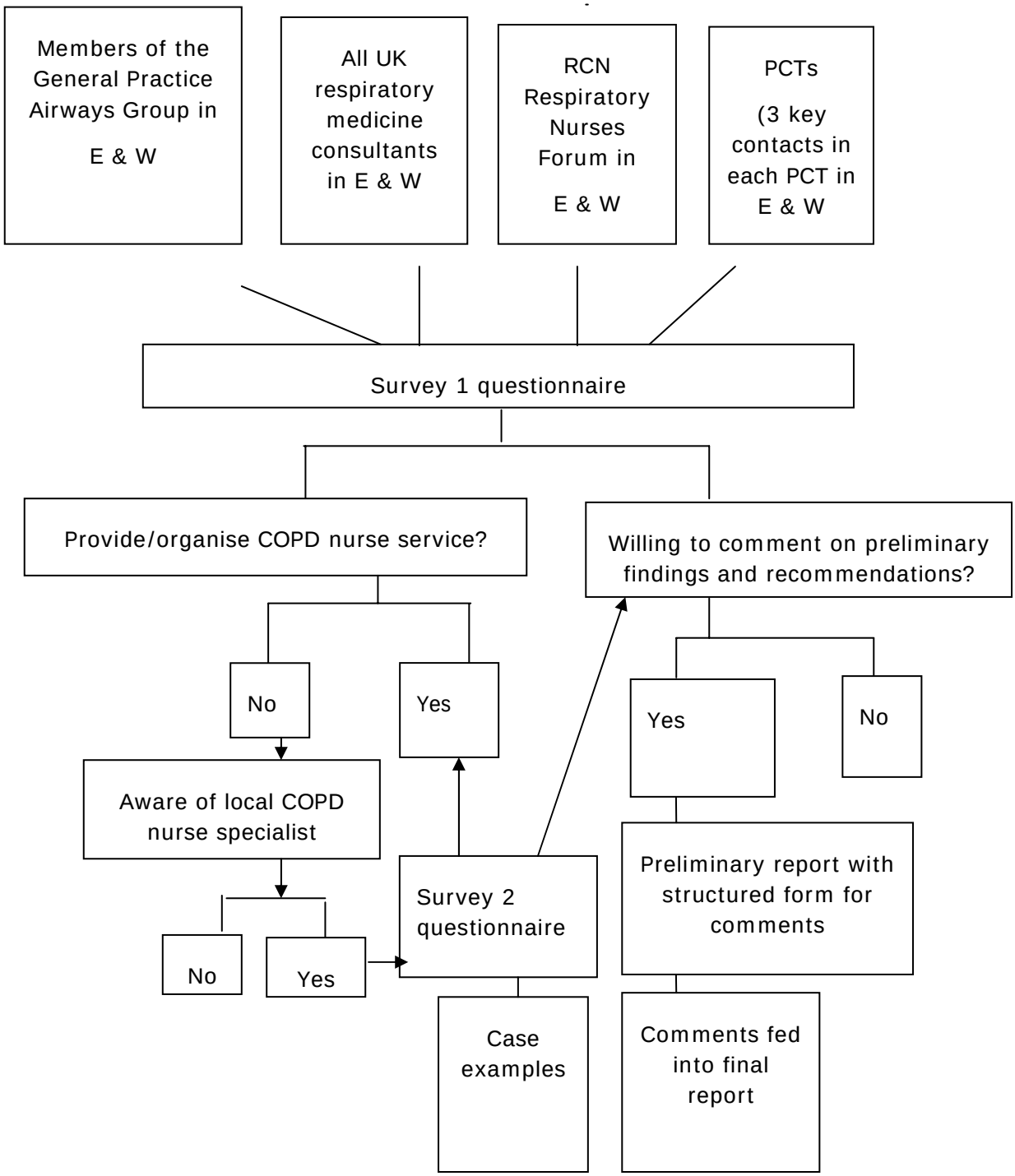
- how long the scheme had been operational.

The second questionnaire also asked respondents to either describe their service in their own words, or to tick 'yes' or 'no' to a list of 15 different potential components. The list included activities such as whether the patients were seen at home or in a clinic, and whether the service carried a caseload of patients.

Respondents were also asked if their service had been the subject of a peer reviewed publication, conference abstract or an unpublished evaluation, and whether they would be interested in commenting on the preliminary findings of the review (see Appendix 15 for a copy of the questionnaire and accompanying letter)

Non-responders to the second questionnaire were sent up to two postal reminders. The second reminder included a question on whether non-response was because their service had been either: inappropriately identified; the respondent had passed the questionnaire on to a colleague to reply; or the respondent had not replied because they knew a colleague had replied already. If there remained no response after the second reminder the provider was contacted via email, if possible, alternatively contact was made with another survey respondent in the same locality to clarify the details of local services.

Figure 3.1 Flow chart for survey of provision of RNS services for COPD in England & Wales



3.3.3 Services groups

To explore service characteristics the services were grouped depending on certain key components. The choice of components were based firstly on the identification in the effectiveness review of two distinct types of services; innovations for acute exacerbation and chronic disease management services. Key components in distinguishing acute from chronic services were the service components 'early discharge schemes/hospital at home schemes' and a 'chronic caseload of patients'. It was planned that other service groups may be generated if further distinctive service groups were identified from the information gathered in the questionnaires. One reviewer undertook service grouping and for validation another checked a random sample of 50 per cent. Where services remained unclear, any accompanying literature was checked and/or the survey respondent was contacted for clarification.

3.3.4 Identifying Respiratory Nurse Specialists (RNS)

In the UK there is no established definition of a 'respiratory nurse specialist' (RNS) or a 'respiratory nurse specialist service' (RNSs). The review group decided to rely on the respondents to identify themselves, or others, as RNS. We excluded services if they did not involve nurses or where the service involved 'generalist' nurses, such as practice nurses or a nurse practitioner, who identified their work with patients with COPD as part of their normal practice and not as an 'advanced or specialist service'. Members of the Nurse Reference Group checked all questionnaires where the project researcher queried eligibility.

3.3.5 Obtaining grey literature and unpublished evaluations

Respondents who stated that their service had been the subject of grey literature or unpublished evaluations were sent a request for a copy along with a freepost envelope.

3.3.6 Case examples

Case examples were included to provide a 'flavour' of the different types of services.

They were drawn from respondents' service descriptions in the questionnaire or from the grey and unpublished material retrieved. Case examples were chosen to represent what the review team believed to be a variety of fairly 'typical' examples of

services, but we have also included some examples of more ‘unusual’ services. Because the case examples were drawn from existing material they are limited by the amount of information reported. Where we have included case examples we have asked the individual service providers to verify the descriptions.

3.4. Results

3.4.1 Stage 1 questionnaire

Following MREC approval 6,332 stage 1 questionnaires were posted in March 2003 and 1,751 completed questionnaires were returned. A total of 1,577 respondents postcodes were complete and were mapped by PCT boundary. This revealed that at least one response had been received from within 300 (97 per cent) of the PCTs in England and Wales (see Appendix 16 for map). Of the nine PCTs without a response, four did not have a service operating within their boundaries and four stated that the service that operated in their boundaries was based within another PCT. One PCT did not respond.

984 (56 per cent) of the 1,751 who responded provided, or were aware of, a local nurse specialist service. After cross-referencing for duplicate identification, 503 potential separate services were identified (see figure 3.2 for survey findings flowchart)

3.4.2 Physiotherapy and respiratory technician led innovations in care for patients in the community with COPD as identified by the stage 1 survey

291 stage 1 questionnaire respondents knew of a local physiotherapy or respiratory technician led service for patients in the community with COPD. It is likely that there was considerable duplication and the actual number of such services was lower. Using the survey respondents' postcodes to map the approximate location of these services they were found to be scattered across England and Wales (see Appendix 17 for a map of service locations)

3.4.3 Stage 2 questionnaire

In April 2003 503 stage 2 questionnaires were sent out to the key informants of services identified from the first survey. 13 were returned marked 'address unknown' or with a blank questionnaire. 80 per cent, 392/490 of questionnaires were returned completed.

For 25 of the 98 questionnaires that were not filled in and returned respondents wrote back stating that their service had either been already detailed by a colleague or that their service had been incorrectly identified. Two completed questionnaires were lost in the post. A further 40 questionnaires that were not returned may either have been duplicates (they had the same or similar addresses to services where respondents had already

returned a questionnaire), or may have been incorrectly identified.

Combining the results of the first and second questionnaire, it was found that 225 heath service locations were identified more than once, with some locations being identified ten times or more. Some respondents described non-RNS services and seven practice nurses respondents stated that their service was not a specialist service. These services were excluded. As a result of this one reviewer and members of the nurse reference group working independently checked the eligibility of all the questionnaires returned by practice nurses, nurse practitioners and GPs. There was good agreement. 117 ‘services’ were found to be ineligible because they were practice nurse run, non-specialist services. After removing all duplicate and ineligible services 234 individual specialist nurse-led, delivered or co-ordinated services were found.

3.4.4 Current provision

Services were mapped by their postcode to PCT boundary and found to be scattered throughout England and Wales (see Map 3.1). Visual comparison with the maps for physiotherapy or respiratory technician led services showed a similar distribution, suggesting that in some cases the same services might have been identified.

Overall, many services had bases in secondary care: 41 per cent secondary care only (98/234); 41 per cent secondary care and primary care bases (98/234); and 16 per cent primary care only (38/234). Most received some funding from recurrent monies: 53 per cent recurrent money from secondary care (123/234); 40 per cent recurrent money from primary care (94/234); 12 per cent one-off/special project funding (28/234); and 2 per cent charitable monies (5/234). The most common source of referrals was secondary care (92 per cent).

Figure 3.2 Survey findings flowchart

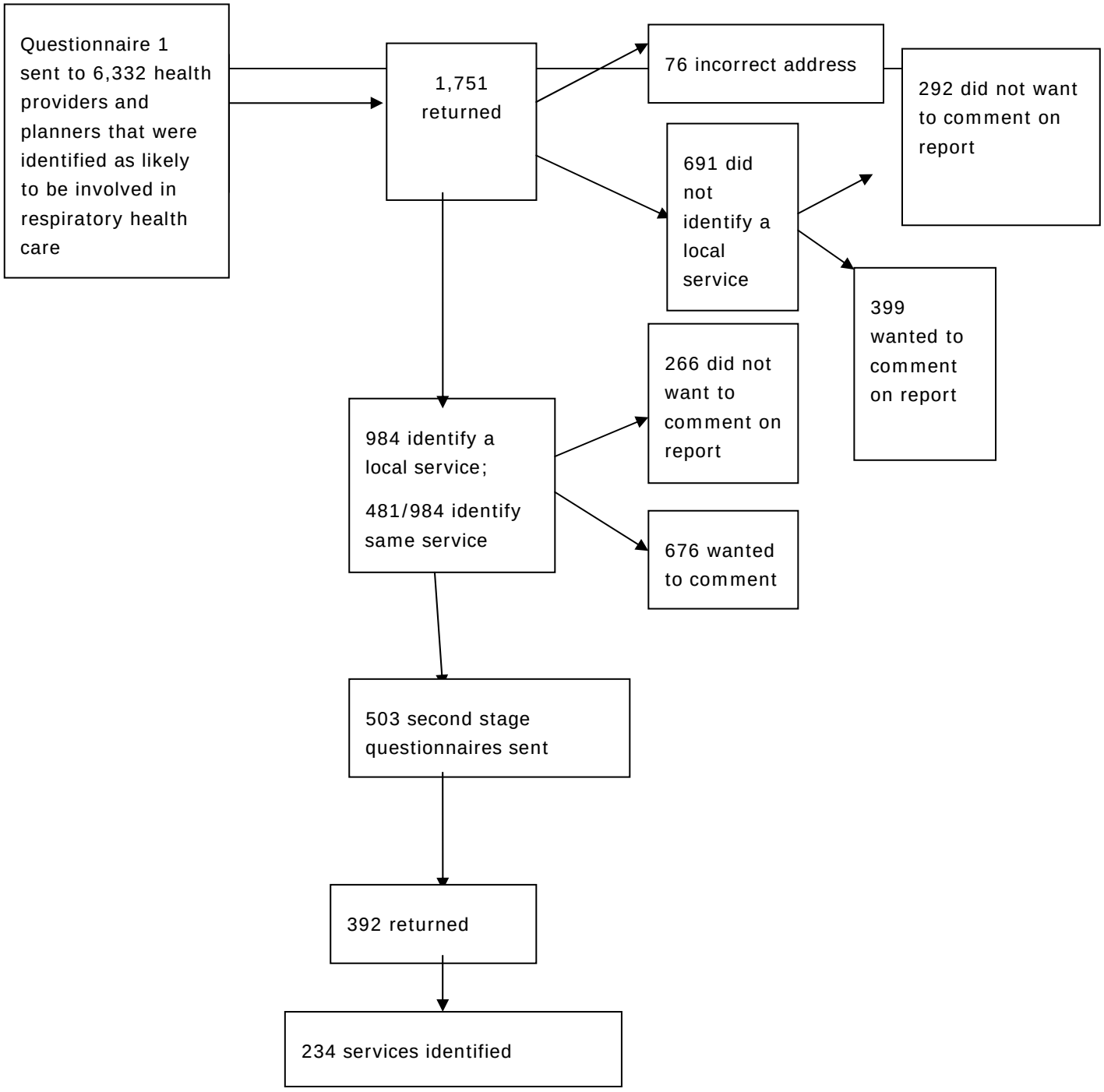
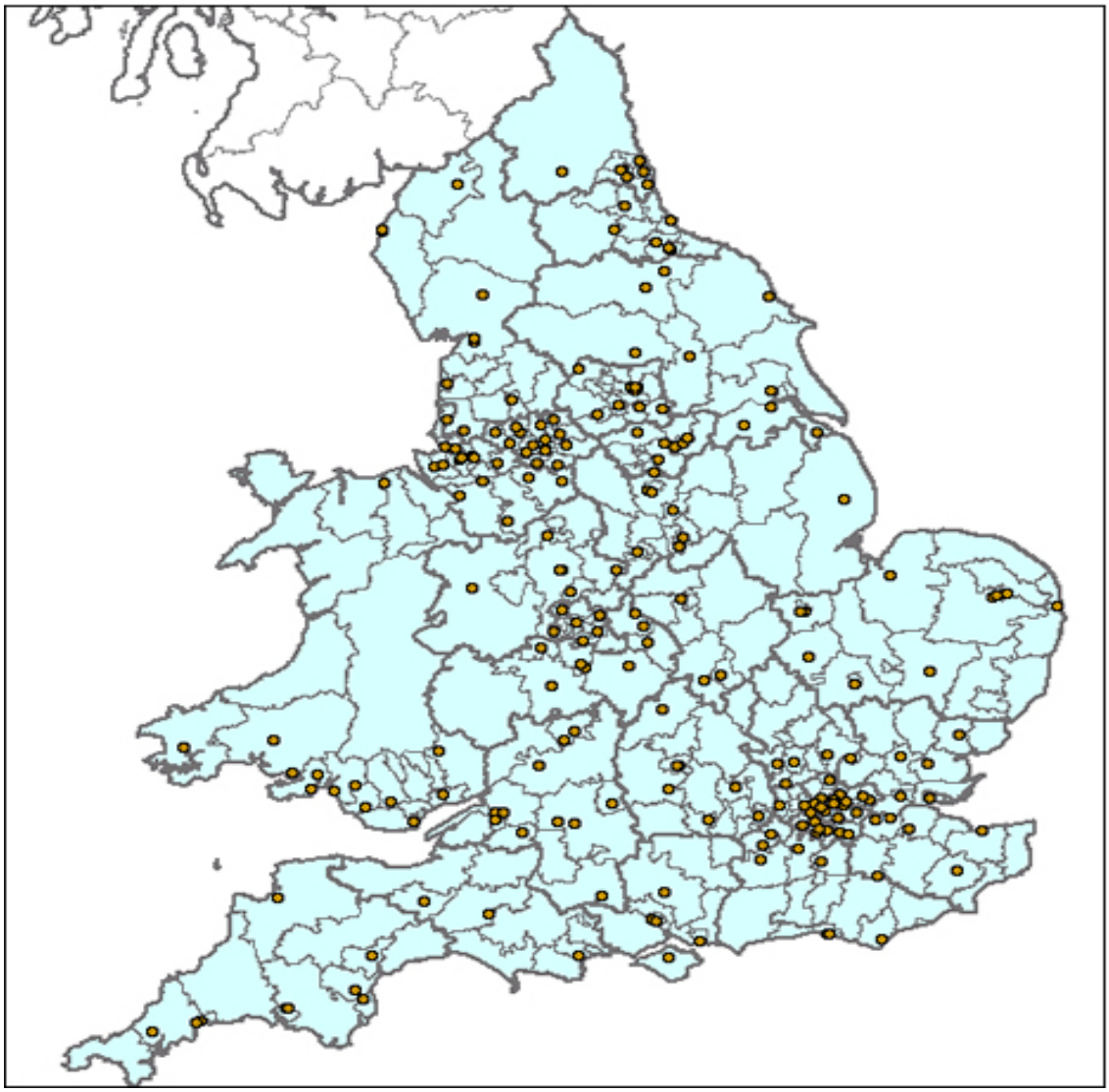


Figure 3.3 Map of specialist nurses services for patients in the community with COPD in England and Wales by Primary Care Trust boundary



Each dot on the map indicates an individual service

Figures 3.4-3.9 Funding and services base by type of innovation

Percentages related to the number of services. Please note that some services had more than one funding source.

Chronic disease management services

Figure 3.4 Funding source

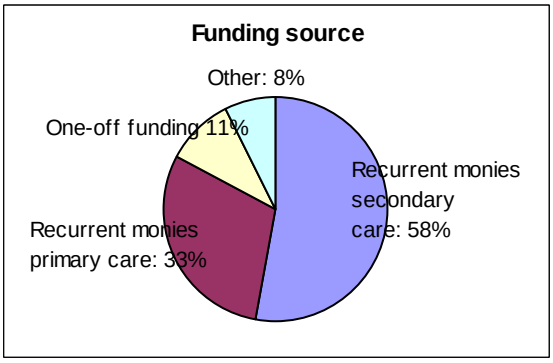
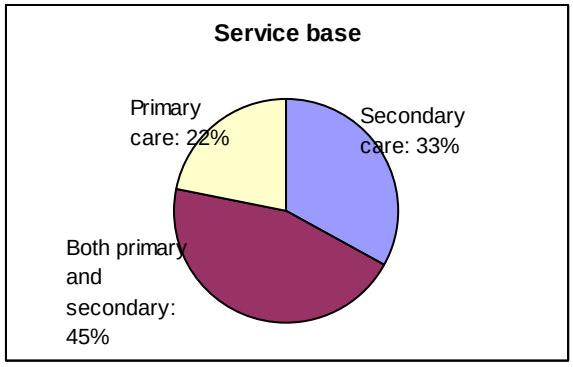


Figure 3.5 Service base



Acute interventions

Figure 3.6 Funding source

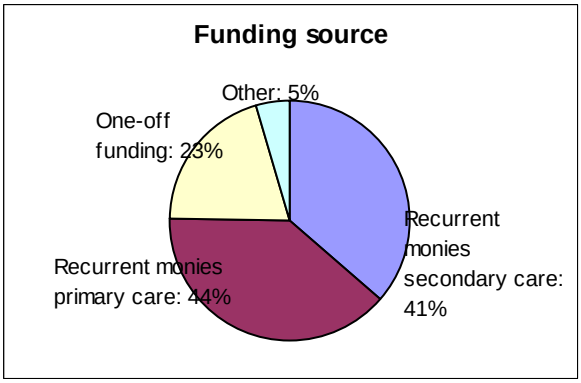
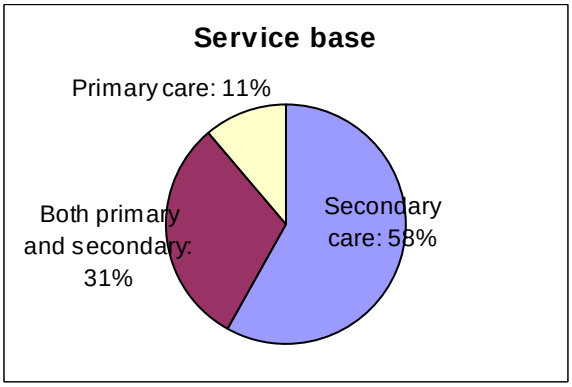


Figure 3.7 Service base



Mixed interventions

Figure 3.8 Funding source

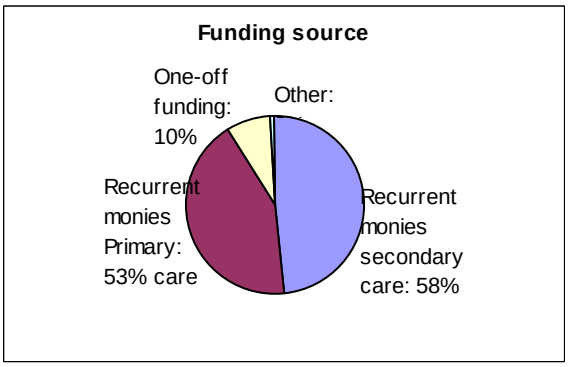
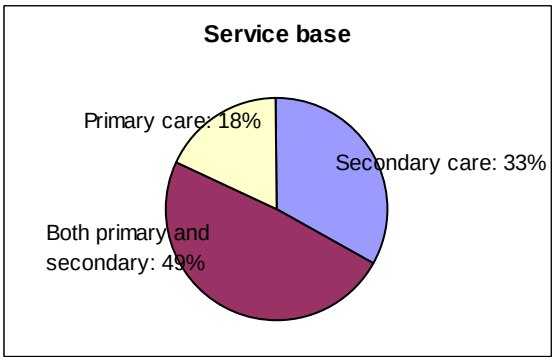


Figure 3.9 Service Base



3.4.5 Types of service

Overall type of service was based on the information provided in the questionnaires and validated: (1) where relevant in some of the 157 items of service literature sent in by respondents; and (2) by contacting 35 respondents where type of service was unclear from the questionnaire response. Services were grouped according to whether they were mainly services for acute exacerbation or chronic disease management. In grouping services it was found that some services did not fit into this dichotomy, these were predominantly (1) services that offered a comprehensive service with both acute intervention and chronic disease management components and (2) specialist services that offered care for a specific group of patients such as patients on LTOT or provided a specific service such as pulmonary rehabilitation.

The most common type of service were those involving chronic disease management either as a stand alone service or in combination with acute services, see Table 3.2 for types of services and number identified.

Table 3.2 Type and number of services found (%)

Chronic disease management services n= 87/234 (37)
Acute n= 39/234 (17)
Combined acute and chronic disease management n= 79/234 (34)
Specialist service n= 11/234 (5)
Other n= 9

Other types of services was a mixed group, including psychological support services, hospital case management plus community follow-up for severe cases, and palliative care

services. The characteristics of these services as a group were not explored.

Nine services could not be grouped as it was unclear the type of overall provision they provided.

3.4.6 Checking the combined acute and chronic management services

We contacted a sample of service providers 49 per cent (39/79), where we inferred that the service provided both acute and chronic care for further clarification. This was felt necessary as some of the respondents provided information that appeared contradictory, in particular very comprehensive services being run by one nurse, or respondents calling their service an early-discharge scheme but having a chronic case load. These types of services were also not identified in the effectiveness review. 22 (71 per cent) service providers responded, one service was found to be incorrectly identified as providing care for chronic disease management and acute care. Several of these respondents provided descriptions of the evolution their service; most were of an acute service that went on to provide a type of long-term follow-up care (box 3.1 provides the comments of two respondents)

Box 3.1 Respondents describing their service as a combined acute and chronic service

‘In essence it is an acute care service, managing minor/moderate exacerbations of COPD at home. Saying that there are a group of patients we have identified that have regular admissions to the hospital and therefore we have adapted our service by providing weekly visits to try to prevent admission’.

‘The service at the time of establishment back in 1999 was a fast track hospital at home type service for patients during the acute phase. However the service has grown to encompass patients on LTOT for assessment and follow up and of course the acute service has led to see patients for longer periods of time than originally planned. We have recruitment issues and currently have a district nurse seconded to the team and a lot of work is being done to support patients during the stable periods. However, the source of our patients remains from secondary care only’.

3.4.7 Chronic disease management services

87 chronic disease management services were identified. The median length of time established was five years (two to eight years, 25th to 75th percentiles). Although chronic disease management services were likely to have included other types of health workers they were run by small teams of specialist nurses; the median number of whole time nurses was 1.5 nurses (1 to 2 nurses, 25th to 75th percentiles).

The most common source of funding was secondary care, while more services were based in both primary and secondary care than in one health care location (the service base and funding of these schemes is summarised in figure 3.4 and 3.5, see appendix 18 for a map of provision of such services)

Although two respondents did not answer the questions on service components, most services undertook a large number of activities. A few identified hospital-at-home and early discharge components but from the questionnaire responses there was no indication that these were formal/main components of their services. Most, 92%, cared for patients with a wide range of respiratory diseases, of these the mean estimated percentage of time allocated to COPD was 59%.

Three types of chronic disease management services were identified;

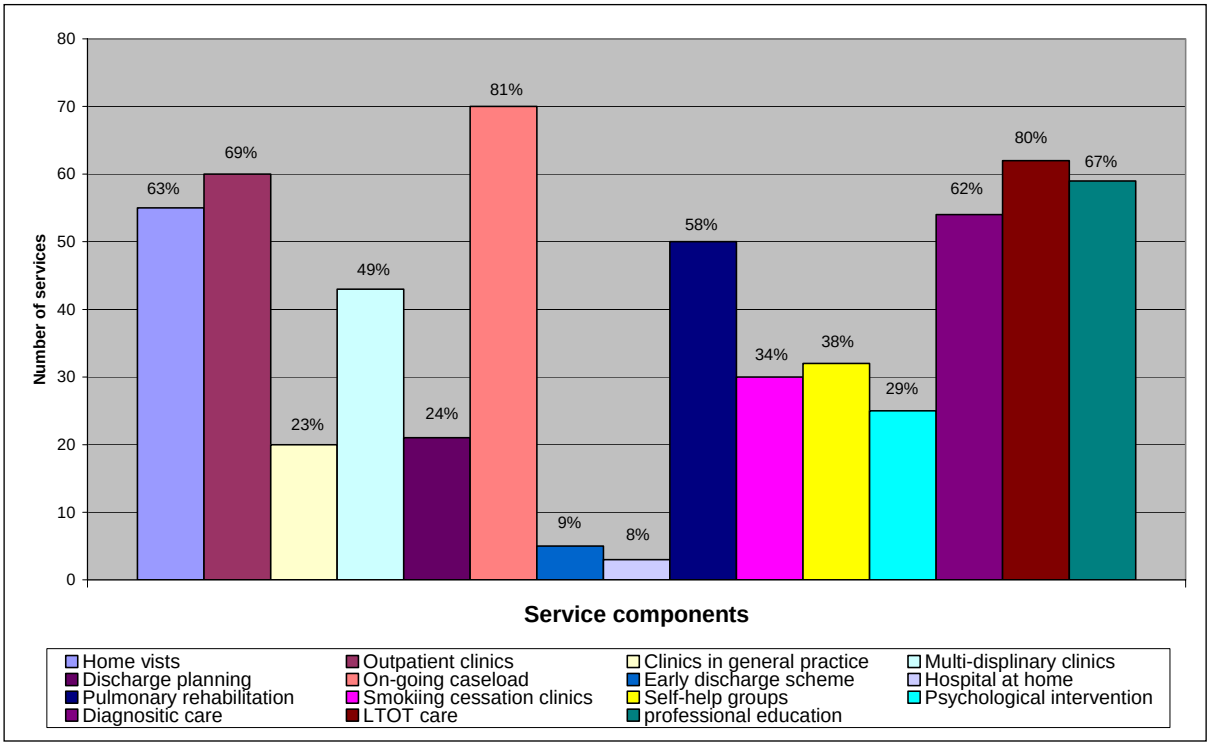
- the most common type (52%) was a home visit service with clinics.

- 36 percent were clinic only services. These services included clinics based at more than one health care location: most, 63%, included specialist nurse led outpatient clinics; 43% included multidisciplinary team outpatient clinics and around a quarter, 26%, included clinics based in general practice.

- home care with on-going caseload but no clinic service was the least common type of service, 8%.

(see Figure 3.10 Components of chronic disease management services)

Figure 3.10 Components of chronic disease management services



(% in figure is the percentage of respondents who answered the question and who stated the component was an aspect of their service)

3.4.8 Case examples of chronic disease management services: typical schemes

Nurse consultant service, University Hospital Leicester

The Nurse Consultant service for patients with respiratory disease at the University Hospital in Leicester was established three years ago. The fundamental presumption behind the service was that although patients may have medical and physical needs addressed by services such as pulmonary rehabilitation, there was little provision for assessing and providing advice on the residual handicap caused by respiratory disease. The service therefore complements established services, including the early discharge service, the community nebuliser service, pulmonary rehabilitation and for patients hospitalised for COPD. Clinic visits or domiciliary support are offered and patients are also seen as inpatients. Some patients are essentially palliative and ongoing nursing support is offered to these patients who would otherwise receive little support from current service provision. Primary care respiratory clinics are run within Beaumont Leys Clinic and Pasley Road Clinic, these sites enable surrounding GP's to refer patients for assessment and advice.

The service is supported by a part time occupational therapist provided through primary care funding.

Community support service. Whipps Cross University Hospital NHS Trust, London.

The respiratory nurse service is funded by Whipps Cross University Hospital NHS Trust, is based at the hospital chest clinic and run by two full-time nurses. It has been running for 10 years. Patients are seen in the clinic, wards and at home. The lead nurse runs a nurse led clinic for airways patients and patients receiving continuous positive airways pressure (CPAP) for obstructive sleep apnoea, and co-ordinates the pulmonary rehabilitation service. She is also the lead in a LTOT Domiciliary Service where she attends six monthly home visits and provides annual support calls. The other nurse supports doctor-led clinics and is now developing a small caseload of LTOT patients for domiciliary support. Both nurses support the local Breathe Easy support group.

Wyre Forest Respiratory Service, Kidderminster Hospital NHS Acute Trust.

The Wyre Forest Respiratory Service has been running for four years, it is run by one full time respiratory nurse. The service provides care for patients with COPD, asthma, tuberculosis, and lung cancer and is funded by the NHS Acute Trust. Referrals are received from the chest physician, the medical consultant for older people, district nurses, practice nurses, the GP unit, other specialist nurses, ward managers and from physiotherapists.

The service involves the nurse working with the chest physician to provide a clinic service, home visits and telephone access for;

- health and safety, and assessment prior to and after installation of oxygen therapy

- ongoing oxygen assessment

- nebulised therapy/inhale therapy

- breathlessness management

- nutritional advice

- exercise

- emotional support

- assessment referral to other agencies such as occupational therapy, physiotherapy, housing, and social services.

Less common schemes

Community outreach pilot service for people with COPD, Healthcare Trust / North Tyneside Local Authority, Northumbria

The Northumbria Healthcare Trust community outreach service for people with COPD targets people with severe COPD in the community who live on there own or in sheltered housing. Established in 2000, the service is managed by a social work team leader and led by a hospital respiratory nurse specialist (RNS). The nurse specialist and a team of six outreach workers deliver the service.

In the first six months of service there were 115 referrals, 15 were not eligible mainly as lived outside of the catchments, and of the 100 accepted 45 were managed solely by the RNS mainly as they required the nurse to make additional referrals to social or other health services. 55 were managed by the outreach workers who adopted the role of lay carer rather than professional provider. Their work involved promotion of activity, independence, socialisation, maintenance of physical health and respite for the patient's carer. If the outreach worker was concerned about a patient then advice was sought from the RNS. Provision of care was either short term (such as for carer respite), on-going (for patients more severely handicapped) or fluctuating in response to patient demand resulting from exacerbations in the condition.

The service was evaluated in terms of patients health related quality of life and functional independence. While the service was found to benefit patients the evaluation was limited in that it was a cross-sectional survey (this evaluation was not included in the review as no further details were available)

Breathlessness support service, Wythenshawe Hospital, Manchester

The Breathlessness support service has been established since 2002. It is based in a tertiary referral centre with patients coming from throughout the North West region of England and is run by a specialist respiratory nurse, who works 24 hours a week. Newly referred patients to the interstitial lung clinic and COPD patients when they are being assessed for lung transplantation are seen in the clinic. Referrals are also accepted for COPD patients who are not coping or adapting to their disease progression. Around 120 new patients were seen in the clinic in the last 12 months.

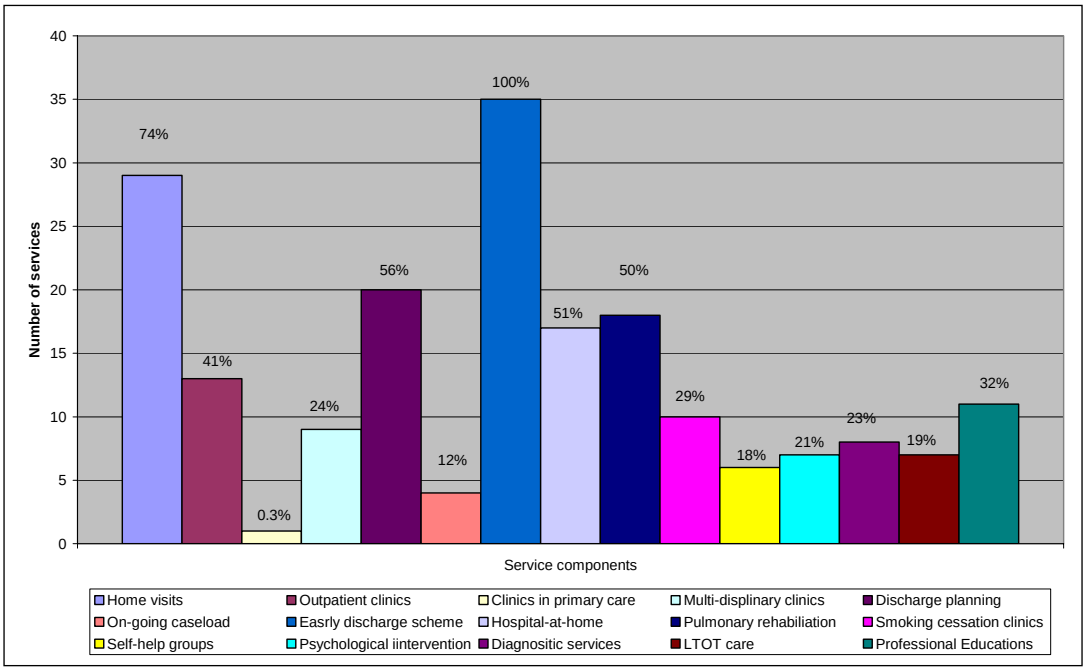
The aims of the clinic include meeting needs concerning optimising domiciliary oxygen therapy, education and developing psychosocial support for patient and carer, including involvement with end of life issues. Telephone review follow-up is also used. An adaptation of established models for breathlessness in lung cancer are used as a framework for developing a patient focused strategy for coping with the physical/psychosocial aspects of breathlessness in all end stage lung disease. The model includes an accurate assessment of breathlessness from the patient perspective focusing on how the patient perceives their current problems. The assessment strives to identify what the most important problems are to the patient, to acknowledge their loss but also to identify other more realistic goals that might yield a feeling of control over events and more importantly the disease.

3.4.9 Acute management schemes

39 services were identified as acute management schemes. The median number of whole time equivalent specialist respiratory nurses was 2.25 nurses (1.25 to 4 nurses, 25th to 75th percentiles). These services were relatively new with the median length of time established being 18 months (0.5 to 3.5 years, 25th to 75th percentiles). Most funding was received from recurrent monies, but a significant proportion were also received from 'one-off' funding schemes. Few had service bases only in primary care (the service base and funding of these schemes is summarised in Figure 3.6 and 3.7, see appendix 19 for mapping of location of services)

Dominant components of these services were included their key characteristics; home visits and early discharge schemes. Not all respondents answered the questions on the components of their service. Some service had multiple components, a few had some elements of chronic disease management, such as an on-going caseload and diagnostic services. These components appeared to be 'minor activities' such as in the case of an on-going caseload only for a few patients.(see figure 3.11 for components of care)

Figure 3.11 Components of acute services



(% in figure is the percentage of respondents who answered the question and who stated the component was an aspect of their service)

42 per cent of services cared for patients with a wide variety of respiratory conditions. Of these, the mean estimated percentage of the service providers' time devoted to COPD was 67%.

Forty nine percent of these schemes described themselves as schemes where the patient is initially admitted to hospital but discharged home early to a supportive nurse scheme (an early discharge scheme). While 51% of schemes offered both Hospital-at-Home (HaH), schemes that avoid admission to secondary care, and early discharge services.

Respondents reported that their services had been the subject of 222 articles and reports that either described or evaluated the service.

Case examples of acute services: typical schemes

Pontefract Emergency Respiratory team, Mid Yorkshire Hospital NHS Trust.

First established in 2000, the Pontefract Emergency Respiratory team (PERT) provides a seven-day a week day time hospital at home service for patients admitted with an acute exacerbation of COPD at both Pontefract General Infirmary (PGI) and

Pindersfields General Hospital (PGH). It is a nurse led service and consists of five whole time equivalent nurses. A multi-disciplinary network supports it, including respiratory clinicians, pharmacists, ambulance services and social services.

At both hospitals assessment for eligibility is undertaken at the medical admissions unit or ward that the patient was referred to. Screening normally takes place in the morning to allow the outreach nurse to home visit the patient later that day. Screening involves an assessment of clinical as well as social circumstances. Patients and their carers need to consent prior to discharge to the home service. A medical consultant or registrar reviews all patients. A fast track pharmacy service ensures discharge medications are available quickly. Medications on discharge include corticosteroids, antibiotics and high dose bronchodilators and a nebuliser compressor if needed. At PGI either the dedicated medical admissions unit ambulance service or the carer transport the patient home. At PGH arrangements by the West Yorkshire Metropolitan Ambulance service transfer PERT patients home wherever possible in the morning. At the time of the report this had worked well and no patient spent an extra night in hospital due to lack of available transport.

At discharge from hospital a nursing team member assesses the patient, and provides education and advice as needed daily in the home for the first 3 days following hospital discharge and thereafter as needed. Short-term social and personal needs are given by the intermediate support at home service. 24 hour telephone access is provided by the hospital and the patient is encouraged to use this as opposed to contacting their GP. Clinical responsibility is divided between four consultants. At discharge from the service, patients are given an outpatient appointment.

Nurse led service for acute exacerbation of COPD. Wrightington, Wigan and Leigh NHS Trust

The service based at the Royal Albert Edward Infirmary in Wigan was established in 1999 and offers HaH and an early discharge scheme.

A feature of the service described in the documentation is Patient Group Direction (PGD) which enables nurse operating the at-home service to supply and administer appropriate drugs without referral to doctor and reduce time taken for dispensing drugs. The drugs that can be dispensed on the PGD include bronchodilators, corticosteroids, antibiotics, and oxygen. PGD may be a component of other services but it was not reported in the information provided.

Pontypridd and Rhondda Early Discharge Scheme (PREDS service), South Wales

The PREDS Service is a multidisciplinary group and is the first of its kind to be set up in South Wales. The team is led by a consultant physician, two respiratory nurses, one occupational therapist, one physiotherapist, with back up from two respiratory nurses employed by the trust to cover sickness and annual leave. The service is provided to patients admitted to the hospital with an exacerbation of their COPD provided they do not have any unstable co-morbid disease and the social environment is safe, and that they consent. If practical, patients can return home with support from the respiratory nurses within 72 hours. The occupational therapist and physiotherapist also assess the patients at home and provide equipment and exercise training. The respiratory nurses and the doctor assess the patients before discharge from the service. Patients once known to the service can self refer if they have another exacerbation. No direct referrals are accepted from primary care if the team does not know the patient. The length and number of visits depends on the severity of the exacerbation and can be from 2 weeks up to 6 weeks.

Less common schemes

Certain schemes reported in the grey literature were novel in their approach.

Intermediate COPD care service, Newcastle Primary Care Trust.

The four bed intermediate COPD nurse-led unit is based in the community at Shield Court, a sheltered housing complex in Newcastle. It is linked to the respiratory team at the Royal Victoria Infirmary in Newcastle via tele-monitoring. Tele-monitoring allows monitoring of blood pressure, temperature, pulse, breathing, and blood oxygen. With the aim to free up hospital acute beds, the unit accepts patients whose medical treatment has been optimized by a 48 to 72 hour stay on an acute ward but who still require 24-hour nursing. The average stay is seven days and the service operates 24 hours a day. In addition to tele-monitoring the nurse service includes psychological support, nutrition advice, and exercise.

Several respondents describe supported discharge services. Although this service could be argued as a post acute service,

some services enabled patients to be discharged earlier. One such example is at North Tees and Hartlepool NHS Trust.

Supported discharge service. North Tees and Hartlepool NHS Trust

At the University Hospital of North Tees a supported discharge service has been developed for patients whose admission for COPD precluded because their exacerbation was severe or complicated an early supported discharge. The service is run by two specialist nurses, a physiotherapist, and a specialist health care assistant for COPD. Dietetic support and secretarial support are also provided.

Patients are assessed for supported discharge service normally the day of, or the day after admission while on the medical admissions unit. Patients who do not meet the criteria initially are re-referred to the service at a later date by the hospital nursing or medical staff.

The package of care that the patient receives from the supported discharge scheme is similar to what they would receive if accepted onto the early discharge schemes. The package of care includes education, physiotherapy, disease process self-management, dietician support, and advice on coping mechanisms. Patients are also given a referral to pulmonary rehabilitation. Patients are normally on supported discharge for up to seven working days post hospital discharge and during this period the COPD team liaises with members of the primary health care team to ensure continual support for the patient when discharged from the service. Patients receiving LTOT are followed up in the community by the team on a six monthly basis.

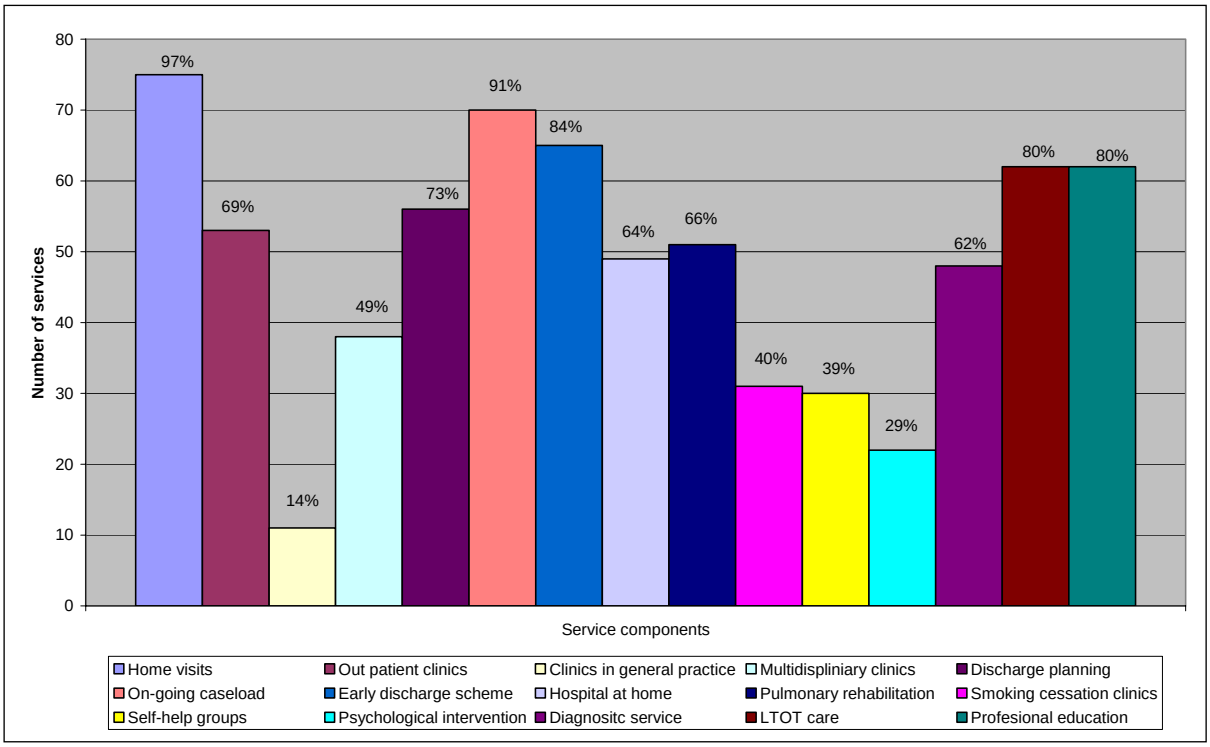
3.4.10 Combined acute and chronic services

80 services were identified that provided both services for an acute exacerbation of COPD and for chronic disease management. The median length of time such services were established was 3.5 years (2 to 5.5 years, 25th to 75th percentiles). While the median number of whole time equivalent specialist respiratory nurses in the teams were two (1 to 3 nurses, 25th to 75th percentiles,). These services could be divided into two distinct groups, the majority, 78%, of service schemes managed a chronic caseload of patients and provided acute care services, while 22% ran several other services such as smoking cessation clinics, pulmonary rehabilitation, and self-help groups. Many of these services received funding from primary and secondary care and had bases in both types of health care (the

base and funding of these schemes is summarised in Figure 3.9 and 3.10, see appendix 20 for location of such services)

Most of these services had many service components (see figure 3.12 Components of combined services).

Figure 3.12 Components of combined services



(% in figure is the percentage of respondents who answered the question and who stated the component was an aspect of their service)

Seventy per cent of these services cared for patients with a wide variety of respiratory conditions, of these the mean estimated percentage of time allocated to COPD was 74%.

Examples of combined acute and chronic disease management services: typical schemes

COPD outreach service, Northern Lincolnshire and Goole Hospitals NHS Trust, Scunthorpe.

The COPD outreach service provides care for patients in the acute stages and follows up acute patients for chronic disease management. The service reviews patients in the nurse led clinics and perform steroid trials and nebuliser assessments, providing nebulisers indefinitely to those patients who have a positive response. Portable nebulisers are also loaned out to patients on a short-term basis. Care is also provided for patients

with asthma, TB, lung cancer and interstitial lung disease. Arterial blood gases are checked for patients on oxygen concentrators, in addition to full LTOT assessments. The nurses also provide a pulmonary rehabilitation programme.

COPD service. Queen Elizabeth Hospital, Kings Lynn. Fenland and West Norfolk Primary Care Trust

Established since 2001, the service employs 2.75 whole time equivalent specialist nurses and is based at Queen Elizabeth Hospital in Kings Lynn and funded by the local PCTs, Fenland, and West Norfolk, and from secondary care. The nurses assess and case manage COPD inpatients from any location or PCT and offer an early discharge service to patients registered under a GP in the Fenland or West Norfolk PCT. Patients on discharge from hospital who do not meet the early discharge criteria, often as they live alone or appear to have poor compliance, are also supported by the service if they live within the local area.

Referrals are accepted from all health professionals within secondary and primary care. In 2003, the monthly referrals were between 50 and 60 patients. Mostly these were inpatients that would be assessed during their hospital admission. Community referrals are reviewed either at the patient's home or in a community clinic, although frequently these patients are housebound or have severe/unstable COPD. Presently the service has a caseload of patients in the community who require ongoing support, these are generally patients with severe/unstable COPD who are not supported by other community staff, such as district or practice nurses. The service staff also visit a few younger patients with emphysema resulting from alpha 1 antitrypsin deficiency and support patients who are referred for consideration for a lung transplant.

A physiotherapist from the community rehabilitation team is jointly involved with a number of patients, and where required joint visits are undertaken with the nurse or occupational therapist.

The service has just purchased two ISTAT machines and plan to take over the running of the LTOT registrar with the aim to avoid admission to secondary care for oxygen assessment (currently patients on LTOT are readmitted to secondary care every 6 months to reassess O2 requirement).

Respiratory nurse specialist service. Musgrove Hospital, Taunton & Somerset NHS Trust.

Currently there are two respiratory nurse specialists, and for the last 11 years they have run independent clinics in the main

hospital, Musgrove, and at four community hospitals. The service has a caseload of around 3,000 contacts. Patients are referred via hospital, pulmonary health visitor, GP or practice nurse and via the outpatients departments at Minehead, Chard, Wellington, Wells, Bridgewater and Taunton. The service provides at the clinic or via the phone;

- LTOT: Patient assessment and six monthly followed up either at the clinic, at a home visit or by phone.

- TB service, including BCG vaccination and provision of education to school nurses.

- severe COPD/Fibrosis patients can contact the service, via phone or in clinic for advice or review, or to assess and prevent where possible admission. There is also a self admit service for vulnerable patients.

- the service runs a pulmonary rehabilitation scheme with the physiotherapist.

- rapid referral for spirometry

- advice for practice nurses.

In addition, the nurses have set up a self-support patient group, this now runs independently with nurses support as required. In is also planned that two COPD nurses will join the service to implement an assisted early discharge scheme (further brief descriptions of such services are in box 3.2)

3.4.11 Specialist services

11 specialist services were identified, eight were pulmonary rehabilitation services, one non-invasive ventilation (NIV) service, and two were LTOT services.

Case example of a specialist nurse service:

Long term oxygen therapy (LTOT) service, Norfolk and Norwich hospital NHS trust.

The LTOT service at the Norfolk and Norwich hospital NHS trust has been established since 1997. One part-time (3 days a week) specialist respiratory nurse runs it. Most referrals are taken from secondary care and presently there are 146 LTOT patients receiving this service. The service covers a large rural area, covering most of the eastern section of Norfolk. Patients are seen in their home at 6 monthly visits where the nurse assesses treatment and provides advice, including;

- check equipment (including nasal cannula, correct equipment for outside use, saturation recording)
- review medication
- procedure for emergency – if equipment breaks
- nasal and eye care
- respiratory assessment
- review benefits

These are the only domiciliary respiratory visits the patients receive, other care being given at clinics. Patients are able to contact the service for phone advice between the six monthly visits.

3.4.12 A dynamic picture

Some respondents including those who were not currently part of a nurse led specialist respiratory service, volunteered information on the level of change in current service provision:

35 stated that their service was, or soon to be, no longer operational. Reasons given included difficulty finding replacement staff or funding withdrawn.

34 stated that their service was at a planning stage or expansion stage.

Some respondents added comments relating to new service developments (box 3.2 provides examples of such comments) While other respondents stated that they wished to have such a service or to expand an already established service (box 3.3 provides examples of such comments)

Box 3.2 An example of respondents of comments on their wish to expand

'I am the only respiratory nurse working in Scarborough and North East Yorkshire Healthcare Trust. We have no specialist COPD Service. I see COPD patients as part as my overall responsibilities. Business plans have been submitted for the past 2 years for a specific COPD Nurse Service to include: 2 nurses, early discharge scheme, and non–invasive ventilation service. Plans were rejected each time'

Box 3.3 Respondents comments on new developments

'Our service is currently undergoing a radical review process. It is merging with our rapid response team who provide hospital at home for any suitable condition, not just COPD. The COPD team will retain its disease specific focus but will expand to include clinic sessions'.

'We have a COPD service in East Lincolnshire PCT. There are three phases to the COPD service programme. Phase 1: Developing a disease register, helping practices to run spirometry clinics. Phase 2: Developing experts in managing COPD in primary care. Phase 3: Development of a primary care COPD team (including a nurse consultant, nurse specialist, GPSI, physiotherapist, dietician, and a primary care worker). We have just had the information by the PCT to fund this third phase and we are aiming to be up and running on this phase within 6 weeks'

Section 4 Discussion, Conclusions and Recommendations

4.1 Introduction

This chapter draws the findings of the extended systematic review and the survey together. The chapter concludes with a series of recommendations aimed at service providers, researchers and research funders.

4.2 Principal findings

4.2.1 Principal findings of the literature review

Our literature review identified 13 RCTs and two Cochrane SRs of innovations involving nurses for patients with COPD normally living in the community and we established that there is considerable work in progress around this area. Unlike the survey, we did not confine the literature review to studies of innovations involving RNSs. However, all the studies we identified did appear to involve nurses with some respiratory expertise and we did not identify any studies involving generalist nurses in innovations for patients with COPD (in one study this sort of intervention made up a control arm).

The RCTs described two distinct types of nurse interventions for COPD: interventions aimed at managing this chronic disease better in general (chronic disease management type models) and interventions aimed at patients experiencing an acute exacerbation of COPD. None of the chronic disease management type models evaluated mentioned managing patients according to care pathways, written guidelines or treatment algorithms. The chronic disease management interventions could be divided into brief (one month) and long term (one year). Most involved home visits by a respiratory nurse but in two studies it was not clear where follow up was carried out. The content of the home visits varied. The interventions for acute exacerbations of COPD were all directed at substituting domiciliary care for hospital care (domiciliary care models). Some interventions involved the avoidance of hospital admission altogether while others were early discharge schemes; the content of these interventions appeared to be fairly similar.

The aims of the evaluations for these two types of interventions were quite different. The chronic disease management trials were generally aimed at evaluating the respiratory health worker in terms of outcomes such as health service use or changes in patients' ability to perform activities of daily living or changes in patients' quality of life. The trials of domiciliary care sought to establish that domiciliary care was as safe as conventional hospital care in terms of survival, risk of hospital re-admission and lung function. However, none of the domiciliary studies was a formal equivalence study.

For both types of interventions few RCTs provided statistical power calculations. All but three were single centre RCTs (the remainder involving two centres each) and all examined interventions based in secondary care (although they are delivered in the community). We considered the quality of the RCTs as described in their published reports - each had some potentially important methodological deficiencies and we assessed the level of evidence from most of the RCT as 2b, two were assessed to be 1b and one 1b-.

We did not identify any evaluations of nurse led clinic interventions. There were very few other published quantitative studies and these were of poor quality and added very little to the findings of the review. We only identified two published qualitative studies and the quality of the reporting of these studies was such that we were not confident that their findings could be transferred to other situations. Similarly our attempts to access Dutch language literature contributed little to the findings of the review although we identified several potentially important ongoing studies from The Netherlands.

From our synthesis we concluded there is some evidence that, for patients with moderate to severe COPD in general, the type of chronic disease management nursing interventions evaluated may not: reduce mortality; improve health related quality of life as determined by disease specific instruments; improve psychological well-being; reduce impairment and disability as determined by total Sickness Impact Profile scores; improve pulmonary function; or reduce all cause hospital admissions. However, they may be associated with patients' having increased knowledge about their disease. For a particular group of patients with COPD, those on long term oxygen therapy, there is weak evidence that a nurse led home care programme involving quarterly home visits and monthly telephone calls may reduce hospital admissions and hospital costs at 12 months follow up.

We identified several potential outcomes of the chronic disease management nurse interventions on which there is currently no,

or very little, evidence. These included the effect on patients' satisfaction, treatment preferences, self management skills, coping, adherence with treatment recommendations and cigarette smoking. Other outcomes on which there is currently no, or very little, evidence included their effect on general practitioner services, what members of the primary care team think of these interventions, what carers think of these interventions or how they might influence carers' quality of life. There was no evidence from the RCTs that brief interventions were any less or more effective than longer chronic disease management interventions.

Considering the domiciliary interventions for acute exacerbations we found reasonable evidence that these do not increase mortality, affect pulmonary function or affect hospital readmission within the following three months. It must be emphasised that these findings relate to the selective patient populations that have been included in trials to date and may not apply if these interventions were extended to other populations. (On average across all the RCTS, only around a quarter of patients presenting with an acute exacerbation has been entered in to the trials). There is weaker evidence that domiciliary intervention for acute care in COPD are the preferred model of care for patients and carers, may improve patients' knowledge and their self management skills and do not increase GP home visits. There is very little, or no, evidence available on the effect of these interventions on patients' or carers' health related quality of life, satisfaction with care and psychological well-being. It is not known what members of the primary care and secondary care team think of these interventions. There is no evidence that early discharge schemes are any more safe than schemes which divert the patient from hospital admission before he/she has been admitted.

Economic evidence

The economic evidence on chronic disease management models for COPD is very sparse indeed. There is evidence from Farrero's RCT (2001) that his intervention for patients on LTOT may be cost effective, and evidence from another RCT to suggest for patients with moderate to severe COPD in general respiratory nurse home care may be more expensive. The very weak evidence on cost effectiveness from Campbell Haggerty's Respi-Care programme (1991) should be set against all the other evidence that these chromic disease management programmes for COPD are not effective.

Three randomised controlled trials study evaluated costs of the domicillary, acute care interventions. Cost considered were only

health care costs including length of inpatient stay, number of emergency department attendances, drug use and GP costs. All trials report the delivery of the intervention as being less costly than the control intervention.

Strengths and weaknesses of the literature review

Strengths of the review include: the scope of the review which brought together quantitative, economic and qualitative research evidence; the robust and reproducible search strategy; the extensive attempts to retrieve unpublished evaluations; the systematic and transparent assessment of the quality of the included studies and the allocation of a level of evidence to the individual studies and to the findings. Weaknesses of the review might include the limitation to English and Dutch language studies (mainly Dutch RCTs), although we found the addition of Dutch language RCTs did not add significantly to the English language findings. Another potential weakness is that we relied on published accounts of the studies and did not attempt to contact authors for any additional information or clarification. This might have led to our underestimating the quality of the included studies.

4.2.2 Implementation issues

There is little information on implementation of innovations involving nurses for COPD anywhere in the literature. Overall the material on implementation gleaned for the literature was very scanty and ultimately it was not clear that this exercise resulted in any better understanding of implementation issues for COPD nurse innovations than applying the generic principals from the Griffiths and Bryar framework (2003).

We are not aware of any previous published attempts to explore systematically the level of information on implementation provided in evaluative studies, unpublished studies and grey literature around a specific health care innovation. Although data extraction was done by two reviewers working independently, ultimately they had to make subjective decisions about what was, or was not an implementation issue. We also recognise that reasons why information on implementation may be lacking include space limitations in published articles.

The lack of information on the implementation of service development issues is not unique to COPD services. Currently, the National Institute of Clinical Excellence is further developing its research and development strategy and has produced a

document that identifies the complexities around the implementation of guidance and putting evidence into practice (NICE, 2003). It suggests the need for an extensive programme of research to support implementation processes.

4.2.3 Comparison with other systematic reviews of specialist nurse interventions for patients with chronic diseases

A rapid review of other SRs of *specialist* nurse interventions for four other conditions (Parkinson's Disease, congestive heart failure, renal failure and diabetes mellitus (DM)) did not identify any reviews for PD or renal failure. Five reviews were identified for the other two conditions but four of these were judged to be of poor methodological quality. The fifth review was a Cochrane SR of specialist nurse interventions for DM. The interventions and outcomes reviewed were very different from those in for COPD and it was difficult to compare the findings with those of the main review. Although this was a rapid review we employed a systematic and reproducible search strategy (described in Appendix 9) however it is possible that we failed to find other relevant reviews.

4.2.4 Consultation with users and carers

The Breathe Easy members who responded were in general supportive of the existing evaluative research and most respondents felt that these studies were looking at appropriate outcomes. Several feedback forms mentioned the need to look at the psychological benefits of treatment, the effect on self-management and the effect on quality of life. However respondents disagreed about whether decisions around service provision should be based on this sort of research evidence. Perhaps not surprisingly, some respondents felt that decisions should take the individual nature of each patient, and the need to ask patients, into account.

The consultation highlighted several issues for researchers and service providers: the need to consult patients and to allow their voices to be heard; the need to ensure that research included carers as well as patients; the importance of outcomes that consider patients' experiences and opinions, psychological aspects and quality of life. Consumers also seem to be interested in interventions that might provide them with a better understanding of their condition. A few of the respondents seemed to be alluding to the need for qualitative research (without expressing it in these terms).

There is no single, gold standard method to access users' and carers' opinions in healthcare. Our approach was chosen after careful consideration and in consultation with experts in this area, however, distilling the preliminary findings into a version that was comprehensible and succinct without being misleading involved compromise. We found it particularly difficult to communicate the dimension of study quality into the consumer feedback. Other approaches to this consultation, such as consulting smaller groups of patients with a stated interest in research, may have been more suited to these complex issues. Another potential difficulty with our approach was that the preliminary findings were posted to every member of the three Breathe Easy groups. Some of these members did not attend the introductory presentation in the spring and therefore had no previous knowledge of the research and some will not have been suffering from COPD. Our real response rate is uncertain because many of the individual feedback forms were completed by groups of people at the Breathe Easy meetings and these individuals were told to ignore the postal copy of the feedback form also sent to them. It is also likely that the Breathe Easy members who did respond were not representative of COPD patients in general.

4.2.5 Consultation with heath care providers

None of the providers who gave feedback on the preliminary report and recommendations disagreed with the way the research evidence was summarised. Around half were surprised by the preliminary findings, usually by the absence of evidence to support chronic disease management schemes. Although nearly two thirds of respondents felt that the individual studies had evaluated the right outcomes, they repeatedly proposed three types of outcomes needing further evaluation; health-related quality of life, self-management skills and carer outcomes. Nearly all respondents agreed with our recommendations but only half agreed that decisions on service provisions should be based on this sort of evidence. Respondents were concerned about the quality of the studies included in the review and the need to explore all relevant outcomes.

This is the only systematic review we are aware of to attempt to consult service providers for feedback on preliminary results and recommendations. However the actual number of responses we received was very small and only amounted to 6% of those invited to respond (a self-nominated group). It is not possible to generalise the findings from our respondents to all health care providers in this area. Asking providers to access our findings over the web may have reduced the number of respondents

although during the consultation the preliminary report was accessed on 655 occasions. It would appear that a substantial number of providers choose not to provide feedback although they viewed the preliminary report and/or the executive summary. The level of response may also have been affected because the request for feedback included the Christmas break.

4.2.6 Principal findings of the Survey

Mapping of the current provision of specialist respiratory nurse services for patients in the community with COPD demonstrated that such services are scattered throughout England and Wales. There appears to be inequality in the provision of these services and, although these services are not necessarily based on PCT boundaries, some PCTs do not have services, particularly acute services, within their boundaries or within any neighbouring PCT. The picture of service provision was dynamic with new services arising and others ceasing due to lack of funding or replacement staff and many services evolving and changing their components.

Overall, most services were based within secondary care, while funding sources were more equally distributed between primary and secondary care. The vast majority of services received at least some recurrent funding and only 14 per cent of services were funded (in part or wholly) from one off funding or charitable moneys. Overall respondents estimated that around 92 per cent of referrals to the services originated from secondary care.

The type and content of the services provided varied greatly, but most involved chronic disease management. In general chronic disease management services had been established longer, were run by smaller teams of nurses and provided a wider range of services than other nurse COPD services. Most provided care in the home and ran clinics, around a third were clinic only services – a type of intervention which has not been evaluated to date (although we did identify some ongoing studies of this type of intervention). Many of the chronic disease management type services in the survey offered components which were not reported in the interventions evaluated in RCTs, for example: 58 per cent offered pulmonary rehabilitation, 29 per cent offered some psychological interventions and 38 per cent offered self-help groups. Where services provided acute care most also provided some elements of chronic disease management as well. This ‘hybrid’ service is a model which has not been evaluated to date.

Strength and weaknesses of the survey

This is the first extensive survey of provision of specialist nurse services for patients in the community with COPD in England and Wales. This survey primarily relied on questionnaire data, but was further informed by the extensive amount of literature sent in by respondents and from phone and email contact (sixty five respondents gave further information on services). The review team was also guided in the conduct of the survey and its interpretation by a Nursing Reference Group largely made up of respiratory nurse specialists.

There are some potential weaknesses in this work. Firstly, there was a low response to the first questionnaire. This could be explained by a lack of apparent relevance of survey to respondent, knowledge that a work colleague had already replied or one respondent being sent several questionnaires (particularly likely if the respondent was on the RCN database as well as the other databases). Because we were concerned that we could have missed services in some areas of England and Wales we mapped respondents locations using their postcodes and found at least one person had responded from within the boundaries of 90% of all PCTs. We were able to contact eight of the nine PCTs that did not appear to have a service and all confirmed they did not have a service based within their PCT boundaries. Another indication that we may not have missed services is the large number, 225, of services that were identified more than once, and in some case more than 10 times.

A second weakness that became apparent in grouping services, between acute, chronic disease management, combined and specialist services, was that some respondents who identified their services as providing HaH or early an discharge scheme may have been identifying an element of care that was not a 'formal' service component. Because we were concerned of that we might have misgrouped some services we undertook a check of a random sample of combined ('hybrid') services, of those we contacted, 21 out of 22 had been grouped correctly. Finally, this survey did not explore in any detail the provision of innovations for COPD where there is more involvement of other health professionals. We are aware from our survey that there are a significant number of physiotherapy led services but the type and range of provision is unknown.

Other studies

This is the first survey in England and Wales to have focused on the extent and scope of specialist nurse services for patients in the community with COPD. A survey on the provision of hospital

at home services for acute exacerbations of COPD in Great Britain took place in 1999 (Johnson, 2001). In this survey, 186 (83%) out of 223 consultants based at each of the Respiratory Medicine Directory listed departments replied to a postal questionnaire. The questionnaire asked for the consultants' awareness and whether they ran a HaH service, thirty stated they ran such a service. While the survey by Johnson was not as extensive in its search for services as ours, it included Scotland, where acute home schemes for COPD were first developed. Johnson's survey found far fewer services (36 including Scotland) than we identified four years later. As in this review, Johnson found staffing levels to vary, the median was two WTE staff and ranged from 1 to 6. Likewise, he found that most stated these acute services involved aspects of chronic disease management such as clinics, long term oxygen therapy support and pulmonary rehabilitation.

4.3 Discussion and conclusions

Hospital at home and early discharge interventions appear to be safe in terms of survival and lung function for selected patients with acute exacerbations of COPD and do not appear to increase hospital readmissions. These schemes may also be less costly in terms of health service costs than conventional care. There is also very limited evidence to suggest they may not increase emergency department visits or general practitioner home visits. Perhaps surprisingly, there is little research evidence of the effect, if any, of these domiciliary interventions on carers. Their impact on patients' and carers' quality of life and psychological well being has not been explored yet. These were outcomes that the consumers who responded to our feedback expressed a particular interest in. Information on the implementation of these interventions is lacking in the existing literature. In our introductory chapter (section 1.1.5) we speculated about potential barriers to implementation, it is interesting to note that none of these were mentioned as actual barriers in our literature review, although we identified a paucity of information on implementation.

We conclude that at present there is no robust evidence to support respiratory nurse chronic disease management services for patients in the community with moderate or severe COPD and there is no evidence that longer chronic disease management interventions are any more beneficial than brief interventions.

There is unequal provision of respiratory nurse specialist services for patients with COPD, with some PCTs in England and Wales

without any type of service at the time of the survey. Taken together the literature review and the survey demonstrate that practice does not reflect evidence. The most common type of provision provided was chronic disease management. Although, the existing research literature does not seem to reflect current practice; it would appear that in 'real life' chronic disease management services are often more complicated than the interventions evaluated to date. Pulmonary rehabilitation was a component of over half the chronic disease management services identified in the survey but was not mentioned as a component in the RCTs. Also, we identified a large proportion of 'hybrid' services with both acute and chronic components. 'Clinic only' services were relatively common but this model of care has not been evaluated in any published randomised trial. (When commenting on the lack of evaluation of a service models we acknowledge that very many existing health care interventions involving other professional groups have also never been evaluated.)

4.3.1 Why is there no evidence to support the effectiveness of chronic disease management?

Does this review suggest why those chronic disease management interventions that have been studied to date might not be effective? The evidence is weak but these interventions did not appear to affect any of the process outcomes examined, apart from increasing patients' knowledge about their condition (see Chapter 2). A Cochrane SR of self-management education for COPD (Monninkhof 2004) found it had no effect on hospital admissions, emergency room visits, days lost from work and lung function. Inconclusive results were observed on HRQOL, studies using the disease specific instruments showed a better quality of life in the patients in the intervention group. The authors concluded that more research is needed on the area. (Recently an intensive self management educational intervention has been shown to shown to reduce hospital admissions for acute exacerbations (Bourbeau 2003). Pulmonary rehabilitation is known to be beneficial in COPD (Lacasse 2004, Cochrane SR); none of the chronic disease management interventions evaluated to date appeared to have a pulmonary rehabilitation component (one began after discharge from a pulmonary rehabilitation scheme). COPD is a challenging disease and it may be that a 'stronger dose' of a chronic disease management intervention in the community, perhaps with many components, is required to exert a measurable improvement in hard outcomes like hospital re-admission or death, if such improvement is possible at all.

In contrast to the findings of this disease-specific review, a meta-analysis of disease management programmes for a wide variety of chronic illnesses including COPD (Weingarten 2002) found patient education and patient reminders (prompts to remind patients perform specific tasks related to their care) were associated with improvements in patients' disease control (none of the COPD studies included in this review were included in Weingarten's meta-analysis and studies included in the Weingarten review did not meet our inclusion criteria). Much of the other evidence on disease management comes from large quasi-experimental studies, such as the Evercare Demonstration Project (Kane 2002, described in Section 1.0), of generic disease management interventions. It may be that generic interventions aimed at high risk individuals are more effective than disease specific interventions for COPD, and/ or that the effect size of the chronic disease management interventions for COPD that have been tested is too small to be seen in the evaluations carried out so far.

When considering the evidence of effectiveness presented in this review it should also be noted that other outcomes, which may be very important to both patients and carers - such as satisfaction with care and coping, have not been evaluated to date.

4.4 Recommendations

4.4.1 Recommendations for service providers

Nurse led hospital at home or early discharge schemes for patients with COPD living in the community should be prioritised over the type of nurse led chronic disease management models that have been studied to date.

Hospital at home or early discharge schemes should include the following components common to most of the interventions which have been subjected to evaluation in randomised controlled trials: a package of care on discharge home including drugs, nebulisers and oxygen concentrators, as indicated, patients to be seen at home within 24 hours of discharge, home visits to include assessment of the patient, the use of explicit care pathways, arrangements for out-of-hours care (usually provided by existing services) and follow up under the scheme lasting at least seven days and probably longer.

Service providers should be aware that five of the six hospital at home or early discharge schemes that have been subjected to evaluation in randomised controlled trials only operated on weekdays. Hospital at home or early discharge schemes that operate over weekends must be robustly evaluated.

There is very little evidence available at present to support the continuation of the *type* of chronic disease management models *that have been evaluated to date*. Existing services providing this sort of care should be robustly evaluated against the aims of the particular service. Alternatively, these services should consider adopting the characteristics of generic disease management programmes, or disease management programmes for other chronic conditions, which have been shown to be effective in well designed evaluations.

If any new, nurse led chronic disease management services for COPD patients living in the community are established they should be robustly evaluated against the aims of the particular service.

Novel service developments should be explored for the type of patients presenting with an acute exacerbation of COPD who were not considered eligible for, or did not wish to participate in, the early discharge or hospital at home schemes evaluated to date. (From our national survey we identified two, at present, unevaluated schemes for such patients: (1) supported discharge

schemes that discharge patients home to nurse support later than a conventional 'early discharge' but discharge earlier than a conventional hospital stay for an acute exacerbation, (2) community nurse unit schemes where a patient is admitted whose exacerbation does not require hospital admission but requires more monitoring than domiciliary nurse visits.)

Information on the successful implementation of new services for patients with COPD in the community should be disseminated. Keeping details on the implementation of new services for patients with COPD in the community should be standard practice and this information should be made easily available and actively disseminated to other health professionals and policy makers.

4.4.2 Recommendations for future research around COPD care

Multi-centre implementation research rolling out hospital at home/early discharge schemes to see if the benefits demonstrated in single centres can be seen across many centres and in different populations is required.

The potential benefits in terms of reduced hospital admissions and emergency department visits with chronic disease management schemes in COPD patients receiving long term oxygen therapy should be explored further.

Studies should look at the effect of domiciliary interventions on other community health care services and on social services.

Health economic studies of hospital at home/early discharge schemes which include the costs carried by patients and carers are needed.

Researchers should consider including patients' health related quality of life and carers' quality of life as outcomes and should explore the effects of interventions on patients' and carers' psychological well being and coping. Wherever possible validated instruments suitable for patients with COPD and their carers should be used.

Researchers should use robust techniques to explore patient and carer satisfaction with services.

There is a need for qualitative research of high quality around these interventions.

For the benefit of future readers, researchers should document the components of interventions clearly in published reports on their work or in linked documents stored on the world wide web.

4.4.3 Recommendations for systematic reviewers

Conducting a survey of the existing provision of services in tandem with a systematic review of the effectiveness of different service models can be a very useful exercise and, where appropriate, should always be considered.

Methods need to be developed to identify the best ways of involving consumers in systematic reviews and consulting them about the findings. In particular, techniques should be developed to explain systematic reviews and communicate their findings to consumers or other lay audiences.

This review demonstrated the potential benefits of drawing on a broader range of evidence than conventional systematic reviews, however in practice in extending the review this way contributed little to our overall findings. Further work should be undertaken to determine whether the benefits of this approach outweigh the resources required to extend the scope of a review in this way.

4.4.4 Recommendations for research funders

Research comparing the effectiveness of generic verses single condition interventions in chronic disease management should be commissioned.

Research which unpicks whether generic interventions and/ or interventions which have been found to be effective in one chronic disease can be transferred with similar benefit to another chronic disease should be commissioned.

4.5 Review Advisory groups

Three advisory groups were established for the project: a Scientific Steering Group, a Nurse Reference Group, and a Project management and Review Group.

The Peer review and management group conducted the project:

Dr Stephanie Taylor, Centre for Primary Care and General Practice, Barts and The London, Queen Mary's School of Medicine and Dentistry.

Ms Bridget Candy, Research Officer, Centre for Primary Care and General Practice, Barts and The London, Queen Mary's School of Medicine and Dentistry.

Dr Jean Ramsey, Centre for Primary Care and General Practice, Barts and The London, Queen Mary's School of Medicine and Dentistry.

Professor Ros Bryar, St Bartholomew School of Nursing and Midwifery, City University

Professor Chris Griffiths, Centre for Primary Care and General Practice, Barts and The London, Queen Mary's School of Medicine and Dentistry.

Mr Brian Schrin, lay member.

Ms Glenda Esmond, St Bartholomew School of Nursing and Midwifery, City University.

Dr Bert Virjoef, Department of Health Care Studies, Maastricht University.

Professor Jadwiga A. Wedzicha, Academic Unit of Respiratory Medicine, Barts and The London, Queen Mary's School of Medicine and Dentistry.

Members of Scientific Steering Group:

Professor Gene Feder

Professor Martin Underwood

MS Annette Boaz

Members of the Nurse Reference Group:

Ms Gill Foster

Professor Ros Bryar

Ms Glenda Esmond

Ms Jill Goddard

Ms Hazel Kilvington

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Appendix 1 Search strategy used to search PubMed for COPD systematic review

#1 COPD 15346 hits

('pulmonary disease, chronic obstructive'[MeSH Terms] OR COPD [Text Word])

This MeSH term is exploded so includes the following MeSH terms

Bronchitis, Chronic

Pulmonary Emphysema

Lung, Hyperlucent

#2 chronic obstructive pulmonary disease 16662 hits

('pulmonary disease, chronic obstructive'[MeSH Terms] OR chronic obstructive pulmonary disease [Text Word])

(The Text Word element works the same as 'chronic obstructive pulmonary disease')

'Chronic obstructive pulmonary disorder' not found as a phrase. It wants to use ((chronic [All Fields] AND obstructive [All Fields]) AND ('lung diseases'[MeSH Terms] OR pulmonary disorder [Text Word])) – left this out

#3 COAD 10077 hits

('pulmonary disease, chronic obstructive'[MeSH Terms] OR COAD [Text Word])

#4 chronic obstructive airway disease 10112 hits

('pulmonary disease, chronic obstructive'[MeSH Terms] OR chronic obstructive airway disease [Text Word])

(The Text Word element works the same as 'chronic obstructive airway disease')

'Chronic obstructive airway disorder' was not found as a phrase. It wanted to use (((chronic [All Fields] AND obstructive [All

Fields]) AND airway [All Fields]) AND disorder [All Fields]) - left this out.

#5 'Chronic obstructive airways disease' 345 hits

'Chronic obstructive airways disorder' not found as a phrase. It wanted to use (((chronic [All Fields] AND obstructive [All Fields]) AND airways [All Fields]) AND disorder [All Fields]) - left this out.

#6 chronic obstructive lung disease 11518 hits

('pulmonary disease, chronic obstructive'[MeSH Terms] OR chronic obstructive lung disease [Text Word])

'Chronic obstructive lungs disease' is not found as a phrase so searches for individual words – left this out.

'Chronic obstructive lung disorder' not found as a phrase. Wants to search for ((chronic [All Fields] AND obstructive [All Fields]) AND ('lung diseases'[MeSH Terms] OR lung disorder [Text Word])) - left this out.

'Chronic obstructive lungs disorder' not found as a phrase. It wants to search for (((chronic [All Fields] AND obstructive [All Fields]) AND ('lung'[MeSH Terms] OR lungs [Text Word])) AND disorder [All Fields]), - left this out.

#7 chronic bronchitis 6413 hits

('bronchitis, chronic'[MeSH Terms] OR chronic bronchitis [Text Word])

This MeSH term is at the end of a tree

(The Text Word element of this works the same as 'chronic bronchitis')

#8 emphysema 16077 hits

(('pulmonary emphysema'[MeSH Terms] OR 'emphysema'[MeSH Terms]) OR emphysema [Text Word])

The MeSH term 'Pulmonary Emphysema' is exploded so includes the MeSH term 'Lung, Hyperlucent'

The MeSH term 'Emphysema' is exploded so includes the MeSH terms 'Mediastinal Emphysema'; 'Subcutaneous Emphysema'

Irreversible airways disease – could find no MeSH term to map to.

((irreversible[All Fields] AND airways[All Fields]) AND ('disease'[MeSH Terms] OR disease[Text Word])) – LEFT THIS OUT

#9 'irreversible airways disease' 3 hits

('irreversible airways disease'[All Fields])

'Irreversible airway disease' not found as a phrase. It wants to search ((irreversible[All Fields] AND airway[All Fields]) AND ('disease'[MeSH Terms] OR disease[Text Word])) - left this out.

'Irreversible airway disorder' not found as a phrase. It wants to search ((irreversible[All Fields] AND airway[All Fields]) AND disorder[All Fields]), - left this out.

'Irreversible airways disorder' not found as a phrase. It wants to search ((irreversible[All Fields] AND airways[All Fields]) AND disorder[All Fields]), - left this out.

#10 Search chronic airflow obstruction 10335 hits

('pulmonary disease, chronic obstructive'[MeSH Terms] OR chronic airflow obstruction[Text Word])

#11 Search chronic airflow limitation 10173 hits

('pulmonary disease, chronic obstructive'[MeSH Terms] OR chronic airflow limitation[Text Word])

Search 'airflow limitation, chronic', not found as a phrase, searches for all terms with AND – leave this out.

#12 Search #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11

32896 hits

#13 nurs*

#14 'Nurses'[MESH] 44266

This is exploded so includes the MeSH terms: Nurse Administrators; Nurse Anesthetists; Nurse Clinicians; Nurse Midwives; Nurse Practitioners; Nurses, Male

If you do not explode it you get 18793 hits

#15 'nursing'[MESH] 142010

This is exploded so includes the MeSH terms:

Nursing Research

Nursing Theory

Specialties, Nursing

Community Health Nursing

Family Nursing

Rehabilitation Nursing

But also other nursing terms which may not be relevant, but when combined with COPD concept should be OK.

If you search it not exploded you get 38186 hits

#16 nursing care 141716

(('nursing'[MeSH Subheading] OR 'nursing care'[MeSH Terms]) OR nursing care[Text Word])

'Nursing Care' is exploded so includes the MeSH terms:

Home Nursing

Respite Care

Primary Nursing Care

Rehabilitation Nursing

And others.

#17 'nursing care'[All Fields] 33468

(#16 NOT #15 = 274)

#18 nursing process 38963

('nursing process'[MeSH Terms] OR nursing process[Text Word])

#19 'nursing process' [All Fields] 5385

(#18 NOT #17 = 1)

#20 'nursing services'[MESH:noexp] 3303

The only more specific MeSH term is 'Nursing Service, Hospital' so not exploded

#21 'nursing services'[All Fields] 4601

#22 nurse-patient relations 17597

('nurse-patient relations'[MeSH Terms] OR nurse-patient relations[Text Word])

This MeSH term is at the bottom of the tree

(#21 NOT ('nurse patient relations' OR 'nurse-patient relations') = 0)

#23 nurse's role 4404

('nurse's role'[MeSH Terms] OR 'nurse s role'[Text Word])

This MeSH term is at the bottom of the tree

#24 community health nursing 13500

('community health nursing'[MeSH Terms] OR community health nursing [Text Word])

This MeSH term is at the bottom of the tree

#25 'community health nursing'[All Fields] 13591

#26 health visit* NOT jrid3991[JOURNAL] 1539

((((health visit [All Fields] OR health visiting [All Fields]) OR health visitor[All Fields]) OR health visitors[All Fields]) NOT jrid3991[JOURNAL]) (ie NOT Health Visitor [journal])

'health educators'[MESH] – no hits!

#27 caregivers 9905

('caregivers'[MeSH Terms] OR caregivers [Text Word])

This MeSH term is at the bottom of the tree

28 caregiver[Text Word] 3482

#29 patient discharge 9303

('patient discharge'[MeSH Terms] OR patient discharge [Text Word])

This MeSH term is at the bottom of the tree

'patient discharge'[All Fields] NOT #28 = 0

#30 'hospital discharge'[All Fields] 5629

#31 'discharge planning' 1216

'planned discharge' not found as a phrase.

#32 discharge plan* 1312

((((discharge planing[All Fields] OR discharge planner[All Fields]) OR discharge planners[All Fields]) OR discharge planning[All Fields]) OR discharge plans[All Fields])

#31 NOT #30 = 96

#33 'outpatients'[MeSH Terms] 2798

This MeSH term is at the bottom of the tree

#34 outpatient* 55552

35 'Outpatient Clinics, Hospital'[MESH] 10504

This MeSH term is exploded and therefore also includes the MeSH term 'Pain clinics'

#36 'Community Health Centers'[MESH] 5278

This MeSH term is exploded and therefore also includes the MeSH term 'Substance Abuse Treatment Centers'

#37 outpatient clinic* 16294

#38 outpatient department* 1908

#39 'home care services'[MESH] 25778

This MeSH term is exploded and therefore also includes the MeSH terms 'Home Care Services, Hospital-Based'; 'Home Nursing'; 'Homemaker Services' and others

#40 home car* 24568

((home care [All Fields] OR home cared[All Fields]) OR home caring[All Fields])

#41 'hospital at home' 119

#42 'community care' 2088

#43 community service* 1656

(community service[All Fields] OR community services[All Fields])

#44 'ambulatory care'[MESH] 30600

This MeSH term is exploded and therefore also includes the MeSH term 'Peritoneal Dialysis, Continuous Ambulatory'

'patient care management'[MESH] 240391 too many hits, use more specific terms or leave out altogether

'managed patient care' phrase not found

'home intervention' phrase not found

#45 'secondary prevention'[All Fields] 4107

#46 home visit* 2104

((((((home visit [All Fields] OR home visitation [All Fields]) OR home visited[All Fields]) OR home visiting[All Fields]) OR home visitor[All Fields]) OR home visitors[All Fields]) OR home visits[All Fields])

#47 home assess* 67

(home assessed[All Fields] OR home assessment[All Fields])

#48 'house calls'[MESH] 1187

This MeSH term is at the bottom of the tree.

#49 house call* 1275

(((((house call[All Fields] OR house calls[All Fields]) OR house calls/economics[All Fields]) OR house calls/standards[All Fields]) OR house calls/trends[All Fields]) OR house calls/utilization[All Fields])

#50 'Patient Education'[MESH] 34395

This MeSH term is at the bottom of the tree.

#51 patient teach* 456

((patient teacher [All Fields] OR patient teachers[All Fields]) OR patient teaching[All Fields])

#52 'Patient Care Planning'[MESH] 30716

#53 patient counsel* 429

((((patient counselled [All Fields] OR patient counselling [All Fields]) OR patient counselled[All Fields]) OR patient counsellor [All Fields]) OR patient counsellors [All Fields])

#54 'Primary Health Care'[MESH] 32712

#54 'primary care'[All Fields] 27804

COPD concept

#12 Search #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11

32896 hits

Nursing concept

(#13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25)

382803 hits

Health / home concept

(#26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #26)

242228 hits

COPD + nursing concepts

622 hits

COPD + Health / home concepts

1517 hits

COPD + nursing OR Health / home concept

1881 hits

Appendix 2 Criteria for selecting abstracts of papers for possible inclusion

A primary research paper

INCLUDE – if all criteria below are met	EXCLUDE
A: COPD (see above)	
B:Adult	Children under the age of 18 years (but not in search strategies).
C: Papers reporting on: Innovation/treatment that is/are nurse-led/co-coordinated or largely provided by nurses for COPD patients normally living in the community and/or for relatives or cares (Examples (1) Referral to specialist respiratory or COPD nurses, (2) Schemes delivered by nurses to advert unplanned hospital admissions (3) 'Hospital at home' schemes for COPD, (4) Referral to nurse led COPD clinics, (5) Proactive homes visits or home assessments delivered by nurses, (6) Specialised discharge planning delivered by nurses.)	Papers reporting on: Nurse-led or delivered educational innovations which consist solely of educating or training other health professionals to manage COPD in the community.
D: English or Dutch title or abstract	Non-English or Dutch title or abstract (full paper may be in foreign language).

Terms which mean COPD for the purposes of this review include:

COPD, Chronic Obstructive Pulmonary Disease	Pulmonary Emphysema
COAD, Chronic Obstructive Airways Disease	Irreversible Airways Disease
Chronic Obstructive Lung Disease	Airflow obstruction, Chronic
Chronic Bronchitis	Chronic Airflow Obstruction
Emphysema	

Appendix 3 Levels of Evidence

Levels of evidence

From the Centre for Evidence-Based Medicine, Oxford
For the most up-to-date levels of evidence, see
http://www.cebm.net/levels_of_evidence.asp

Therapy/Prevention/Etiology/Harm:

1a: Systematic reviews (with homogeneity) of randomized controlled trials

1a-: Systematic review of randomized trials displaying worrisome heterogeneity

1b: Individual randomized controlled trials (with narrow confidence interval)

1b-: Individual randomized controlled trials (with a wide confidence interval)

1c: All or none randomized controlled trials

2a: Systematic reviews (with homogeneity) of cohort studies

2a-: Systematic reviews of cohort studies displaying worrisome heterogeneity

2b: Individual cohort study or low quality randomized controlled trials <80% follow-up)>

2c: 'Outcomes' Research; ecological studies

3a: Systematic review (with homogeneity) of case-control studies

3a-: Systematic review of case-control studies with worrisome heterogeneity

3b: Individual case-control study

4: Case-series (and poor quality cohort and case-control studies)

5: Expert opinion without explicit critical appraisal, or based on physiology, bench research or 'first principles'

Diagnosis:

1a: Systematic review (with homogeneity) of Level 1 diagnostic studies; or a clinical rule validated on a test set.

1a-: Systematic review of Level 1 diagnostic studies displaying worrisome heterogeneity

1b: Independent blind comparison of an appropriate spectrum of consecutive patients, all of whom have undergone both the diagnostic test and the reference standard; or a clinical decision rule not validated on a second set of patients

1c: Absolute SpPins And SnNouts (An 'Absolute SpPin' is a diagnostic finding whose Specificity is so high that a Positive result rules-in the diagnosis. An 'Absolute SnNout' is a diagnostic finding whose Sensitivity is so high that a Negative result rules-out the diagnosis).

2a: Systematic review (with homogeneity) of Level >2 diagnostic studies

2a-: Systematic review of Level >2 diagnostic studies displaying worrisome heterogeneity

2b: Any of: 1)independent blind or objective comparison; 2)study performed in a set of non-consecutive patients, or confined to a narrow spectrum of study individuals (or both) all of whom have undergone both the diagnostic test and the reference standard; 3) a diagnostic clinical rule not validated in a test set.

3a: Systematic review (with homogeneity) of case-control studies

3a-: Systematic review of case-control studies displaying worrisome heterogeneity

4: Any of: 1)reference standard was unobjective, unblinded or not independent; 2) positive and negative tests were verified using separate reference standards; 3) study was performed in an inappropriate spectrum of patients.

5: Expert opinion without explicit critical appraisal, or based on physiology, bench research or 'first principles'

Prognosis:

1a: Systematic review (with homogeneity) of inception cohort studies; or a clinical rule validated on a test set.

1a-: Systematic review of inception cohort studies displaying worrisome heterogeneity

1b: Individual inception cohort study with > 80% follow-up; or a clinical rule not validated on a second set of patients

1c: All or none case-series

2a: Systematic review (with homogeneity) of either retrospective cohort studies or untreated control groups in RCTs.

2a-: Systematic review of either retrospective cohort studies or untreated control groups in RCTs displaying worrisome heterogeneity

2b: Retrospective cohort study or follow-up of untreated control patients in an RCT; or clinical rule not validated in a test set.

2c: 'Outcomes' research

4: Case-series (and poor quality prognostic cohort studies)

5: Expert opinion without explicit critical appraisal, or based on physiology, bench research or 'first principles'

Key to interpretation of practice guidelines

Agency for Healthcare Research and Quality:

A: There is good research-based evidence to support the recommendation.

B: There is fair research-based evidence to support the recommendation.
C: The recommendation is based on expert opinion and panel consensus.
X: There is evidence of harm from this intervention.

USPSTF Guide to Clinical Preventive Services:

A: There is good evidence to support the recommendation that the condition be specifically considered in a periodic health examination.

B: There is fair evidence to support the recommendation that the condition be specifically considered in a periodic health examination.

C: There is insufficient evidence to recommend for or against the inclusion of the condition in a periodic health examination, but recommendations may be made on other grounds.

D: There is fair evidence to support the recommendation that the condition be excluded from consideration in a periodic health examination.

E: There is good evidence to support the recommendation that the condition be excluded from consideration in a periodic health examination.

University of Michigan Practice Guideline:
A: Randomized controlled trials.
B: Controlled trials, no randomization.
C: Observational trials.
D: Opinion of the expert panel.

Other guidelines:
A: There is good research-based evidence to support the recommendation.
B: There is fair research-based evidence to support the recommendation.
C: The recommendation is based on expert opinion and panel consensus.
X: There is evidence that the intervention is harmful.

Appendix 4 Studies excluded after full text retrieval

First author, date of publication and title of paper	Type of paper and reason for exclusion*
Allee M. Excellence in respiratory nursing practice: exemplars and commentaries. Perspect.Respir Nurs 1996;7:1, 3.	Case report on respiratory rehabilitation.
Anonymous. National trend pushes more pulmonary disease patients into home care. Homecare Education Management. 1998;3:89-91.	Discussion paper on developments in US, no reference to nursing services.
Anonymous, Teaching your patient to live with C.O.P.D. Nurs Life 1985;5:31-2.	Discussion paper on breathing techniques.
Avis M, Bond M, Arthur A. Exploring patient satisfaction with out-patient services. Journal of Nursing Management. 1995;3:59-65.	Patient satisfaction study of a non-nurse led service for a mixed illness group.
Benner P. The wisdom of caring practice. Nursing Management (Harrow). 2000;6:32-7.	Discussion paper on nursing.
Bertolotti G,.Carone M. From mechanical ventilation to home-care: the psychological approach. Monaldi Arch.Chest Dis 1994;49:537-40.	Discussion paper on psychological approach to rehabilitation.
Booker R. Respiratory clinic. Practice Nursing. 2002;13:130.	Discussion paper on differential diagnosis in lung disease.
Breslin AB, Colebatch HJ, Engel LA, Young IH. Adult domiciliary oxygen therapy. The Thoracic Society of Australia and New Zealand. Med J Aust. 1991;154:474-7.	Discussion paper on an aspect of care.
Brooks D, Krip B, Mangovski-Alzamora S, Goldstein RS. The effect of postrehabilitation programmes among individuals with chronic obstructive pulmonary disease. Eur.Respir.J. 2002; 20:20-9.	Randomised controlled trial of two types of post rehabilitation programme with no or minor nurse involvement.

Brown CJ, Martelle D, Gorman SM, Graham M. Continuing care partnership: seamless services to COPD patients. Disch.Plann.Update 1994;14:16-23.	Descriptive paper of a non-respiratory nurse services.
Brundage DJ, Swearengen P, Woody JW. Self-care instruction for patients with COPD. Rehabil.Nurs 1993;18:321-5.	Study on an evaluation of teaching tool for patients with COPD.
Burton LC. Acceptability to patients of a home hospital. J.Am.Geriatr.Soc. 1998;46:605-9.	Study with a mixed illness group.
Callahan M. C.O.P.D. makes a bad first impression, but you'll find wonderful people underneath. Nursing (Lond). 1982;12:67-72.	Discussion paper on common COPD problems.
Calverley P,.Bellamy D. The challenge of providing better care for patients with chronic obstructive pulmonary disease: The poor relation of airways obstruction? 1594. Thorax 2000;55:78-82.	Discussion paper on care for patients in the community with COPD. No mention of nurse services.
Carroll P. Ask Home Healthcare Nurse. Home Healthcare Nurse. 1996;14:822-4.	Discussion paper on various aspects of COPD home care.
Chaney JC, Jones K, Grathwohl K, Olivier KN. Implementation of an oxygen therapy clinic to manage users of long-term oxygen therapy. Chest 2002;122:1661-7.	Study of non-nurse led clinic for patients on long-term oxygen therapy.
Chen Q, Kane RL, Finch MD. The cost effectiveness of post-acute care for elderly Medicare beneficiaries. Inquiry 2000;37:359-75.	Discussion paper on physicians' role in home management of COPD.
Clay T. In praise of the respiratory nurse specialist. Br.J Hosp.Med 1994;51:313.	Letter discussing COPD care in UK.
Clough P, Harnisch LA, Cebulski P, Ross D. Method for individualizing patient care for chronic obstructive pulmonary disease patients. Health Soc.Work 1987;12:127-33.	Descriptive paper of a education program, minor nurse are involvement.
Crouch RH. Community-based pulmonary rehabilitation of the patient with chronic obstructive	Descriptive paper of a non-nurse pulmonary rehabilitation programme.

pulmonary disease. Phys Ther Health Care 1989;3(1-2):39-46.	
Cullen DL. Delineating clinical effectiveness research priorities for the respiratory care profession. AARC Times; 1994; July: 16-20.	Study of research priorities for respiratory therapists.
D'Agostino JS. Teaching tips for living with C.O.P.D. at home. Nursing (Lond). 1984;14:57.	Advice paper on teaching a patient to cope with COPD.
Davido J. Pulmonary rehabilitation. Nurs Clin North Am 1981;16:275-83.	Discussion paper on pulmonary rehabilitation. The nurses' role is not discussed.
Davidson C. Key developments in respiratory medicine. Practitioner 1999 May;243(1598):364-75. 1999;364-75.	Discussion paper on aspects of COPD management. Nursing services not covered.
De Vito AJ. Rehabilitation of patients with chronic obstructive pulmonary disease. Rehabil.Nurs 1985;10:12-5.	Study of various discharge packages tailored to a wide range of chronic diseases, not specifically for COPD.
Dennis LI, Blue CL, Stahl SM, Benge ME, Shaw CJ. The relationship between hospital readmissions of medicare beneficiaries with chronic illnesses and home care nursing interventions. Home Healthc.Nurse 1996;14:303-9.	Paper on patients with various illnesses.
Dettenmeier PA. Planning for successful home mechanical ventilation. AACN Clinical Issues in Critical Care Nursing. 1990;1:267-79.	Paper on an aspect of care.
Donner CF, Polu J-M, Braghiroli A, d'Orbcastel OR. Home respiratory assistance network 1493. European Respiratory Monograph 2001;6:281-92.	Discussion paper on a support and advisory network.
Dranove D. An empirical study of a hospital-based home care program. Inquiry 1985;22:59-66.	Study with mixed illness group.
Dunn NA. Keeping COPD patients out of the ED. RN. 2001;64:33-7.	Discussion paper on aspects of nurse care for patients with COPD.
Eakin EG,.Glasgow RE. The patients' perspective on the self-management of chronic obstructive pulmonary disease. Journal of Health Psychology	Study on factors relating to self-management.

1997;2:245-53.	
Ellum S,.Chisholm H. Home support for chronic obstructive pulmonary disease. Inspiration 2001;19:6.	Descriptive study of an intervention not led or primarily involving nurses.
Falck S. Chronic ventilator patients. Alternatives to hospital care. Respir Ther 1985;15:27-35	Discussion paper on a non-nursing program to enable nursing homes to accept chronic ventilated patients.
Fauroux B, Howard P, Muir JF. Home treatment for chronic respiratory insufficiency: the situation in Europe in 1992. The European Working Group on Home Treatment for Chronic Respiratory Insufficiency. Eur.Respir J 1994;7:1721-6.	Discussion paper on home treatment with no reference to nurse services.
Fischer DA,.Prentice WS. Feasibility of home care for certain respiratory-dependent restrictive or obstructive lung disease patients. Chest 1982;82:739-43.	Study of a home care service for certain lung diseases, no mention of nurse involvement.
Flynn M. Management of chronic obstructive airways disease. Br.J Nurs 1993;2:717-23.	Case study of respiratory inpatient.
Frasca C,.Weimer M. Establishing a respiratory therapy program in the home: the South Hills program. Home Healthc.Nurse 1985;3:8-12.	Descriptive paper of a non-nurse programme.
Frehcn WA. RCPs tackle emphysema in the home. Rt: the Journal for Respiratory Care Practitioners. 2000;13:95-May.	Discussion paper of respiratory care practitioner *caring for patients at home with emphysema.
Gallefoss F, Bakke PS, Rsgaard PK. Quality of life assessment after patient education in a randomized controlled study on asthma and chronic obstructive pulmonary disease. Am J Respir Crit Care Med 1999;159:812-7.	Randomised controlled trial of the effect of an education intervention from a multidisciplinary team.
Gallefoss F,.Bakke PS. Patient satisfaction with healthcare in asthmatics and patients with COPD before and after patient education. Respir Med 2000;94:1057-64.	Education program, not a nurse service.
Gilmartin M,.Make B. Home care of the ventilator-dependent	Discharge planning paper, little reference to nursing.

person. Respir Care 1983;28:1490-7.	
Glass C, Grap MJ, Battle G. Preparing the patient and family for home mechanical ventilation 2611. Medsurg Nurs. 1999;8:99-7.	Discussion paper on an aspect of nurse care.
Goldstein, 1996. Model program development and outcomes in chronic obstructive pulmonary disease	Discussion paper of various non-nurse-led or principally involving nurse pulmonary rehabilitation program models.
Goldstein RS, Gort EH, Guyatt GH, Feeny D. Economic analysis of respiratory rehabilitation. Chest 1997;112:370-9.	Study of a non-nurse respiratory rehabilitation programme.
Griffiths TL, Phillips CJ, Davies S, Burr ML, Campbell IA. Cost effectiveness of an outpatient multidisciplinary pulmonary rehabilitation programme. Thorax 2001;56:779-84.	Study of a multidisciplinary pulmonary rehabilitation programme where the nurse does not play a central role.
Guyatt GH, McKim DA, Austin P, Bryan R, Norgren J, Weaver B et al. Appropriateness of domiciliary oxygen delivery. Chest 2000;118:1303-8.	Descriptive paper on a domiciliary service that did not involve a nurse.
Haggerty MC. Outpatient management of common problems in patients with chronic obstructive pulmonary disease. Nurse Pract.Forum 1993;4:16-22.	Discussion paper covering aspects of care.
Hall IP, Callow IM, Evans SA, Johnston ID. Audit of a complete home nebulizer service provided by a respiratory nurse specialist. Respir Med 1994;88:429-33.	Audit of service that includes patients with a range of respiratory illnesses.
Hansen-Flaschen JH. Palliative home care for advanced lung disease. Respir Care 2000;45:1478-86.	Discussion paper on an approach to palliative home care of patients with advanced lung disease-primarily for physicians.
Harman R. Management of COPD with oxygen therapy at home. Community Nurse 1999;5:25-6.	Discussion paper on an aspect of care.
Harrison G. Out of breath, into rehab. Nursing Times 1999 Apr 28;95(17):58-61. 1999;58-61.	Discussion paper on how to set up a pulmonary rehabilitation service.
Harrison G. COPD taskforce. Nurs Manag.(Harrow) 2000;7:30-2.	Descriptive paper of an initiative to improve health professional's care

	of patients with COPD.
Henteleff PD. Dyspnea management: 'to take into the air my quiet breath'. Journal of Palliative Care. 1989;5:52-4.	Descriptive paper of a pharmacological treatment of dyspena.
Hernandez MT, Rubio TM, Ruiz FO, Riera HS, Gil RS, Gomez JC. Results of a home-based training program for patients with COPD. Chest 2000;118:106-14.	Study of a home-based program that does not mention involvement of a nurse.
Heslop A,.King M. Let's treat body and mind. Collaborative rehabilitation for chronic breathlessness. Prof.Nurse 1994;10:188-92.	Case report of a patients rehabilitation programme.
Heslop A,.Shannon C. Assisting patients living with long-term oxygen therapy. Br.J Nurs 1995;4:1123-8.	Discussion paper on care of patient with LTOT.
Hodgkin JE, Kigin CM, Nett LM, Tiep BL. Your role in COPD home care. Patient Care. 1992;26:147-50.	Discussion paper on care of patients with COPD, with no special reference to nursing services.
Hudson LD,.Pierson DJ. Comprehensive respiratory care for patients with chronic obstructive pulmonary disease. Med Clin North Am 1981;65:629-45.	Discussion paper on respiratory care, with little reference to nurse services.
Issac, 1980. Establishing rapport with the emphysema patient: prelude to effective teaching.	Discussion paper on care of patient with COPD.
Jain S,.Hanania NA. Current management options for chronic obstructive pulmonary disease. Home Healthcare Consultant. 1999;6:31-6.	Discussion paper on the clinical management of COPD.
Janelli LM, Scherer YK, Schmieder LE. Can a pulmonary health teaching program alter patients' ability to cope with COPD? Rehabil.Nurs 1991;16:199-202.	Study of non-nurse education program.
Johannsen JM. Chronic obstructive pulmonary disease: current comprehensive care for emphysema and bronchitis. Nurse Pract. 1994;19:59-67	Discussion paper on nursing management of various aspects of care.
Johnson AP. The elderly and COPD. J Gerontol.Nurs	Discussion paper on nurses' role in educating patients in self-care.

1988;14:20-4.	
Jonsdottir H. Outcomes of implementing primary nursing in the care of people with chronic lung diseases: the nurses' experience. J Nurs Manag. 1999;7:235-42.	Qualitative study on nurses experience of inpatient care of people with COPD.
Jonsdottir H, Jonsdottir G, Steingrimsdottir E, Tryggvadottir B. Group reminiscence among people with end-stage chronic lung diseases. Journal of Advanced Nursing. 2001;35:79-87.	Study of group reminiscence intervention for people who have end-stage chronic lung disease.
Kent C. COPD is not a Cinderella disease. Nurs Times 2001;97:I.	Discussion paper on COPD care.
Ketelaars C. Quality of care of patients with chronic obstructive pulmonary disease provided by specialized community nurses: a process evaluation. Health & Social Care in the Community 1996;4:200-7.	Study did not evaluate effectiveness of specialised nurse services but evaluated the difference of a specialist compared to a generalist.
Kirilloff LH, Carpenter V, Kerby GR. Skills of the health team involved in out-of-hospital care for patients with COPD. Am.Rev.Respir.Dis. 1986;133:948-9.	Descriptive study of a multidisciplinary team intervention.
Koh A. A rapid response. Nurs Stand. 2000;14:24.	Inpatient case study.
Kollef MH, Shapiro SD, Clinkscale D, Cracchiolo L, Clayton D, Wilner R et al. The effect of respiratory therapist-initiated treatment protocols on patient outcomes and resource utilization. Chest 2000;117:467-75.	Study of inpatient treatment protocols.
Kubacki AM. A saint I ain't. Rehabil.Nurs 1988;13:259-60.	Case report of a carers experience of a patients COPD.
Lee DT, Lee IF, Mackenzie AE, Ho RN. Effects of a care protocol on care outcomes in older nursing home patients with chronic obstructive pulmonary disease. J Am Geriatr.Soc. 2002;50:870-6.	Study of intervention in a nursing home, not patients living in their own home.
Leff B, Burton L, Guido S, Greenough WB, Steinwachs D, Burton JR. Home hospital	Study with mixed illness group.

program: a pilot study. J Am Geriatr.Soc. 1999;47:697-702.	
Levin DC. Home care for respiratory problems. Clin Geriatr.Med 1991;7:777-86.	Discussion paper on home care with no discussion on nurse involvement.
Lynn J, Wesley, Zhong Z, McNiff KL, Dawson N. Living and dying with chronic obstructive pulmonary disease 3066. J.Am.Geriatr.Soc. 2000;48:S91-S100.	Study exploring patients with COPD last 6 months of life. Patient preferences explored but no reference to nursing services.
MacDonell RJ, Jr. Suggestions for establishment of pulmonary rehabilitation programs. Respir Care 1981;26:966-77.	Discussion paper on program that is multidisciplinary not nurse-led or principally involving nurses.
Mackay L. Health education and COPD rehabilitation: a study. Nurs Stand. 1996;10:34	9.
Maguire M, Miller TV, Young P. Teaching patients' families to provide ventilator care at home. Dimens.Crit Care Nurs 1982;1:244-55.	Discussion paper on teaching inpatients and families how to provide ventilator care at home.
Mair FS, Wilkinson M, Bonnar SA, Wootton R, Angus RM. The role of telecare in the management of exacerbations of chronic obstructive pulmonary disease in the home. J Telemed.Telecare 1999;5 Suppl 1:S66-S67.	Study of intervention that is non nurse led.
Mair FS, Wilkinson M, Bonnar SA, Wootton R, Angus RM. The role of telecare in the management of exacerbations of chronic obstructive pulmonary disease in the home. J Telemed.Telecare 1999;5 Suppl 1:S66-S67.	Study of a non nurse led service.
McLean DL, Maddox SE, Hodgkin JE, Hodge-Hilton T, Zorn EG, Hills R et al. Self-administration of medical modalities (SAMM): another method of rehabilitation education. Respir Care 1983;28:1462-7.	Descriptive paper of a hospital based patient-education program.
Meighan-Davies J,.Parnell H. Management of COPD. Journal of Community Nursing. 2000;14:20.	Discussion paper on the management of COPD- no mention of nurse involvement.
Meyer C. In COPD, a little patient education goes a long way.	Discussion paper of an education program.

Am.J.Nurs. 1992;92:14-5.	
Middlemiss MA. Integrating Nursing Care of the Elderly Patient with COPD. Nurs Educ.Microworld. 1991;5:28.	Discussion paper of a training module for nursing students.
Moser KM, Bokinsky GE, Savage RT. Results of comprehensive rehabilitation program. Physiologic and functional effects on patients with chronic obstructive pulmonary disease. Arch.Intern.Med. 1980;140:1596-601.	Study of a non nurse-led service.
Namie M. Clinical notes. The value of clinical pathways in home care. Caring. 1997;16:42-4.	Discussion paper on clinical pathways, does not discuss a specific COPD nurse service.
Omdahl DJ. When chronic illness calls for more than chronic care. AJN, American Journal of Nursing. 1988;88:1494-6.	Discussion paper on how in the US service providers can get reimbursed.
Openbrier DR,.Covey M. Ineffective breathing pattern related to malnutrition. Nurs Clin North Am 1987;22:225-47.	Discussion paper on an aspect of care.
Openbrier DR, Hoffman LA, Wesmiller SW. Home oxygen therapy. Evaluation and prescription. Am J Nurs 1988;88:192-7.	Case study of a patient on home oxygen therapy.
Palmer Cable E. Discharge planning effect on length of hospital stay. Arch Phys Med Rehabil 1983; 64:57-60	Study with a mixed illness group.
Powell SG. Medication compliance of patients with COPD. Home Healthc.Nurse 1994;12:44-50.	Study that evaluates only a component of a service.
Rifas EM. How you and your patient can manage dyspnea. Nursing (Lond). 1980;10:34-41.	Discussion paper on an aspect of care.
Roberts LJ,.Ross E. Chronic airflow limitation. Nurse Pract. 1983;8:21, 24-1, 25.	Discussion paper on clinical and psychosocial assessment of patient with chronic airflow limitation.
Roselle S,.D'Amico FJ. The effect of home respiratory therapy on hospital readmission rates of patients with chronic obstructive pulmonary disease. Respir Care 1982;27:1194-9.	Study of a non nurse respiratory therapy.

Rosser R. Psychological approaches to breathlessness and its treatment. J.Psychosom.Res. 1981;25:439-47.	Discussion paper that does not describe a nursing service.
Rosser R, Denford J, Heslop A, Kinston W, Macklin D, Minty K et al. Breathlessness and psychiatric morbidity in chronic bronchitis and emphysema: a study of psychotherapeutic management. Psychol.Med 1983;13:93-110.	Survey of an intervention that is not specifically a nurse service and in a mixed respiratory group.
Ryan S. Chronic obstructive pulmonary disease: boosting quality of life. Community Nurse. 2000;6:31-2.	Discussion paper on general management of COPD. Minor description of a community nurse and physiotherapist pulmonary rehabilitation programme.
Sahn SA, Nett LM, Petty TL. Ten year follow-up of a comprehensive rehabilitation program for severe COPD. Chest 1980;77:311-4.	Study of a non nurse service.
Scherer YK, Janelli LM, Schmieder L. The effects of a pulmonary education program on quality of life in patients with chronic obstructive pulmonary disease. Rehabilitation Nursing Research. 1994;3:62-8.	Study of an education program.
Scherer YK, Janelli LM, Schmieder LE. A time-series perspective on effectiveness of a health teaching program on chronic obstructive pulmonary disease. J Healthc.Educ.Train. 1992;6:7-13.	Discussion paper of an education program.
Schwartzman K, Duquette G, Zaoude M, Dion MJ, Lagace MA, Poitras J et al. Respiratory day hospital: a novel approach to acute respiratory care. CMAJ 2001;165:1067-71.	Descriptive study of not a specialised nurse led service.
Shamash J. Catching their breath... chronic obstructive pulmonary disease. Nursing Times. 2002;98:14-20.	Discussion paper on practice nurses role in care of patients with COPD.
Shaw A. Home based oxygen therapy for COPD. Nurse 2 Nurse 2002;2:51-2.	Paper on care of patient with LTOT – not about a specific service.
Shekleton ME. Coping with chronic respiratory difficulty. Nurs Clin North Am 1987;22:569-81.	Discussion paper that includes various intervention strategies for care but does not indicate that

	they are primarily nurse managed.
Shepperd S, Harwood D, Jenkinson C,Gray A, Vessey M, Morgan P. Randomised controlled trial comparing hospital at home care with inpatient hospital care. I: three month follow up of health outcomes. BMJ 1998;316:1786-91.	Randomised controlled trial of a hospital at home trial for mixed illness group.
Shirley K,.Kelly R. COPD management within primary care. Nurs Times 2002;98:52-3.	Descriptive study on COPD training and service implementation programme for health professionals.
Skilbeck J. Nursing care for people dying from chronic obstructive airways diseases. International Journal of Palliative Nursing 1997 Mar-Apr;3(2):100-6. 1997;100-6.	Study exploring experience of living with COAD and evaluation of care received but little covering of community /specialist services.
Smith BJ, McElroy HJ, Ruffin RE, Frith PA, Heard AR, Battersby MW et al. The effectiveness of coordinated care for people with chronic respiratory disease. Med.J.Aust. 2002;177:481-5.	Study of a multidisciplinary team intervention coordinated by GP.
Spann SJ. Impact of spirometry on the management of chronic obstructive airway disease. J Fam.Pract. 1983;16:271-5.	Study on the impact of introduction of a spirometer in the care of COPD patient.
Stockdale-Woolley R. Sexual dysfunction and COPD: problems and management. Nurse Pract. 1983;8:16-7, 20.	Discussion paper on a specific problem not on a service.
Stockdale-Woolley R. The effects of education on self-care agency. Public Health Nurs 1984;1:97-106.	Study of a non-nurse innovation.
Stollenwerk R. An emphysema client: self care. Home Healthcare Nurse. 1985;3:36-40.	Qualitative evaluation of patients 'needs'.
Strijbos JH, Postma DS, van Altena R, Gimeno F, Koeter GH. A comparison between an outpatient hospital-based pulmonary rehabilitation program and a home-care pulmonary rehabilitation program in patients with COPD. A follow-up of 18 months. Chest 1996;109:366-72.	Study of an intervention delivered by a multidisciplinary team.
Strijbos JH, Postma DS, van	Study of a multidisciplinary

Altena R, Gimeno F, Koeter GH. Feasibility and effects of a home-care rehabilitation program in patients with chronic obstructive pulmonary disease. J Cardiopulm.Rehabil. 1996;16:386-93.	rehabilitation program with nurses' role comparatively minor.
Suleyman F. Nurses are making it happen. Community Nurse 2000;5:8.	Discussion paper on spirometry.
Sutton FD. A team approach to pulmonary rehabilitation. Rt: the Journal for Respiratory Care Practitioners. 1999;12:47-8.	Descriptive paper of non-nurse service.
Swearengen PA, Brundage DJ, Woody JW. Self-care in COPD: an assessment project by practice and education. Nursingconnections. 1989;2:67-73.	Study of a non nurse service.
Taylor JD. Helping your patient cope with COPD (continuing education credit). Nurs Life 1986;6:33-40.	Paper on care of a COPD patient – not about a specific service.
Tin K, Keller G, Kaufman E. The effect of community-based respiratory therapy on hospital readmission rates for patients with chronic obstructive pulmonary disease. RRT - the Canadian Journal of Respiratory Therapy. 1995;31:68-73.	Study of a respiratory therapist service, not a nurse service.
Tregonning M,.Langley C. Chronic obstructive pulmonary disease. Elder.Care 1999;11:21-5.	Descriptive paper of a pulmonary rehabilitation programme that is co-ordinated by a physiotherapist with input from a multidisciplinary team including a nurse. Paper does not indicate that the nurse has a major role in programme.
Truesdell S. Helping patients with COPD manage episodes of acute shortness of breath. Medsurg Nurs 2000;9:178-82.	Discussion paper on an aspect care of a COPD patient – not about a specific service.
Trudeau ME,.Solano-McGuire SM. Evaluating the quality of COPD care... chronic obstructive pulmonary care. AJN, American Journal of Nursing. 1999;99:47-50.	Study of quality of COPD inpatient care.
Turner-Lawlor P. New breath of	Descriptive paper on pulmonary

life. Therapy Weekly. 1999;26:12.	rehabilitation service not specified as a nurse service.
Von Sternberg T, Hepburn K, Cibuzar P, Convery L, Dokken B, Haefemeyer J et al. Post-hospital sub-acute care: An example of a managed care model. Journal of the American Geriatrics Society, Vol 45(1) (pp 87-91), 1997 1997.	Study of nursing home patients who had undergone a rehabilitation programme following an acute incidence.
Walsh RL. Occupational therapy as part of a pulmonary rehabilitation program. Occupational Therapy in Health Care 1986;3:65-77.	Study of a non nurse intervention.
Weinberger M, Oddone EZ, Henderson WG. Does increased access to primary care reduce hospital readmissions? Veterans Affairs Cooperative Study Group on Primary Care and Hospital Readmission. N.Engl.J Med 1996;334:1441-7.	Study of a non nurse service.
Westra B. Assessment under pressure: when your patient says 'I can't breathe'. Nursing (Lond). 1984; 14:34-40.	Discussion paper on in-patient care.
Yohannes AM, Roomi J, Connolly MJ. Elderly people at home disabled by chronic obstructive pulmonary disease. Age Ageing 1998;27:523-5.	Survey on domiciliary support.

**Please not that where the reason for exclusion is given as 'a non nurse led service', this also includes studies where the nurse is not the principal health provider of the service. **Please note Respiratory Therapists in the US are not nurses.*

Appendix 5 Conference abstracts identified but unclear in eligibility (unable to contact)

Author, title, conference	Intervention
Boyd. The impact of outreach respiratory nurse specialist service on secondary care in COPD. British Thoracic Society conference 1997	Nurse outreach care to enhance earlier discharge and to reduce readmission when deterioration occurred.
Civitico. Multidimensional COPD program reduces utilization of inpatient bed day. A&NZ Thoracic Society 2003.	Three concurrent interventions 1-nursing outreach early discharge, 2-smokers clinic, 3-extended PR.
Jeffs. A retrospective, case controlled evaluation of the effect of a post acute respiratory outreach service on COPD patient outcomes and hospital readmission rates. A&NZ Thoracic Society 2003.	Post acute respiratory outreach service for COPD patient to provide education and practical support.
Lamont. Integrated case management between primary and secondary care for COPD patients: Perspectives from the Respiratory Nurse Specialist. Department of Medicine, University of Auckland A&NZ Thoracic Society 2002	GP practices randomised into control with usual care or intervention that utilized case management and care plans. Team involve RNS, practice nurse and GP. Mthly care planning meetings with pt. RNS co-case managed and provided a link to resources.
Mansfield. A home nebuliser service- improving patients' knowledge of maintenance of equipment. ERS 1997.	The effect of a nurse led nebuliser clinic for COPD on patients knowledge of maintenance of equipment.
Narsavage. Comparison of hospital readmission of COPD patients who did and did not receive home care nursing. ERS 1998.	Comparison of hospital readmission of COPD patients who did and did not receive home care nursing.
Rudkin. Hospital vs home	Effects of PR programme on

rehabilitation: the effects on carers of patients with severe COPD. ERS 1998.	anxiety and depression in carers at baseline and at 3 months.
Tregonning. RCT of home exercise and education in COPD. North Bristol NHS Trust. ERS 2001	For stable COPD post discharge for 8 wks- 2 visits by respiratory nurse and physiotherapist advice managing breathlessness and exercise. Telephoned monthly for progress and advice.

Appendix 6 Data abstraction sheets

Author, year	**Poole 2001**
Title	Case management may reduce length of hospital stay in patients with recurrent admissions for chronic obstructive pulmonary disease.
Design	Mixed prospective cohort and before and after study (pilot study) (patients assigned to groups according to admitting hospital). Duration of follow up: 12 months
Country and setting	New Zealand, two centres
Objectives clearly described	Y/N: yes 'The aim of the study was to determine whether case management of patients with recurrent hospital admissions for COPD can reduce hospital days without reducing quality of life.'
Participants (reported as intervention vs. comparison)	Sample size: 16 (63% male) vs. 16(56% male) (but one control patient dies and was replaced). Age (mean years): 70 (SD not given) vs. 75.4 (SD not given), p=0.04 Males 63% vs. 53 % Severity of COPD at recruitment: Mean FEV1 0.64 L (SD 0.24) vs. 0.72 (SD 0.22) Were the groups similar at baseline regarding the most important prognostic indications?: no and not much information about the groups given Inclusion criteria case managed group: Patients who had been admitted to Auckland hospital for COPD 4 or more times in past 2 years with at least 2 admissions in the past 12 months. Inclusion criteria comparison group: as above but from North Shore Hospital (15 km away). Exclusion criteria both groups: 'overwhelming co-morbidities such as severe cardiac failure or cancer'; discharged to institutional care.
Interventions	Components of intervention clearly described? Y/N: yes Duration of intervention: unclear, probably 12 months Intervention group: Case management by RNS Referral: not clear Assessment: patients were seen at home by clinical nurse specialist and a social worker. A medical history was taken along with a detailed social assessment and a problem plan formulated. Patients were encouraged to discuss any problems. Discharge: If patient admitted to hospital medical staff

	informed the RNS who visited patient daily whilst in hospital and helped with discharge planning. Home visits: monthly or more frequently if required especially after hospital discharge. Patients received education about the COPD disease process, correct use of medicines, smoking cessation, how to recognise and manage exacerbations, and were encouraged to obtain yearly influenza vaccinations and to see their GP on a regular basis and when unwell. Some patients received a supply of prednisone and antibiotics to commence at home. Family members were included in education where appropriate. All patients given a home exercise programme. (One patient had medication supervised by the RNS). Telephone calls: weekly from RNS to patients and patients were encouraged to contact RNS if they had any concerns. Out-of-hours cover: not clear Procedure for clinical deterioration: if possible patients were assessed in A&E by RNS prior to admission and admission averted if possible. Additional services and health carers involved in intervention: Patients also followed up every 6 months by hospital physicians at out patient clinic. Assessment by a liaison psychiatrist if indicated. Some patients also attended a pulmonary rehabilitation programme. Comparison group: Patients at another hospital 15 km away – junior staff rotate between intervention and comparison hospital. Description: 'This group did not receive any specific intervention'.
Outcomes	Were outcome measures well described? Yes Primary endpoints: hospital admissions and lengths of stay (probably) (hospital records of all 4 hospitals in area which COPD patients could be admitted to). Other outcomes examined: Deaths In the intervention group only: Hospital Anxiety and Depression Scale (HADS) and Chronic Respiratory Questionnaire (CRQ) at baseline, 6 and 12 months.
Methods	Statistical methods clearly described? Yes Rational for sample size: pilot study – no power calculation. Risk of attrition bias: unlikely Risk of detection bias: not clear Risk of caregiver performance bias: not clear Recruitment dates: 1/9/1996 to 1/3/1997
Results (All given as	Hospital admissions before intervention and year of intervention (medians): 3.0 to 2.1, p=0.13 vs. 3.0 to 1.5,

intervention group vs. comparison group)	p=0.06 Total bed days/year before intervention and year of intervention (medians): 21.5 to 8.0, p=0.02 vs. 17.0 to 8.5, p=0.30 LOS in year before intervention and year of intervention (medians): 5.6 to 3.5, p=0.02 vs. 5.5 to 5.8, p=0.11 Number of patients with no hospital re-admissions at one year follow up: 4 vs. 2 Deaths 1 vs. 3 Intervention group only HADS: no significant improvement in scores at 6 or 12 months. CRQ: probably clinically relevant improvement in score compared to baseline after 6 months, not clear if significantly better at 12 months.
Comments	Data source: published data only Generalisability: 3 (19%) eligible patients refused to participate Level of evidence: 4 Other points: One patient died within 12 months of recruitment and was replaced by another eligible subject. Retrospective data collected for the year ending 1/9/1996 for all patients. Prospective data collected from date of recruitment for intervention group but from 1/9/96 for comparison group. Comment from statistician: They may have not done the right comparison in Table 2, because the control group also reduced bed days moving from before to afterwards. It would have been preferable to compare the difference in the reduction in bed days, which may not have been significant.

Author, year	Bergner 1988
Title	The cost and efficacy of home care for patients with chronic lung disease.
Design	RCT (three arms) and cost effectiveness analysis Duration of follow up: 12 months
Country and setting	USA, multicentre study, with 10 Seattle hospitals with more than 100 physicians referring patients into the study.
Objectives clearly described	Y/N: Yes 'What is the efficacy and cost of health care for patients receiving sustained home care (RHC and SHC) as compared to patients receiving office care? What is the efficacy and cost for patients in the SHC as compared with patients in the RHC program?'.
Participants (All reported as intervention group vs. control group)	Sample size: office care program 100 patients (67% male), standard home care 102 patients (78% male), intervention group 99 patients (64% male) Age (mean years,): 65.1 Severity of COPD at recruitment: mean FEV1% predicted 33.8% Were the groups similar at baseline regarding the most important prognostic indications? Yes Study eligibility specified? Yes Inclusion criteria: aged 40-75 years, a clinical diagnosis of COPD as the patient's major limiting disease, post-bronchodilator FEV1 < 60% predicted, FEV1:FVC < 60%, local resident, meet the Medicare definition of being housebound i.e. unable to use public transport on a routine basis without assistance, able to administer aerolized metaproterenol. Exclusion criteria: primary diagnosis of asthma manifested by slowing of forced expiration which clears spontaneously or as a result of therapy; a primary diagnosis of other functionally limiting disease (except cor pulmonale) which could significantly affect patient mortality within one year of entry into the study (e.g. malignant neoplasm) or co-operative participation in the study (e.g. severe alcoholism, psychosis, receipt of standard home nursing care during the 6 months prior to entry into the study or receipt of the specialised respiratory home care program at any time in the past.
Interventions	Components of intervention clearly described? Y/N: No, only a small amount of detail given - actual content, duration and average length missing. Duration of intervention: 1 year Intervention Group: Specialised respiratory home care program (RHC) delivered by trained respiratory nurses. Referral: Physician referral following an inpatient stay or while using outpatient services (such as clinic or physician office). Assessment: not specified

	Home visits: home care nurse within 24 hours and then as frequently as the nurse considered necessary, but at least once a month, during the study year. They provided acute and continuing care - no other details given. Out-of-hours cover: not specified Procedure for clinical deterioration: not specified Clinical support to nurses: nurses worked with the primary physician and could provide care, medications etc only with the physicians approval. Additional services and health carers involved in intervention: not specified Comparison Groups: Two groups 1) - a standard home care program with general nurses (SHC), 2) an office care program (OC). Description: OC received 'whatever care the needed except for home care'. Physicians whose patients were assigned to the office program agreed not to order home nursing services for their patients during the study year.
Outcomes	Were outcome measures well described? Yes Primary outcome: Costs Other outcomes: The Sickness Impact Profile, the General Well-Being Schedule and a walking tolerance test developed by investigators, survival rates, pulmonary function.
Methods	Recruitment dates : unclear Randomisation:1-Sequence generation-: not specified, 2-Allocation concealment: not specified Statistical methods clearly described?-Yes-life tables and regression analyses, analysis of variance Rationale for sample size: Yes Analysis done on intention to treat basis? Yes Consort flow chart: Not supplied- pre 1996 Risk of attrition bias: Moderate, at follow up data on 77/99 of those in intervention group, in standard home care this was 81/99 and in office care it was 86/100. Risk of detection bias: unclear. Risk of care giver performance bias: high, physicians were aware whether patients were in the study or not.
Results (intervention (NHC) vs. standard home care (SHC) vs. office care (OC))	Numbers analyzed: 77 in intervention (NHC), 81 in standard home care (SHC), 86 in office care (OC). Primary endpoint Costs: Total costs per study year, mean (SD) $9,797 vs. $8,058 vs. $5,051 Annual inpatient costs, mean (SD) RHC incurred the highest medical care costs in the study but not statistically different

	from those in NHC. The three subcategories of costs that were significantly different across the three treatment groups were special needs, home nursing costs and inpatient costs. RHC had higher home nursing and inpatient costs. ALSO SEE ECONOMIC ANANLYSIS CHECKLIST ATTACHED Secondary endpoints: Overall Sickness Impact Score at 6 months, mean 15.2 vs. 13.7 vs. 14.1, Overall Sickness Impact Score at 12 months, mean 16.2 vs. 15.3 vs. 13.5 General well being score at 6 months, mean (SD) 36.1 (8.2) vs. 36.6 (8.8) vs. 36.8 (8.4) General well being score at 12 months, mean (SD) 36.8 (8.3) vs. 37.2 (8.3) vs. 35.9 (9.1) Walking rate 'virtually identical across treatment groups at one year follow up'. Other endpoints: Survival probability at 12 months 0.85 vs. 0.84 vs. 0.87, p>0.33, Lee-Desu statistic for all pair wise comparisons. FEV1 % predicted at 12 months 35.1% vs. 35.6% vs. 35.1%, p=0.97, ANOVA Were point estimates and measures of variability presented for the primary outcome measures? Yes
Reviewers Comments	Generalisability: Difficult to ascertain as no details on number screened, refusal rate etc. Level of evidence: 2b

Economic analysis

Bergner 1988	The cost and efficacy of home care for patients with chronic lung disease, Bergner et al, Medical Care. 1988.
Checklist	
1. Subject of study	Health technology: All patients maintained their physician care, but differed in terms of the type of nursing care: 1) Respiratory Home Care Group (RHC) - Received care from nurses with a special training in respiratory disease; 2) Standard Home Care Group (SHC) - Received care from nursing in home care program. 3) Office Care Group (OC) - Did no receive home care nurses services. Disease: COPD Type of intervention: Treatment and Rehabilitation Hypothesis/study question: The main question is whether RHC, SHC and OC are cost effective.
2. Key elements of	Economic study type: cost-effectiveness analysis from

study	the societal perspective. Study population: Patients with COPD were admitted if they meet the medicare criterion of homebound etc. Exclusion criteria included those who had received home nursing care in the previous 6-months (other inclusion and exclusion criteria reported in pages 568 and 569). Setting: Primary care, USA Dates on which data relate: The dates of the effectiveness and resources used are not cleared stated in the paper. Source of effectiveness data: Derived from a single study Modelling: None Link between effectiveness and cost data: The collection of resource use data were undertaken on same patient sample as used in the effectiveness analysis, and were collected prospectively.
3. Details of clinical evidence	3A study sample: 301 patients: 91 patients in RHC, 102 patients in SHC and 100 patients in OC. Study Design: Randomised controlled trial in the Visiting Nurse Service of Seattle-Kind County in the State of Washington, USA. Unit of randomisation patient. Power calculations suggest there was an 80% chance to detect differences of 5% points in the Sickness Impact Profile. Duration of follow-up: 6-months and 12-months Analysis of effectiveness: Intention to treat Effectiveness results: Index of Independence in activities of daily living; Sickness Impact Profile (SIP), General Well-being schedule and a walking tolerance test (developed by investigators). Secondary criterion, which expected to be unchanged as survival rates and pulmonary function. Clinical conclusions: No improvement in everyday performance of daily activities, sense of general well-being or pulmonary function.
4. Economic analysis	Measure of health benefits: Index of Independence in activities of daily living; Sickness Impact Profile, General Well-being schedule and a walking tolerance test (developed by investigators). Direct costs: Resources and prices were used but only average costs and use was reported: Direct resources: 1) Inpatient costs 2) Non inpatient costs - i.e. residential costs 3) Outpatient visits including physician visits and emergency room visits 4) Family costs - imputed costs of unpaid help by

	family members and friends (based on the carers reported time assisting the patient) 5) Travel costs- travel to and from health care providers Prices were based on market prices The hourly cost of home health aide's time during the period of the study was used to impute carer costs (page 575). Indirect costs: None considered Currency: units of costs expressed at 1982 dollars. No discounting rate was required as the study reported data from one year. Statistical analysis of quantities/costs: Regression analysis to consider the effects on costs. Sensitivity analysis: None performed
5. Results	Estimated benefits used in the economic analysis: No statistical differences between RHC, NHC and OC. Costs results: The average annual cost of care for patients in the RHC was $9,768, for those in SHC group $8,058 and those in OC group $5,051. RHC incurred the highest medical care costs in the study but not statistically different from those in NHC. The three subcategories of costs that were significantly different across the three treatment groups were special needs, home nursing costs and inpatient costs. RHC had higher home nursing and inpatient costs. Synthesis of costs and benefits: Not attempted, as the benefits were the same for all groups (RHC, NHC and OC). Author's conclusion: The provision of home care services to unselected patients does not seem to improve the health outcomes of these patients nor does it reduce their health care costs (page 577). This suggests that home care regimens led to additional health services utilization, rather than substitution of ambulatory care for inpatient care.
6. Critical commentary?	Choice of comparator: Hospital Care was not considered as a comparator, but rather the study was interested in different forms of nursing care. Validity of estimate of effectiveness: The study design seems appropriate to the hypothesis. Baseline characteristics of the groups were not statistically different. Validity of estimates of health benefits: 5% of the patients crossed over, and in the RHC/NHC groups refused home services or in the OC demanded home services. They were still analysed as part of their original groups, to avoid selection bias (i.e. least sick refuse home care and most sick require home care),

	and so maintained the intention to treat categorisation. Validity of estimates of costs: No clear sources given for the prices assigned to inpatient and outpatient costs. No clear how the costs of family care were assessed. Other issues:
Action	

Appraisal of economical analysis

Author, year	Campbell Haggerty, 1991
Checklist	
1. Subject of study	Health technology: Hospital-based home care programme called Respi-Care co-ordinated by a hospital-based pulmonary clinical nurse specialist, with a pulmonologist serving as medical advisor. Formal liaison between the hospital-based services and the community agencies to provide a more comprehensive and coordinated service. Disease: COPD Type of intervention: Treatment and Rehabilitation Hypothesis/study question: The main question is whether home hospitalisation is more cost effective than pre-test.
2. Key elements of study	Economic study type: cost-effectiveness analysis from the health service provider perspective. Study population: Patients with COPD. Priority given to patients who have a family member or friend who would be the caretaker and who had an increased use of hospitalizations due to COPD. No exclusion criteria cited. Setting: Tertiary care, Norwalk Hospital Conn. USA. Dates on which data relate: Effectiveness and resources used January 1985 to January 1989. No allowance for inflation or discounting. Source of effectiveness data: Derived from a single study Modelling: None Link between effectiveness and cost data: The collection of resource use data were undertaken on same patient sample as used in the effectiveness analysis. Pre-test data was collected retrospectively and post-test data prospectively.
3. Details of clinical evidence	3A study sample: 20 patients admitted over time to the scheme: 2 withdrew in the initial evaluation phase, 1 died within 4-months, leaving 17 patients. Study Design: Pre-post design in 1 hospital. Pre-test data was collected retrospectively and post-test data prospectively. Compared each patient's time spent on the program to an equal time before the program. Patients were included in the analysis once they had spent at

	least 6-montsh on the programme. Duration of follow-up: The patients remained in the programme from 6 to 37-months. Analysis of effectiveness: Intention to treat Effectiveness results: Pulmonary function data measured at the start of the programme, but not measured again. Therefore no effective result. Clinical conclusions: None
4. Economic analysis	Measure of health benefits: No measure given Direct costs: Resources and prices were calculated separately but were not reported separately: Direct resources: Only health care costs considered: 1) hospital stay 2) ER visits not requiring admission to hospital 3) hospital outpatient visits to specialists 4) primary care physician visits 5) visits for social support 6) nurse visits at home 7) treatment prescriptions 8) phone calls 9) transportation of hospital personnel Prices were based on standard fees Indirect costs: None considered (as indirect costs reported by the author are classified in this abstract as direct costs). Currency: units of costs not adjusted for inflation or discounting, but should have been. Statistical analysis of quantities/costs: None considered Sensitivity analysis: None performed
5. Results	Estimated benefits used in the economic analysis: None Costs results: Days spent in hospital and ER visits decreased post-programme. Home care costs increased but over all the average cost per patient fell, from $908,031 pre-programme to $802,999 post-programme. Synthesis of costs and benefits: No Author's conclusion: Home hospitalisation reduces inpatient and ER visits, and is less costly.
6. Critical	Choice of comparator: Pre-programme data

commentary?	was retrospectively collectively, and post-programme data was prospectively collected. It is likely therefore that retrospective data collection is less accurate. Validity of estimate of effectiveness: A RCT would have been more appropriate. Small sample size. Validity of estimates of health benefits: No benefit measure Validity of estimates of costs: No concern for costs to patients and their carers. Other issues: -The study is limited in that it only considers public health care costs. They compare their result with that from Berger et al (1988), who found that home care had little impact on inpatient and ER visits and therefore overall the costs were higher. They attribute Berger's finding to less selective patient entry arguing that patients with multiple medical problems and those with more frequent hospitalizations may benefit more from this programme. However, it is likely that the difference between the results is partly due to the more integrated nature of the care programme offered by Repi-Care, and the focus upon providing an integrated package of care from the hospital to home.

Author, year	Cockcroft 1987
Study title	Controlled trial of respiratory health worker visiting patients with chronic respiratory disability.
Methods	RCT Duration of follow up: assessed twice, 9 months apart - so probably 9 months.
Country and setting	UK, single centre, teaching hospital, two respiratory nurses delivered intervention.
Objectives clearly described	Y/N: Yes To evaluate the role of a respiratory health worker to help with the care of people with chronic respiratory diseases at home.
Participants (All reported as intervention group vs. control group)	Sample size: 42 (69% male) vs. 33 (67% male) Age (mean years, range): mean 69.2 (46-84) vs. 70.5, (range 51-84) Severity of COPD at recruitment: FEV1 (mean, SD) 0.78 L (0.31) vs. 0.88 L (0.43). PEFR (mean, SD) 202 L/mim (97) vs. 206 L/min (96) Were the groups similar at baseline regarding the most important prognostic indications? Yes Study eligibility specified? Yes Study inclusion criteria: Chronic respiratory disability (mainly from COPD), had been admitted twice in last 3 years or were new patients seen within last year. Study exclusion criteria: Unable to understand questionnaire, other major disability not caused by respiratory condition.
Interventions	Components of intervention clearly described? Y/N: yes Duration of intervention: not clear Intervention Group: Respiratory health worker visiting patients. Referral: not specified Assessment: not specified Discharge to home intervention: not relevant Homes visits: patients visited about once per month. Visits were educative and supportive, tailored to individual needs. Intervention structured to a published nursing model that entailed identifying problems in activities of daily living and setting goals to increase independence in these activities. Patient encouraged to recognise signs of deterioration and to take appropriate action, including contacting the doctor themselves. Nurses did not contact doctors except in cases of emergency (which happened once only). Out-of-hours cover: not specified Procedure for clinical deterioration: not specified Clinical support to nurses: the nurses were supported by a consultant chest specialist and a consultant physiotherapist

	who were independent of the study. Additional services and health carers involved in intervention: not specified Comparison Group: presumably usual care, no details provided.
Outcomes	Were outcome measures well described? Yes Primary outcome: not clear Other outcomes: mortality (hospital records), number and duration of admissions (hospital records), quality of life (General Household Questionnaire, GHQ, 28 question version), patient questionnaire about mobility, knowledge of condition and medicines designed for the study, questionnaire on physical and psychological aspects of patients' lives designed for study. Patients' disability and distress rated by independent assessors.
Methods	Recruitment dates: follow up 1984 to 1985, recruitment dates not given Randomisation: 1-Sequence generation no details, stratified according to the number of admissions in the previous 3 years, 2-Allocation concealment: no details Statistical methods clearly described? methods not fully described Rationale for sample size: not supplied Analysis done on intention to treat basis? no Risk of attrition bias risk: low Risk of detection bias: unclear, outcome assessors were 'independent' and patients notes were reviewed by a respiratory specialist 'who did not otherwise participate in the study'. Risk of care giver performance bias: low, GPs and hospital doctors not aware of allocation status of patients
Results (All reported as intervention group vs. control group)	Numbers analysed: 40 in intervention group (after first visit by respiratory health worker), 33 in control group. QOL or disability and distress ratings at follow up: no significant differences between groups (data not given). Patient knowledge about condition as judged by two independent doctors at follow up: more in intervention group improved knowledge about condition, RR 1.39 (95% CI 1.1 to 1.9). Patient knowledge about medicine as judged by two independent doctors at follow up: tendency for more in intervention group to improve knowledge about medications, RR 1.19 (95% CI 0.99 to 1.42). Hospital admissions

	Number of all cause 25 vs. 17 Number of respiratory cause 16 vs. 11 Proportion of time spent in hospital for respiratory causes greater in intervention group, RR 3.26 (95% CI 2.6 to 4.0), statistical analysis not clear. Length of stay for respiratory admissions greater in intervention group, RR 2.79 (95% CI 1.38 to 5.64), statistical analysis not clear. Deaths (on intention to treat basis): 5/42 vs. 7/33 Smoking cessation: 4 vs. 0 (and 2 ex-smokers in the control group started smoking again but none in the intervention group) Not clear if smoking data validated. Other endpoints: Of 335 goals set in 40 patients in the intervention 258 (77%) were considered by interventionist to be achieved. Four months after the study 33/36 (92%) patients in the intervention group said that they wished to have further visits. Were point estimates and measures of variability presented for the primary outcome measures? No
Reviewer comments	Data source: published data only Generalisability: Difficult to determine - no recruitment time scales given and not clear how many were screened, 92 patients were invited to participate, 79 (86%) agreed, 2 excluded, 2 died therefore 75 participated. Other points Not all patients had COPD; 'All patients suffered from chronic respiratory disability that was caused mainly by chronic obstructive airways disease' Level of evidence: 2b

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Author, year	Egan 2002
Title	A randomised control trial of nursing-based case management for patients with COPD.
Design	RCT plus 1) survey of nursing and allied health staff members and 2) qualitative study of patients and caregivers and respiratory physicians, QUALITATIVE WORK REVIEWED ELSEWHERE. Duration of follow up: 3 months
Country and setting:	Australia, single centre, private hospital
Objectives clearly described	Y/N: Yes 'To compare the effects of a brief nursing-based case management intervention with that of normal care for patients hospitalised with COPD'.
Participants (All reported as intervention group vs. control group)	Sample size: 33 (36% males) vs. 33 patients (60% males) Age (mean): 67.2 years vs. 67.8 (SD not provided) Severity of COPD at recruitment: 19 in each arm of the trial (58%) had FEV1 % predicted < 35%. Were the groups similar at baseline regarding the most important prognostic indications? More males in control group, P=0.049 Study eligibility specified? Yes Inclusion criteria: Aged 18 or older, admitted with COPD, history of chronic bronchitis, emphysema, chronic airway obstruction, chronic asthma, FEV1 <50% predicted, cognitive functioning adequate, admission to a respiratory unit bed within 72 hours of admission to hospital. Exclusion criteria: Not specified
Interventions	Intervention Group: Nursing-based case management Components of intervention clearly described? Y/N Yes Duration of intervention: 6 weeks Referral: not specified Assessment: The case manager (CM) conducted a comprehensive nursing assessment to identify physical, psychosocial and resource needs. In hospital: The CM co-ordinated the patient's care during hospitalisation utilising a clinical path. The CM provided education for patient and carer on managing the disease, treatment, rehabilitation and available community services, conducted a case conference as part of discharge planning and arranged discharge planning. After discharge: The CM provided ongoing support and acted as a referral point for community services for the patient. Phone calls to the patient and caregiver on a regular basis. Home visits: not clear. Follow-up care at 1 and 6 weeks post

	discharge but not clear if CM visited patient at home. Out of hour cover: not specified Procedure for clinical deterioration: not specified Clinical support to nurses: not specified Additional services and health carers involved in intervention: not specified Both groups treated on standardised clinical pathways during admission. Comparison Group: usual care Description: Control group. Received normal care meaning no contact with case manager, no case conference and no post discharge follow up by nursing staff for respiratory visit.
Outcomes	Were outcome measures well described? Yes Primary outcomes: not specified Other outcomes: St Georges Respiratory Questionnaire (SGRQ); Social Support Survey; Hospital Anxiety and Depression Scale (HADS); Subjective Well-Being Scale. Unscheduled hospital readmissions.
Methods	Randomisation:1-Sequence generation: patients stratified into two groups based on FEV1 (35% to 50% predicted, and < 35% predicted) random number tables used as basis for allocating patients, 2-Allocation concealment: unclear. Statistical methods clearly described? Yes, Wilcoxon matched pairs signed ranks test for within group comparisons, Mann Whitney U to compare groups at each time point. Rationale for sample size: not given Analysis done on intention to treat basis? No Consort flow chart: not given Risk of attrition bias: high, authors state 24% control, 15% intervention lost to follow up at three months (5 died and 8 withdrew), however SGRQ total at 3 months on only 22 intervention (67%) and 19 control patients (58%). Risk of detection bias: unknown, not clear if outcome assessors blinded. Risk of care giver performance bias: high, since hospital team would be aware who was receiving intervention and who was not. Recruitment dates: June 1999 to September 2000
Results (intervention vs. control)	Numbers analysed: 27 in each arm (maximum) Median change scores Change from baseline to 1 month post discharge SGRQ Symptoms -17.5 vs. -9.3, p=0.4, Activities 0 vs. 0.4, p=0.7, Impacts -0.2 vs. -0.9, p=0.9, Total -1.6 vs. -1.5,

	p=0.6 Social Support Survey Tangible support 0 vs. 0 (p=0.5), Affectionate support -6.7 vs. 0, p=0.03, Positive social intervention 0 vs. 0 (p=0.6), Emotional support 0 vs. 0 (p=0.9) HADS Anxiety -1.0 vs. -2.5 (p=0.4), Depression 0.5 vs. -1 (p=0.4) Total Subjective well being 2.8 vs. -2.8 (p=0.4). Numbers analysed: 26 intervention patients, 24 control patients (maximum, see note about attrition bias) Median change scores Change from 1 month to 3 months post discharge SGRQ Symptoms 2.0 vs. 0.5, p=0.96, Activities 0 vs. –6.4, p=0.01, Impacts 2.5 vs. –1.5, p=0.4, Total 0.6 vs. -3.2, p=0.4 Social Support Survey Tangible support –2.5 vs. –5.0, p=0.7, Affectionate support 10.0 vs. 0, p=0.3, Positive social intervention 0 vs. –2.5 (p=0.8), Emotional support –3.6 vs. 2.5 (p=0.2) HADS Anxiety 0 vs. -1.5 (p=0.8), Depression -0.5 vs. 0.5 (p=0.3) Total Subjective well being -2.8 vs. 0 (p=0.3). Unscheduled hospital readmissions mean 2.1 (range 10 (n=1) to 5(n=2)) vs. 2.6 (range 1 (n=11) to 6 (n=3)), NS Deaths: 5 in total, not given by group Questionnaire survey of nursing and allied health personnel Response rate 65% Subjects were asked to rank the impact of case management on a number of items, top ranked items were: ‘improved co-ordination of care outside hospital’; ‘improved co-ordination of care within hospital’; ‘improved patient’s knowledge of their disease’; ‘improved patient compliance with prescribed regimens’. Lowest ranking items were: ‘reduction in unplanned admissions’; ‘reductions in average length of patient stay’; ‘increased sense of involvement in patient care’. Were point estimates and measures of variability presented for the quantitative outcome measures? : no but all non-significant
Reviewers comments	Data source: published data only Generalizability: 66/127 (51%) potentially eligible patients were included. 61 potentially eligible patients were excluded from study because for 57% no FEV1 was performed or they were unable to be transferred to a respiratory bed unit

	within 72 hours of admission. A further 25% were excluded as they had previously been case- managed and the remainder were excluded for reasons including frail condition and cognitive impairment. Two patients refused, reason not reported. Level of evidence: 2b

Author, year	Farrero 2000
Title	Impact of a hospital-based home-care program on the management of COPD patients receiving long-term oxygen therapy.
Design	RCT and cost effectiveness analysis COST EFFECTIVENESS ANALYSIS REVIEWED SEPARATELY BELOW. Duration of follow up: 12 months
Country and setting	Spain, single centre, university hospital.
Objectives clearly described	Y/N: Yes 'To evaluate the effects of a hospital based home care program for severe COPD patients receiving LTOT. Program designed to combine home-care management and easy access to hospital resources'
Participants (All reported as intervention gp. vs. control gp.)	Sample size: 60 vs. 62 patients (Proportion of males not given but authors state no difference between groups). Age (mean years, SD): 68(7) vs. 69 (8) Severity of COPD in study subjects at recruitment: FVC, % predicted mean (SD): 40(11) vs. 38 (11) FEV1, %predicted mean (SD): 28 (8) vs. 27 (9) PaO2, mm Hg mean (SD): 51 (6) vs. 50(7) PaCO2, mm Hg mean (SD): 54 (7) vs. 56 (8) Were the groups similar in baseline regarding the most important prognostic indications? Yes Study eligibility specified? Yes Inclusion criteria: COPD requiring long term oxygen therapy (LTOT); on LTOT for at least 6 months prior to entry into study; residing in one of two large cities within easy reach of the hospital. Exclusion criteria: Not specified
Interventions	Components of intervention clearly described? Y/N: Yes Duration of intervention: Monthly telephone call and home visit every 3 months, average number of visits 4.8 Intervention Group: Hospital-based home-care program Referral: not applicable Assessment: in outpatient department, FVC, FEV1, arterial

	blood gasses on room air; hospital admissions and length of stay and emergency department visits in the last year. Discharge: not applicable Home visits: every three months by respiratory nurse under physician supervision. Visits included: questionnaire designed to detect changes in underlying respiratory symptoms; spirometry; pulse oximetry breathing room air and oxygen. Phone calls: monthly phone calls to the patient by the respiratory nurse. Out-of-hours cover: not stated Procedure for clinical deterioration: patient could initiate attention depending on problem resolved either by phone call, home visit or hospital visit to day hospital equipped to carry out chest radiography, arterial blood gases, ECGs and to provide intensive medical treatment if necessary. Clinical support to nurses: respiratory nurse supervised by respiratory physician. Additional services and health carers involved in intervention: not specified Comparison Group: usual care Description: Outpatient visits by their chest physician and GP. Frequency of visits at discretion of each attending physician. No specific instructions were given about emergency visits or hospital admissions. Seen by study team at initial assessment and at 12 months follow up.
Outcomes	Were outcome measures well described? Primary outcomes: not specified Other outcomes: arterial blood gas values; FEV1, FVC; number of hospital admissions; emergency department visits; hospital LOS; and quality of life in the first 40 consecutive patients using Spanish version of the Chronic Respiratory Questionnaire, (CRQ) at 3 and 12 months of follow up.
Methods	Randomisation: 1-Sequence generation not specified 2-Allocation concealment: 'codes of randomisation were kept in sealed envelopes'. Statistical methods clearly described?: Yes, comparison between both groups by t-tests and chi squared, Mann-Whitney U, survival analysis using log-rank test. Rationale for sample size: not given Analysis done on intention to treat basis? n/s Consort flow chart: not supplied. If not supplied were participant flow details given? Yes 23 patients died vs. 21 (Sept 1994 to January 1997, not all followed up for same length of time). 46/62 vs. 48/60 completed 1 year follow-up. Risk of attrition bias: high, at one year 23% of original cohort

	lost to follow up. Risk of detection bias: high, patients in control group evaluated by HCP team at 12 months. Risk of care giver performance bias: unclear, probably high risk as hospital team likely to have been aware patients were in study. Recruitment dates: September 1994 to December 1996.
Results (All reported as intervention gp. vs. control gp.)	Numbers analyzed: 48 in the comparison group and 46 in the intervention Health care use at 12 months follow up, mean (SD) Emergency department visits 0.45 (0.83) vs. 1.58(1.96), p=0.0001, Mann-Whitney U test (see comment on analyses below) Hospital admissions 0.5 (0.86) vs. 1.29(1.7), p=0.001, Mann-Whitney U test (see comment on analyses below) Days in hospital 7.43 (15.6) vs. 18.20 (24.55), p=0.01, t test FVC % predicted at 12 months follow up, mean (SD) 37 (19) vs. 35 (13), NS, p not given FEV1 % predicted at 12 months follow up mean (SD) 25(6) vs. 24 (6), NS, p not given Arterial O_2 at 12 months follow up mean (SD) 50 (7) vs. 48 (9), NS, p not given Arterial CO_2 at 12 months follow up mean (SD) 55 (8) vs. 56 (8), NS, p not given Quality of life 33/40 completed 12 months follow-up (17/20 intervention, 16/20 control). No significant differences between the two groups in any of the 4 domains of the questionnaire (figures not reported). Also looked at: Deaths: 23/60 vs. 21/62, median survival time 20 months in both groups, p = 0.79, log-rank test. The number of home in the intervention group (mean, SD): 4.8 (0.8) The number of hospital visits in the intervention group (mean, SD): 4 1.5 (1.7). Were point estimates and measures of variability presented for the primary outcome measures? No confidence intervals for mean differences or cost supplied
Reviewers comments	Data source: published data only Generalisability: unknown. Unable to determine-recruitment over 27 months, does not state number eligible and number recruited. Level of evidence: 2b. Statistical analyses: Mann-Whitney U test not valid for

	emergency admissions and hospital admissions because of too many tied results (i.e. chance of having a second readmission is not independent of chance of having initial readmission). Use of Mann-Whitney U here will result in too small an estimate of p value.
Commentary on economic aspects of this study (taken from The University of York, NHS CRD document*)	
Key economic elements	Economic study type: cost effectiveness. Dates on which data relate: Resources use data were gather from September 1994 to December 1996, The price year was not reported Link between effectiveness and cost data: The costing was undertaken prospectively on the same patient group as that used in the effectiveness analysis.
Economic analysis	Clinical outcomes were not aggregated and no summary benefit measure was used, therefore a cost-consequences analysis was carried out. department visit were calculated according to diagnosis-related group and included staffing costs, costs of routine examinations (laboratory arterial blood gases, chest radiography, ECG), and costs of drugs prescribed. The costs of HCP included staffing costs, administrative costs (secretary and telephone), costs of home visits (travel expenses and drugs administered), and costs of extra hospital visits (including the routine examinations, drugs administered, and cost of office space used such as electricity and maintenance). Data on costs were derived from the Financial Department at the authors' institution, based on Spanish NHS fees. Discounting was not relevant since costs were incurred over a one-year period of time. Quantities and costs were analyzed and presented separately. The quantity/cost boundary adopted was that of the hospital. The resource use data were gathered from September 1994 to December 1996. The price year was not reported. Primary care data were not included as they were not available. Indirect costs Indirect costs were not included Currency Spanish pesetas (Pta). The authors provided a conversion of the costs to US dollars ($). Statistical analysis of costs No statistical analysis was reported. Sensitivity analysis No sensitivity analysis was carried out
Economic Results	Cost results: The costs of hospital admissions were Pta8, 328,487 ($47,591) in the HCP group and Pta21, 283,911 ($121,622) in the control group. The costs of emergency visits were Pta740, 869 ($4,233) in the HCP group and Pta2, 681,241 ($15,321) in the control group. Finally, the costs of HCP were Pta6, 701,796 ($38,296). The total costs of treatment were Pta15, 771,152

	($90,121) in the HCP group and Pta23, 965,152 ($136,944) in the control group. The total saving associated with HCP was 8.1 million pesetas ($42,214).
CRD commentary	Selection of comparators: The rationale for the choice of the comparator was clear. The comparator was chosen because it represented routine care provided for patients suffering from COPD in Spain. You should consider whether it is a widely used strategy in your own setting. Validity of estimate of measure of effectiveness: The effectiveness estimates were derived from a randomised controlled trial and several statistical tests were performed in order to take into account potential confounding factors. The internal validity of the study is thus likely to be high. However, the effectiveness results could have been biased because, for patients with severe COPD, the home care was probably the best option and the routine care was not a feasible strategy. Validity of estimate of measure of benefit: Not relevant Validity of estimate of costs: Primary care costs were not available and were not included in the study. Their omission could have affected the authors' conclusions. Statistical analyses of resources and sensitivity analysis of costs were not performed and this may limit the interpretation of the study findings. In addition, the price year was not reported. The cost estimates used in the model are likely to be specific to the Spanish setting. The authors performed appropriate currency conversions. Other issues: The issue of the generalisability of the results was not specifically addressed and this may represent a limitation for the external validity of the study, given that sensitivity analyses were not conducted on cost and benefit estimates. The authors made appropriate comparisons with other studies and these appear to confirm their results. A possible limitation of the study, as recognised by the authors, was the use of the Spanish version of the Chronic Respiratory Questionnaire, which may not be a valid instrument to detect changes in the quality of life of patients with severe COPD and chronic respiratory failure. In addition, a longer follow-up could have been useful to identify significant differences in survival between the groups.

*(source: economic extraction was complied by The University of York, NHS Centre for Reviews and Dissemination commissioned reviewers. http://nhscrd.york.ac.uk/online/nhseed/200010471.htm accessed 10/2/04).

Author, year	Hermiz 2002
Title	Randomised controlled trial of home based care of patients with chronic obstructive pulmonary disease.
Design	RCT

	Duration of follow up: 3 months
Country and setting	Australia, two centres a tertiary teaching hospital and a district hospital.
Objectives clearly described	Y/N: Yes 'To evaluate the usefulness of limited community based care for patients with COPD after discharge from hospital'. 'We hypothesised that home visiting would improve patients knowledge about the disease, improve their quality of life and reduce hospital representation'.
Participants (reported as intervention vs. control)	Sample size: 84 (49% male) vs. 93 patients (46% male) Age (mean years): 67.1 vs. 66.7 Severity of COPD at recruitment: not given Were the groups similar at baseline regarding the most important prognostic indications? Yes Inclusion criteria: aged 30-80 years, attended emergency department or admitted for COPD during recruitment period. Exclusion criteria: living outside the region, insufficient spoken English skills, resident in nursing home, presence of dementia or confusion.
Interventions	Components of intervention clearly described? Y/N: Yes Duration of intervention: one month Intervention Group: Home based care Referral: not applicable Assessment: not applicable Discharge: not applicable Home visits: two visits by community nurse at one week post discharge and at one month post discharge. First visit included: detailed assessment of the patient's health status and respiratory function; written and verbal education on the disease and advice smoking cessation (if applicable); managing activities of daily living and energy conservation; exercise; understanding and use of drugs; health maintenance; and early recognition of signs that require medical intervention. The nurse also identified problems and, if indicated, referred patients to other services, such as home care. A care plan documenting problem areas, education provided, and referral to other services was posted to patient's GP, and the GP was contacted by phone, if necessary. Second visit included: progress and need for further follow up reviewed. Patients encouraged to refer to the education booklet for guidance and to keep in contact with their GP. Out-of-hours cover: not applicable Procedure for clinical deterioration: not applicable Clinical support for nurses: not specified Additional services and health carers involved in intervention: not specified

	Comparison Group: usual care Description: Discharge to GP care with or without specialist follow up. Discharge did not include routine nurse or other community follow up.
Outcomes	Were outcome measures well described? Yes Primary endpoint: Presentation to hospital (sample size calculation based on this) Other endpoints: Collected via patient interview: patient attendance and admission to hospital, St Georges respiratory Questionnaire (SGRQ), knowledge, self-management and satisfaction. Collected via patient and GP interview: GP and nurse visits, care provided and their satisfaction with care.
Methods	Randomisation: 1-Sequence generation: 'We had intended to use randomised permuted blocks with a block size of four at both sites but because of the smaller number of cases at Macarthur Health Service we used a simple randomisation at that site', 2-Allocation concealment: no details given. Statistical methods clearly described?: Yes, to compare groups by t-tests, chi squared tests. Rationale for sample size: given, however they did not achieve intended sample size and power estimates revised. Analysis done on intention to treat basis?: N/S Consort flow chart: supplied Risk of attrition bias: low to moderate, overall 17% of original study population lost to follow up, intervention group 17/84 lost (9 dies, 7 withdrew, 1 lost contact), in comparison group 13/93 lost (10 died, 1 withdrew, 2 lost contact). Risk of detection bias: high, project officer conducted outcome interviews and GP interviews Risk of care giver performance bias: not clear Recruitment dates: September 1999 to July 2000
Results (reported as intervention vs. control)	Numbers analyzed: In intervention 67/84, in comparison 80/93 Primary endpoints Proportion admitted during 3 months follow up (all causes) 16 (24%) vs. 14 (18%), NS Number of readmissions during 3 months follow up (all causes) 25 vs. 19 Number of readmissions during 3 months follow up (acute respiratory condition) 12/25 vs. 14/19 Other endpoints: Patient Knowledge name of disease 36 (54%) vs. 26 (33%), p=0.04, role of vaccination 41 (61%) vs. 16 (20%),p<0.01, factors that prevent worsening 26 (39%) vs. 10 (13%), p<0.01, when to seek help 57 (85%) vs. 55 (69%), p=0.07 GP contact and action Patient visited GP 60 (90%) vs. 75 (94%), p=0.4)

	Mean number of visits to GP Patient report 6.06 (n=60) vs. 5.54 (n=74), p=0.3, GP report 5.21 (n=57) vs. 5.11 (n=64), p=0.9) GP prescribed drugs 42/57 (74%) vs. 53/64 (83%), p=0.2 GP arranged follow-up 37/57 (65%) vs. 41/64 (64%), P=0.4 GP provided patient with education 39/57 (68%) vs. 44/64 (69%), p=0.9) GP provided carer with education 14/57 (25%) vs. 11/64 (17%), p=0.3) Patient satisfied with care provide by GP 56/60 (93%) vs. 72/75 (96%) Patients behaviour: Smoking at follow-up 15/67 (22%) vs. 26/80 (33%), p=0.17 Had influenza vaccination 48 (72%) vs. 60 (75%), p=0.65 Had pneumoccocal vaccination 42 (63%) vs. 42 (53%), p=0.28 SGRQ: Difference in change between baseline and follow up (95% CI) Activity subscale: Baseline 79.29 vs. 75.54, Follow-up 74.83 vs. 74.05 2.97 (-2.72 to 8.66), NS Impact subscale: Baseline 54.57 vs. 51.52, Follow-up 48.48 vs. 45.22 -0.21 (-5.57 to 5.16), NS Symptoms subscale: Baseline 64.50 vs. 62.97, Follow-up 66.05 vs. 67.65 3.18 (-1.83 to 8.18), NS Total score: Baseline 63.71 vs. 60.69, Follow-up 59.39 vs. 57.68 1.32 (-2.97 to 5.67), NS Were point estimates and measures of variability presented for the primary outcome measures? On most outcomes
Reviewers comments	Data source: published data only Generalisability: Unclear, 'recruitment rate fewer than expected, few refused'. Level of evidence: 2b. Other points: does not state that the nurses were respiratory specialists.

Author, year	Ketelaars 1998

Title	Effects of a specialized community nursing care in patients with chronic obstructive pulmonary disease.
Design	Prospective, non-randomised cohort study (patients assigned to groups according to place of residence). Duration of follow up: 9 months
Country and setting	The Netherlands, single centre
Objectives clearly described	Y/N: Yes 'The hypothesis under study was that patients receiving care from community nurses specialized in respiratory care after discharge from a pulmonary rehabilitation centre show a reduced deterioration in HRQL, have less change in coping strategies, have higher compliance rates, have fewer hospital admissions and demonstrate higher patient satisfaction , when compared with patients receiving care from general community nurses'.
Participants (reported as intervention vs. control)	Sample size: 48 (75% male) vs. 67 patients (74 %male) Age (mean years, SD): intervention 64 (10) , comparison group vs. 64 (8) Severity of COPD at recruitment: FEV1 % predicted, mean (SD): intervention 41 (14), comparison group 38 (16) Were the groups similar at baseline regarding the most important prognostic indications?: yes Inclusion criteria: aged, 40 to 80 years, recruited from a pulmonary rehabilitation centre, COPD according to ATS guidelines, not receiving help with activities of daily living from a health care professional. Exclusion criteria: Other severely disabling illness unrelated to their respiratory illness, patients not discharged to their homes.
Interventions	Components of intervention clearly described? Y/N: Yes Duration of intervention: unclear Intervention Group: Referral: not applicable Assessment: not applicable Discharge: not applicable Home visits: visited at home after discharge by specialized respiratory community nurses from a home care agency. During the home visits no physical examinations were performed. Instead relevant topics were discussed with patients, information and advice was given and referrals to other services were made based on individual needs. Visits were as frequent as nurse and patient considered necessary – in most cases one or two visits were made. Out-of-hours cover: not specified Procedure for clinical deterioration: not specified Clinical support for nurses: not specified Additional services and health carers involved in intervention: not specified

	(The specialised nurses had had in service training in respiratory diseases and their treatment and periodic meetings aimed at promoting expertise were regularly held). Comparison Group: usual care Description: Patients were assigned general community nurses from one of three other home care agencies. Home visits as above for intervention group.
Outcomes	Were outcome measures well described? Yes Primary endpoint: not specified Other endpoints: St George's Respiratory Questionnaire (SGRQ); the 'well-being component' of the Medical Psychological Questionnaire for Lung Diseases (MPQL); COPD Coping Questionnaire (CCQ) (derived from the Asthma Coping Questionnaire); compliance (patient self -report on frequency of carrying out breathing retraining and physical exercises and inhaler technique); satisfaction with care (five point scale); lung function; respiratory muscle strength; 12 minute walk test; hospitalisation.
Methods	Statistical methods clearly described?: Yes, multiple regression models Rationale for sample size: not given Risk of attrition bias: high. Massive attrition at 9 months 39/48 (81%) intervention groups patients and 39/67 (58%) comparison group patients remaining. The researcher's imputed values for missing items based on mean responses for subjects with similar baseline characteristics and demonstrated that this did not alter mean findings much so they used just used unimputed values for final analyses. Risk of detection bias: unclear Risk of care giver performance bias: unclear Recruitment dates: October 1992 to April 1994
Results (reported as intervention vs. control)	Numbers analyzed: 39 vs. 39 Health Related Quality of Life (SGRQ) at 4 and 9 months No differences between intervention and comparison group scores except significantly better activities component score in comparison group at 4 but not 9 months. Coping (CCQ) no differences in coping scores related to group Compliance no difference in scores related to group Patient satisfaction only differences were in: Knowledge, mean score (SD) 4.1 (0.58) vs. 3.57 (0.73), $p < 0.01$ (not clear of clinical significance, if any) Information/advice, mean score (SD) 4.11 (0.67) vs. 3.74

	(0.75), p <0.05 01 (not clear of clinical significance, if any) Hospitalisation no difference in hospitalisations related to group Were point estimates and measures of variability presented for the primary outcome measures? no
Reviewers comments	Data source: published data only Generalisability: Not clear Level of evidence: 4

Author, year	Littlejohns 1991
Title	Randomised controlled trial of the effectiveness of respiratory health in reducing impairment, disability, and handicap due to chronic airflow limitation.
Design	RCT Duration of follow up: 12 months
Country and setting:	UK, single centre, teaching hospital outpatient clinics in one health district.
Objectives clearly described	Y/N: Yes 'Whether a respiratory health worker was effective in reducing respiratory impairment, disability and handicap experienced by the patient with chronic airflow limitation'.
Participants (All reported as intervention group vs. control group)	Sample size: 73 (67% males) vs. 79 (63% males) Age (mean, SD): 62.9 (7.6) vs. 62.5 (7.6) Severity of COPD at recruitment: FEV1% predicted mean (SD): 45.2 (S22.4) vs. 50.2 (23.0), FVC % predicted mean (SD): 70.0 (17.3) vs. 73.2 (19.0), arterial O_2 saturation at rest mean (SD): 95.6 (3.0) vs. 96.1 (2.7), on exercise 91.5 (4.6) vs. 91.7 (4.3) Were the groups similar at baseline regarding the most important prognostic indications?: Yes Study eligibility specified?: Yes Inclusion criteria: Age 30-75 years, no other major disease, pre-bronchodilator FEV1 < 60% predicted, COPD stable and no change or perceived need for change in medication for last 6 weeks.
Interventions	Intervention Group: Respiratory health worker (Intervention provided by a single respiratory health worker) Components of intervention clearly described? Y/N: Yes, but not clear how long intervention lasted, how often patients were seen or indeed where patients were seen (clinic or home). Duration of intervention: Unclear Referral: outpatients Assessment: on entry into the study baseline measurements were obtained on two separate days, assessment included: pulmonary function tests; arterial saturation measured by ear oximeter; six minute walk test; paced step test; Hospital Anxiety and Depression Scale (HADS); Sickness Impact Profile (SIP); satisfaction questionnaire designed for the study. Intervention: patients received normal care at the chest clinic plus a respiratory health worker who provided: health education directed at the patient and primary care team, monitoring of treatment compliance and optimisation of treatment by ensuring correct inhalation techniques and supervision of domiciliary oxygen etc,

	monitoring of spirometry results and symptoms to enable acute exacerbations and worsening heart failure to be detected and treated early, liaison between hospital based services (including domiciliary physiotherapy and social services) and GP. Out-of-hours cover: Not stated Procedure for deterioration: Not stated Clinical support to nurses: Not stated Additional services and health carers involved in intervention: not specified Comparison Group: usual care Description: Normal service provided by the chest clinic. Both groups visited at home for study assessment.
Outcomes	Were outcome measures well described?: Yes Primary outcomes: FEV1, HADS, SIP, six minute walking test (used for sample size calculation). Other outcomes MRC chronic Bronchitis questionnaire; satisfaction questionnaire; patient diary record of prescriptions and health service use.
Methods	Randomisation: 1-Sequence generation: generated by tables in permuted blocks of four stratified by age and sex; 2-Allocation concealment: yes, allocation was held in sealed numbered envelopes, held centrally. Statistical methods clearly described? Yes- compared groups by paired t-tests, Mann Whitney, chi sq tests, RR with 95% CI, regression analysis. Rationale for sample size: given Analysis done on intention to treat basis? No Consort flow chart: Not applicable, pre 1996. If not supplied were participant flow details given?: Yes Risk of attrition bias: moderate, after randomisation before intervention commenced 14 subjects withdrew, after intervention a further 7 were lost to follow up, 2 patients in the intervention group and 5 from the comparison group were lost to follow up (4 moved, 2 withdrew and 1 failed to co-operate). Including patients who died: 80% of those who were invited to take part in the study completed it and 88% of those who actually started the study. Risk of detection bias: unknown, not clear if outcome assessors blinded. Risk of care giver performance bias: high, physician aware which group patient was in. Recruitment and follow-up dates: not given
Results (All reported as intervention	Primary endpoints: blank Numbers analyzed: 68 in intervention group, 65 in comparison group.

gp. vs. control gp.)	Mean change scores (95%CI) % predicted FEV1 -2.06 (-4.81 to 0.69) vs. -0.15 (-3.74 to 3.40), p=0.44, % predicted FVC -4.34 (-7.74 to 0.94) vs. -1.68 (-5.10 to 1.72), p=0.28, Arterial saturation O2 (%) Rest 0.80 (-0.10 to 1.72), 1.05 (0.24 to1.86), p=0.70, Exercise 2.01 (0.72 to 3.30) vs. 1.13 (0.03 to 2.23), p=0.32 Six minute walking distance (m) -1.40 (-23.40 to 20.50), -4.90 (-28.70 to -18.80), p=0.83, HADS Anxiety 1.06 (0.34 to 1.78), 0.55 (-0.10 to 1.20) p=0.32, Depression 0.44 (-0.20 to 1.13), 0.11 (-0.49 to 0.71) p=0.48 Sickness impact profile Total score 0.63 (-1.60 to 2.87), _0.4 (-1.85 to 1.05) p=0.46, Physical 5.53 (3.70 to 7.40), 1.65 (0.18 to 3.12) p=<0.01, Psychosocial 2.38 (-0.35 to 5.10), 1.28 (-0.5 to 3.07) p=0.52 Other endpoints: Paced step test (number) -8.50 (-16.1 to -0.9), -15.01 (-22.05 to -7.96), p=0.22 Reported drug prescriptions during the study year (%) Bronchodilator inhaler 62(91) vs. 56 (86), Aminophylline 50 (74) vs. 46 (71), Inhaled steroids 56 (82) vs. 43 (66), Ipratropium 42 (62) vs. 27 (42) p=0.02, Oral steroids 33 (49) vs. 24 (37), Nebuliser 19 (28) vs. 8 (12) p=0.03, Oxygen 2 (3) vs. 3 (5), antibiotics 54 (79) vs. 34 (52), p=<0.001. Use of services during the year: Outpatient attendances, n (%) (I=68, C=65): 0 1(1) vs. 5(8), 1 2(3) vs. 2 (3), 2 8 (12) vs. 10 (15), 3 7 (10) vs. 7 (11), 4 10 (15) vs. 10 (15), >5 40 (59) vs. 31 (48). Mean 5 vs. 5. Home consultation with GP n (%) (I =60, C =56): 0 39(65) vs. 41 (73), 1 8 (13) vs. 5 (9), >=2 13 (22) vs. 10 (18), p=0.61 Surgery consultation with GP n (%) (I =60, C =56): 0 15 (25) vs. 11 (20), 1 3 (5) vs. 12 (21), >=2 42 (70) vs. 33 (59), p=0.03 Admissions to hospital n (%) (n=68, n=65): 0 56(82) vs. 51 (79), 1 6 (9) vs. 8 (12), >=2 6 (9) vs. 6 (9), p=0.80. LOS 5 days both groups Satisfaction with service very satisfied 60/68 (88%) vs. 51/65 (78%), given sufficient info about condition 41 (60%) vs. 43 (66%), thought they used medication appropriately 59 (87%) vs. 56 (86%) Were point estimates and measures of variability presented for the primary outcome measures? Yes Deaths at one year: 3/73 vs. 9/79, RR = 2.9 (95% CI 0.8 to 10.2) (Logistic regression model controlling for age and FEV1 OR 5.5 (95% CI 1.2 to 24.5)

Authors conclusions	This study suggests that an intervention may improve the effectiveness of a service in prolonging life but at increased (at least initially) cost to the health service. No evidence of reduction in impairment, disability or handicap. Intervention group had increased GP attendance and prescriptions of some drugs but no increase in hospital attendance or re-admissions.
Reviewers Comments	Data source: published data only Generalisability: difficult to assess as authors do not state number screened, proportion eligible for study or duration of recruitment period. Clinical meaning of difference in SIP physical score unclear. Overall death rate for study subjects during study: 79 per thousand per year Proportion of patients with at least one hospital re-admission during the year of follow up: not clear (only available for those remaining in study and surviving at 12 months). Level of evidence: 2b

Author, year	Smith 1999
Study title	The effect of a respiratory home nurse intervention in patients with chronic obstructive pulmonary disease (COPD).
Methods	RCT Duration of follow up: 12 months
Country and setting	Australia, single centre
Objectives clearly described	Y/N: Yes 'Our hypotheses were that an outreach nurse/shared care approach to COPD management would result in reduction of the following: 1. hospital admissions and length of stay, 2. emergency department and hospital outpatient department attendances, 3. Mortality, 4. FEV1 and HRQL of patients, 5. HRQL for patient carers.' (NB. FEV1 and HRQL only examined in intervention group).
Participants (All reported as intervention group vs. control group)	Sample size: 48 (56% males) vs. 48 (65% males) Age (mean years , SD): 70.0 (1.2) vs. 69.8 (1.2) Severity of COPD at recruitment: overall FEV1(mean, SD): 0.84 L(0.06) vs. 0.90 L (0.07) FEV1 % predicted (data provided for intervention group only) 33% Were the groups similar at baseline regarding the most important prognostic indications? Yes, but limited data provided. Study eligibility specified? Yes Study inclusion criteria: Aged over 40, COPD patients attending one centre as inpatients or outpatients, or referred by GP, FEV1:FVC < 60%, in stable state, with a carer involved in their management, able to read and speak English. Study exclusion criteria: '0ther active major illness'.
Interventions	Component of intervention clearly described? Y/N: Yes Duration of intervention: After discharge visit within a week, then 2/4 weekly visits over 1 year. Intervention Group: 'Respiratory home based nursing intervention' (HBNI). Assessment: Inpatients visited by HBNI nurse on ward, discharge planning with goals for discharge. Case conference with social worker, hospital medical officer, GP and HBNI nurse if considered beneficial. Outpatients and GP referrals: evaluated at home, discussion with GP on patient's needs, involvement of domiciliary services facilitated, appliances provided and need for O2 therapy assessed at home. Referral: from outpatients and inpatients or by GP Home visits: Inpatients usually seen within a week of discharge by the HBNI nurse. All referrals were then followed up by 2-4 weekly visits over 12 months with spirometry and oximetry performed at

	each visit and results communicated to the GP. Ongoing education including inhaler medication use, medication compliance and fitness advice (when needed included upper and lower limb training, intimacy advice and coping strategies for shortness of breath). The nurse also aimed to make early identification of exacerbations. Educational material was provided in liaison with GP if need on smoking and patients were counselled and given ongoing encouragement to reduce or stop smoking and referral to GP for nicotine replacement. Intervention group also received usual outpatient care. Out-of-hours cover: not specified Procedure for clinical deterioration: not specified Clinical support to nurses: not specified Additional services and health carers involved in intervention: not specified Comparison Group: usual care Description: usual outpatients care and education from outpatients and GP service.
Outcomes	Were outcome measures well described? Yes Primary endpoints: Health service utilisation (admission, length of stay (LOS), out patient department visits, emergency room visits from case notes), all cause mortality. Changes in health related quality of life (HRQOL) (Modified Dartmouth Primary Care Co-operative QOL questionnaire) and FEV1 and carer QOL only recorded in intervention group.
Methods	Recruitment dates: Not specified Randomisation:1-Sequence generation : Randomly computer generated numbers, 2-Allocation concealment: No details given Rationale for sample size: provided but unclear Statistical methods clearly described? Yes (T-tests/Fishers exact test and chi squared test) Analysis done on intention to treat basis? Yes Consort flow chart: Risk of attrition bias risk: low Risk of detection bias: unclear Risk of care giver performance bias: High, study unblinded.
Results (All reported as intervention group vs. control group)	Numbers analysed: 47 vs. 45 All cause deaths over one year follow up: 8 vs. 7 Respiratory related deaths over one year follow up: 7 vs. 4 (not clear how defined) Hospital admissions frequency (%) over one year follow up: No admissions 14 (30) vs. 20 (44), 1 admission 16 (34) vs. 11 (24), 2 admissions 8 (17) vs. 6 (13), 3 or more 9 (19) vs. 8 (18), p=0.52 (Chi square test). Total hospital bed days (%) over one year follow up: None 14 (30) vs. 20(44), 1-10 days 13(28) vs. 9(2), 11-20 days

	8(17) vs. 10(22), 21-90 days 12 (25) vs. 6 (13), p=0.26 (Chi square test). Outpatient department visits frequency (%) over one year follow up: None 10(21) vs. 10 (28), 1-2 20(42) vs. 17 (40), 3-4 12(25) vs. 13(28), 5+ 5(11) vs. 6 (13), p=0.95 (Chi square test). Emergency department visits (%) over one year follow up: None 33 (70) vs. 40(87), 1 9(19) vs. 5 (11), 2+ 5 (11) vs. 1 (2), p=0.1(Chi square test). INTERVENTION GROUP ONLY HRQL: COOP scores fell significantly in the intervention group between baseline and 12 months follow up (29 patients) but the mean fall in scores was small, from 33.2 at baseline (SE 1.1) to 30.2 at 12 months (p = 0.01), and the clinical significance is unclear. No change was seen in carers' HRQOL between baseline and follow up. FEV1: fell in 35 intervention subjects between baseline and 12 months follow up 0.82 L to 0.74 L, SD not given , p = 0.04.
Reviewers comments	Generalisability: not clear how many people were screened for eligibility, 'of 105 approached, 96 (91%) accepted'. Level of evidence: 2b Other points: Difficult to interpret the information on patient HRQOL since only in intervention group and clinical significance not clear. In addition, since some subjects were recruited as inpatients it is likely that their HRQOL was lower than usual at baseline. Difficult to judge methodological quality of the study because of lack of information. No significant differences seen in heath service utilisation or mortality seen over 12 months follow up, but the sample size was small.

Author, year	HMM Van Alphen, 2003
Title	Evaluation report COPD
Design	Pretest-posttest design (before and after study) with two different cohorts who received slightly different interventions. Duration of follow up: 12 months
Country and Setting	Country: Netherlands Secondary care setting: Hospital Walcheren
Objectives clearly described	Y/N: Yes To organise, implement and evaluate a model of care wherein the care patients with stable COPD is transferred from medical specialist to respiratory nurse.
Participants (All reported as intervention group vs. control group)	Sample size: 52 (m/f –not specified) Age of study subjects: not specified Severity of COPD at recruitment: patients with mild/moderate COPD were included. Were the groups similar at baseline regarding the most important prognostic indications? not relevant Study eligibility specified? No Inclusion criteria: Group 1: having COPD for longer time, FEV1>30%. Group 2: newly diagnosed with FEV1 30-70% Exclusion criteria: Not specified
Interventions	Components of intervention clearly described? Y/N Yes Duration of intervention: ('intensity, frequency, maintenance phase): 12 weeks Interventionist: Respiratory Nurse Specialist Intervention Group: Group 1: consultations with RNS instead of doctor; Group 2: explanation and instruction by RVS. Description as detailed as possible: Referral: Not specified Group 1: first consultation by medical specialist, consultations by RNS in the hospital at 3, 6 &9 months after initial consultation. Consultations took 45 minutes and included spirometry, inhalation technique, insight in disease , complaints, rules of life, nutrition, weight control, exercise training. Group 2: after first consultation by medical specialist, 2-3 consultations by RN in hospital, and 10-12 weeks after initial consultation again consultation by medical specialist. Content of consultations as in group 1 plus assessment of BMI. 24 hour cover; Not specified Procedure for clinical deterioration: Not specified Clinical responsibility: Not specified Comparison Group: not applicable
Outcomes	Were outcome measures well described? No Primary endpoint: Health related quality of life measured by SGRQ

	Other endpoints: Number of consultations
Methods	Recruitments dates: May 2001 to June 2002 Statistical methods clearly described?Not specified Rationale for sample size: Not specified Analysis done on intention to treat basis? Not specified Risk of attrition bias: Possible, 37/53 (71%) analysed Risk of detection bias/ Outcome assessor blinded? unknown Risk of are giver performance bias: unknown
Results (intervention vs. control)	Numbers analyzed: 37 (three measurements) Primary endpoint (all quoted as median change): results are described, but do not seem to be statistically analysed. It is said that 'results of measurements of QOL show that patients experience positive effects from intervention by RNS. These effects are: less coughing, less sputum, less shortness of breath, less wheezing, less heavy attacks, less negative effects of disease and better adjustment of medication'. Other endpoints: 9 patients quit smoking and 4 smoked less at the end. Death rates: unknown Hospital readmission rate during f/up: unknown Were point estimates and measures of variability presented for the primary outcome measures? No
Authors conclusions	Referral of tasks took place and contacts were made with primary caregivers by the RNS. Of patients who filled out the questionnaire almost all experienced positive effects of the intervention or remained equal due to more insight of patients in disease. Smoking behaviour was influenced for 61% of patients.
Reviewers comments	Data source: published data only Generalizability: unknown Level of evidence: not ascribed, very poor quality report

Eijkelberg 2001: Critical Appraisal Skills Programme (CASP) appraisal tool

Was there a clear statement of the aims of the research?

The stated aims of the project were to determine:

How do patients judge nurse-led shared care?

What quality issues are given priority by them?

What lessons can be drawn form the improvement of this care and the qualitative methods of focus groups?

This study reports the findings of three focus groups with patients diagnosed as having COPD and Diabetes which aimed to establish their perceptions of receiving a model of shared care.

Is qualitative methodology appropriate?

Yes.

Was the research design appropriate to address the aims of the research?

Strictly speaking this is not a wholly qualitative paper since the researcher's state: 'focus groups can generate cumbersome and complex data. To facilitate the collection of data we applied elements of quantitative methodology as an additional means'. In essence this appears to be a paper which is attempting to develop a method for synthesising qualitative and quantitative methods. However, there is no full discussion of the inherent epistemological traditions within which both are rooted.

Was the recruitment strategy appropriate to the aims of the research?

Patients were sampled to participate in these focus groups at random. This approach is not applicable to qualitative research which has its different sampling techniques.

Were data collected in a way that addressed the research issue?

Contemporaneous notes were taken and reported – this is good practice with qualitative interviews and focus groups.

Has the relationship between researcher and participants been adequately considered?

The Focus group moderator was a GP yet there is no discussion as to the possibility that this might influence the nature of the respondents' contributions. Though there is a discussion about the moderator's input into the focus group, there is no recognition that the groups might perceive this person as other than a representative of medicine – with the possibility of the responses being influenced by this.

Have ethical considerations been taken into account?

No information is provided on this.

Was the data analysis sufficiently rigorous?

The data is reported and interpreted in a quantitative way 'Four said…. Eight said…' The data is not subjected to any theoretical analytical interpretation but is simply reported as self evident. This is a major problem for the robustness of the study – especially given that the focus group should allow the moderator to explore respondents' beliefs and expectations in depth. To base a focus group on a pre-formulated schedule against which individuals measure up their experiences severely limits the potential of this methodology for analytic interpretation.

Is there a clear statement of findings?

'Most patients experience shared care models as positive and prefer them compared to traditional care. The main quality aspect concerns the provision of information although its performance needs improvement. The outcome indicates that the qualitative method of patient focus groups should become standard procedure in evaluating the shared care, supported by quantitative means'.

How valuable is the research?

It is unlikely that this study has generated findings that are transferable because the influence of the moderator as a GP remains unknown and unexplored.

Egan 2002: Critical Appraisal Skills Programme (CASP) appraisal tool

Was there a clear statement of the aims of the research?

The objectives of the qualitative study were not clearly stated although the study aimed; 'To understand patient-focused outcomes'. This qualitative study was conducted along side a RCT and the stated purpose of the study; 'to compare the effect of a brief nursing based case management intervention with that of normal care for patients hospitalised with COPD,' seems to apply to the qualitative study.

Is qualitative methodology appropriate?

Given that the exact aims of the qualitative study are unclear, the answer is probably 'yes'.

Was the research design appropriate to address the aims of the research?

This paper reports the findings of an assessment of a RCT of nursing based management of patients with chronic obstructive pulmonary disease. A small part of this assessment involved a qualitative element. The qualitative study is described as including:

A postal questionnaire to 34 nursing and allied health professional staff based on interviews with key informants. The questionnaire had 16 questions measured on a 4 point likert scale with higher scores indicating greater impact. These were analysed quantitatively and the findings are reported in the quantitative data abstraction sheet.

Semi-structured interviews with two respiratory physicians at the end of the study.

Eight caregiver/patient couples and two patients without caregivers were interviewed in depth with semi-structured interviews 'regarding their experiences during the study period…and focussed on issues associated with patient and caregiver satisfaction with care.'

Was the recruitment strategy appropriate to the aims of the research?

The sampling procedure is vague with only a mention of maximum variety sampling. There is no indication as to the basis

for this sampling approach and we are not told what exactly the issues were that they wanted to ensure a variety of.

Were data collected in a way that addressed the research issue?

There is a contradiction in their argument to have undertaken depth interviews, as they then go on to argue that a semi-structured interview schedule was used.

Has the relationship between researcher and participants been adequately considered?

No information is provided on this.

Have ethical considerations been taken into account?

No information is provided on this.

Was data analysis sufficiently rigorous?

The purported analytical approach is vague – reference is made to coding the transcripts to identify recurrent themes and patterns, but this is to impose a quantitative paradigm on what is qualitative data. There appears to be no attempt made to interpret the data and locate it in anything other than a descriptive framework. From the qualitative analytical approach taken, it is difficult to interpret their findings as little more than narrative accounts – simply reproduced text from the interviews.

One of the 'findings' - that participants in the control group were 'very satisfied with their care in hospital' – provides no understanding of what these participants define as satisfactory.

There is no evidence of an interpretative stance being taken, no clear sense of the emergent themes, and no acknowledgement of dissonant cases.

Is there a clear statement of findings?

No

How valuable is the research?

It is questionable whether these findings are sufficiently robust to be transferable to other settings.

Author, year	Cotton 2002 (RCT evaluation) /Gravil 1998 (paper providing further description of intervention)
Title	Early discharge for patients with exacerbations of chronic obstructive pulmonary disease: a randomised controlled trial/ Home treatment of exacerbations of chronic obstructive pulmonary disease by an acute respiratory assessment service.
Design	RCT-stratified by sex, living alone and whether ever smoked. Duration of follow up: 60 days
Country and setting	UK, single centre, hospital
Objectives clearly described	Y/N: Yes Comment: Evaluates the effectiveness of a policy of early discharge followed by domiciliary respiratory nurse support.
Participants (All reported as intervention group vs. control group)	Sample size: 41 (male 46%) vs. 40 (male 40%). Age: 65.7 yrs (sd 1.6) vs. 68.0 yrs (sd 1.2) Severity of COPD at recruitment: Home nebuliser 24 (59%) vs. 19 (48%), home oxygen 8 (20%) vs. 5 (13%), oral steroids 4 (10%) vs. 5 (13%), Pao2 (kPa) 8.5 (s.e 0.4) vs. 9.2 (s.e 0.4), H(nM) 39.3 (s.e 0.8) vs. 40.0 (s.e 0.8), FEV1 (l) 0.95 (s.e 0.08) vs. 0.94 (s.e 0.06), FEV1 (% predicted) 41 (3) vs. 44 (3), FEV1/FVC (%)45 (2) vs. 46 (2) Were the groups similar in baseline regarding the most important prognostic indications? Yes Study eligibility specified? Yes Study inclusion criteria: Admitted as an emergency with a diagnosis of an exacerbation of COPD to Glasgow Royal infirmary. Study exclusion criteria: Not resident in Glasgow, homeless, unable to give informed consent or had no access to telephone. Extensive co morbidity.
Interventions	Intervention: 'Early discharge' using the Acute Respiratory Assessment service(ARAS) model (developed earlier by group). Comments of intervention clearly described? Yes Duration of intervention: Patient visited by the respiratory nurse on the first morning after discharge and thereafter at intervals determined by the nurse. The median duration of nurse scheme was 24 days, and median number of visits 11. Referral: Respiratory nurse visited medical wards each morning to identify patients admitted with COPD. Assessment: Weekday service only. Discharge to home care: The early discharge group was sent home on the next working day after recruitment,

	ideally within 3 days of admission. Home visits: Patients were visited by the respiratory nurse on 1st morning after discharge and thereafter at intervals determined by the nurse. Treatment at home was adjusted if needed by respiratory nurse after discussion with respiratory medical staff. Home management followed the practice developed for ARAS. In brief, the nurse assessed patient's progress based on subjective feelings and bedside observations. The nurse did not prescribe but could advise on use of required medication. Out-of-hours cover: GP. Exacerbation care pathway: The nurses liased with respiratory staff to arrange admission if required'. Clinical support to nurses: Respiratory medical team. Additional support services: Did not automatically include support from other services such as community physiotherapy or social services Comparison Group: Usual care Description: Conventional inpatient management
Outcomes	Were outcomes measures well described? Yes Primary endpoint: Readmission rate and additional numbers of days in hospital after initial admission, and deaths.
Method	Recruitment and follow-up dates given: Recruitment over 14 months. Rationale for sample size: Not given Randomisation:1-Sequence generation: Not specified, 2-Allocation concealment: Held remotely by non-clinical member of staff based in a separate building who held the treatment allocation schedule. Risk of care giver performance bias: Unknown Risk of attrition bias: Low Risk of detection bias: Unknown Statistical methods clearly described? Yes- t-tests, Fishers exact test, and Mann-Whitney U test Analysis done on intention to treat basis? Yes
Results (All reported as intervention group v control group)	Numbers analyzed: 36 vs 39 Primary endpoint: No difference in readmission rate or duration of stay on readmission, days to readmission or mortality. Length of initial admission 3.2 (1-16) v 6.1 (1-13), Readmissions-No (%) 12 (29.3) v 12 (30.0%). Days to readmission from day of 1st admission (n=12) 29.6 v 25.6, Additional days (n=12) 7.83 v 8.75. No (%) deaths within 60 days 1 (2.4%) v 2 (5%). Number/% presenting to emergency services with an acute exacerbation that participated: 20%, 37/151 refused to take part –reason not given.
Reviewers Comments	Summary: RCT of discharged to Hospital at Home scheme within 72 hrs of admission. No difference in clinical outcomes between the two trial arms. Methodological quality of study: Difficult to judge because of lack of information in published paper. Small sample. No sample size calculation or confidence interval for results.

	Level of evidence: 2b

Author, year	Davies, 2000
Study title	'Hospital at home' versus hospital care in patients with exacerbations of chronic obstructive pulmonary disease: prospective randomised controlled trial.
Methods	Randomised controlled trial Duration of follow up: 3 months
Country and setting	UK, single centre, hospital
Objectives clearly described	Y/N: Yes 'Hospital at home' versus hospital care in patients with exacerbations of chronic obstructive pulmonary disease and in the introduction they state 'we hypothesised that selected patients currently admitted with exacerbations of COPD could be safely cared for at home with sufficient support'
Participants (all reported as intervention group vs. control group)	Sample size:100 (m:f 45:55) v 50 (m:f 30:20).Age mean (sd): 70 (8) v 70(8) Severity of COPD at recruitment: Prebronchodilator FEV1 (litres) 0.71 (0.33) v 0.65 (0.21), Post bronchodilatorFEV1 (litres) 0.82 (0.37) v 0.76 (0.28). , % predicted FEV136.1 (17.2) v 35.1 (14.7), Respiratory rate (breaths/minute) 24 (4) v 23 (4) Arterial blood gases; PH (geometric mean) 7.4 (0.05) v 7.39 (0.04) PO2 (kPa)-9.7 (2.9) v 9.0 (1.2) PCO2 (kPa)- 5.2 (1.0) v 5.2 (0.8) Were the groups similar at baseline regarding the most important prognostic indications? More males in control, 60% v 45% in intervention group. Study eligibility specified? Yes Inclusion criteria: The diagnosis of COPD was based on BTS criteria. An exacerbation was defined as increased breathlessness and an increase in at least two of the following symptoms for 24 hours or more: cough frequency or severity, sputum volume or purulence, and wheeze. FEV1 <80% predicted, FEV1/FVC ratio <70%, Minimental state score >7, Pulse rate <100 beats/minute, Systolic blood pressure >100 mmHG, pH >7.35, pO2 >7.3 kPa, pCO2 <8 kPa, Total white cell count 4-20x10^9/1 Exclusion criteria: Personal history of asthma, marked use of accessory muscles, suspected underlying malignancy on chest x-ray film, pneumothorax or pneumonia, uncontrolled left ventricular failure, acute changes on an electrocardiogram, requirement for full time nursing care, requirement for intravenous therapy.
Interventions	Intervention Group: 'Hospital at home' Components of intervention clearly described? Yes Duration of intervention: At least 3 days, twice a day visits, thereafter at the nurse's discretion. Mean and standard deviation; 11 visits (sd 3)

	Referral: By GP or emergency physician. Assessment: Patients presenting with exacerbation of COPD in A&E by intervention team. Management and entry into trial agreed by doctor from respiratory team. Service involves three whole time equivalent nurses, and operates 7 days a week, 8 am to 6 p.m. Discharge to home intervention: With no overnight hospital stay. Patients were escorted home by specialist nurse. Social support was immediately available if required. Nebulised ipratropium bromide and salbutamol with a compressor, oral predisolone for 10 days and antibiotics for five days were prescribed. Homes visits: Nurses visited the patients in the morning and evenings for first three days and thereafter at their discretion. Out-of-hours cover: Evening and night cover was provided with the agreement of pre-existing services by district nurses. Exacerbation care pathway: If progress was unsatisfactory the nurse or the patient could trigger admission. Clinical support to nurse: With hospital respiratory physicians until the exacerbations had resolved. Additional support services: Social support was immediately available if required. Comparison Group: Usual care Precise details: Inpatients received the same drugs, with all other management being at the discretion of the ward team. Median hospital stay 5 days.
Outcomes	Were outcome measures well described? Yes Primary endpoint: Number of subsequent admissions to hospital during the first 2 weeks of home care, the number of admissions to hospital in the three months after this period and changes in FEV1 after the use of a bronchodilator and mortality. Health status examined in a subgroup of those randomised to the two treatment arms. A random subgroup of 90 patients completed a St Georges respiratory questionnaire during the first week of the exacerbation and fifty went onto complete a second such questionnaire at three months-(34 in the intervention group and 16 in the control group).
Methods	Recruitment and follow-up dates given: Recruitment dates (February 1998- August 1999) given but not follow-up. Rationale for sample size: Yes Randomisation sequence generation: No details; allocation concealment: blind sealed envelopes Statistical methods clearly described: Yes-data presented as means (95%CI) unless otherwise stated. Groups compared by t-tests and chi squared tests. Analysis done on intention to treat basis: Yes Risk of attrition bias: low, but 50/90 of subgroup completed a HRQL 2nd questionnaire (34 in home care and 16 in hospital group). Risk of detection bias: High Risk of care giver performance bias: Unclear

Results (All reported as intervention group v. control group)	Numbers analyzed: 84 v 41 FEV1- mean % predicted FEV1 after the use of the bronchodilator At 2 weeks: 42.6% (13.4% to 81.8%) v 42.1% (5.1% to 79.1%). No patient in the intervention group had called their GP during the exacerbation. At 3 months: 41.5% (8.2% to 74.8%) v 41.9% (6.2% to 77.6%) Mean (SD) change in postbronchodilator FEV1 (litres): 0.11 (0.34) v 0.14 (0.32). Readmission rates: 37 (37%) v 17 (34%) at 3 months. Causes of readmission: Exacerbation of COPD 31 (31%) v 16 (32%). 91/100 exacerbations resolved at home. (9 required readmission within 14 days). There was no significant difference in mortality, 9 deaths (9%) v 4 deaths (8%). Subgroup analysis of patients who completed St George's respiratory questionnaire. Mean initial scores were 71.5 (43.4 to 99.6) v 71.0 (43.4 to 98.6). At three months there was no difference in the scores either from admission or between the groups. The score in the intervention group had decreased by a mean of 0.48 (sd 16.92) and in those in comparison by 3.13 (14.02). Twenty four intervention patients required social referral (median 20 hrs): 15 patients had home help; 8 assistance for washing and dressing; 9 meals on wheels; 5 night sitters; 3 day and night sitters. Number presenting to emergency services with an acute exacerbation that participated: 150/583 participated (25.7%). 42 refused, no reasons given.
Reviewers conclusions and comments	Summary: RCT Hospital at home with no overnight stay. No significant difference in mortality, admission or health status. Methodological limitations: Difficult to judge methodological quality of study because of lack of information. Level of evidence: 2b

Author, year	Hernandez, 2003
Title	Home hospitalisation of exacerbated chronic obstructive pulmonary disease patients
Design	RCT and cost effectiveness analysis. COST EFFECTIVENESS ANALYSIS REVIEWED SEPARATELY BELOW Duration of follow up: eight weeks
Country and setting	Spain, two centre, hospital base
Objectives clearly described	Y/N: Yes 'It was postulated that home hospitalisation with free patient phone access to a specialised nurse should generate a better outcome at lower direct costs than an inpatient hospitalisation. Namely 1-a lower rate of emergency room relapses, 2-greater improvement of health related quality of life, and 3-better patient self-management of the disease'.
Participants (all reported as intervention group vs. control group)	Sample size- 121(male:female 97:4) vs. 101 (males:female 97:4), Age (mean years and SD): 71.0 (9.9) vs. 70.5 (9.4) Severity of COPD at recruitment: Exacerbations requiring admission in last yr (% of subjects): 40.8 vs. 40.6, number of episodes 0.7+/-1.2 vs. 0.9+/-1.4, oxygen therapy at home (% of subjects) 12.4 vs. 18.8, arterial blood gases: F1, O2 21.7+/-1.4 vs. 22.1 +/-2.3, pH 7.4 +/-0.04 vs. 7.4 +/-0.3, Pa, O2 vs. 65.0 +/-13.6 vs. 64.7 +/-16.4, Pa, CO2 42.7 +/-7.5 vs. 43.8 +/-8.9, blood sampling at F1, O2=0.21(% patients) 77.6 vs. 72.6, PaO2 breathing F1, O2=0.21 63.2+/-10.5 vs. 62.9 +/-13.9. Were the groups similar at baseline regarding the most important prognostic indications? Yes Study eligibility specified? Yes Inclusion criteria: COPD exacerbation as a major cause of referral to the ER and absence of any criteria for imperative hospitalisation as stated by the BTS guidelines. Exclusion criteria: 'Extremely poor social conditions', admitted from a nursing home, other 'severe' diseases, no phone, or living out of locality.
Interventions	Components of intervention clearly described? Y/N: Yes Duration of intervention: 8 weeks, up to 5 visits if needed, plus free phone access. (average number of nurse visits: 1.66+/-1.03 (0-4)), phone call to patients 1.56 +/-1.31 (0-6), phone calls to nurse 0.76=/-1.34 (0-9), overall number of calls 2.33 =/-2.05 (0-10) Intervention Group: 'Home hospitalisation' Referral: Not specified Assessment: On A&E admission by specialised team after

	assignment to intervention scheme (one chest physician and one nurse in each hospital), decision on discharge from A&E or after a short period of inpatient hospitalisation, assessment only on weekday office hours only. Hospital discharge to scheme: Pharmacological therapy, plus 2 hours devoted to education on adherence and recognition/prevention of triggers of exacerbations, selection of equipment and training on using drug therapy, smoking cessation, patient empowerment of daily life activities, dietary advice and on socialisation.- tailored to individual. Home visits: 1-First nurse visit at home within 24 hrs of discharge, last 1 hour – to assess drug therapy, action plan and education. 2-8 week follow-up-here number of home visits and duration of home hospital decided by nurse. Phone calls: Patient free phone access ensured and nurse calls patient to reinforce action plan. Out-of-hours cover: Not specified Care pathway: Not specified Clinical support to nurse. Remote supervision by clinician, weekly meeting held by specialist team. The length of home hospitalisation set by nurse. Additional support services: Not specified Comparison Group: usual care Descriptions: Patients in group were assessed by attending physician in A&E who decided whether to admit or discharge. Pharmacological therapy followed standard protocols, at discharge primary care physician usually supervised patient. Average lengths of inpatient stay 8 days.
Outcomes	Were outcome measures well described? Yes Primary endpoint (clinical): Mortality, Hospital utilisation-ER visits and hospital readmissions, health-related quality of life (SGRQ) (SF-12), patient self-management, patient satisfaction, lung function, knowledge.
Methods	Randomisation: 1-Sequence generation: computer generated random numbers and-references consort statement, 2-Allocation concealment: references consort statement Statistical methods clearly described? Yes, t-test, Mann-Whitney or Chi squared tests, or Wilcoxon test on comparison between the two groups. Rationale for sample size: Not specified Analysis done on intention to treat basis? Not specified Consort flow chart: No, 5 patients died vs. 7. Number of patients completed final follow-up not specified. Risk of attrition bias: Unknown Risk of detection bias: Unknown for clinical assessment, questionnaire blindly administered Risk of care giver performance bias comment. Unknown

	Recruitment and follow-up dates given: November 1999 to November 2000
Results (all reported as intervention vs. control group)	Numbers analyzed: Not specified Deaths n (%) 5(4.1) vs. 7 (6.9) Inpatient initial hospitalisation (% of patients): <1 day 67.8 vs. 38.6 p=<0.001, 2 days 5.8 vs. 4.0, 3 days 9.9 vs. 9.9 16.5 vs. 47.5 Number of days of initial hospitalisation 1.71 +/-2.33 vs. 4.15+/-4.10 p=<0.001. Average length intervention 3.56 days, in control 8.1. Inpatient readmission Patients n (%) 23 (20.0) vs. 26(27.7), Number of episodes 0.24+/-0.57 vs. 0.38+/-0.70. Emergency room attendance Patients n (%) 11(9.6) vs. 21(22.3)p=0.02, Number of episodes 0.13+/-0.43 vs. 0.31+/-0.62 p=0.01 Health-related quality of life Mean SGRQ scores: total = -6.9 vs. -2.4 p=0.05, symptoms = -8.7 vs. -8.4, activity = -4.8 vs. -0.09, impact = -7.6 vs. -1.9 p=0.03 Mean SF-12 scores: physical 1.7 vs. 1.9, mental 2.0 vs. -0.05 Compliance on inhalation technique: 81% vs. 48 p=<0.001 Rehabilitation at home: 51% vs. 21% p=0.01 Patient's satisfaction mean score 8.0 vs. 7.5 p=0.03 Lung function: Forced spirometry scores: FVC L (% predicted): 2.4 +/-0.6 (64) vs. 2.2 +/-0.9 (60), FEV1 L (% predicted): 1.2 +/-0.6 (43) vs. 1.1 +/- 0.4 (41), FEV1/FVC % 50 +/-13.3 vs. 50 +/-13.1. Knowledge of disease: 58% vs. 27% p= <0.01 Number/% presenting to emergency services with an acute exacerbation that participated: 222/629 (35.3%). 3.5% refused, n=22, reasons not given.
Clinical effectiveness reviewers conclusions and comments	Summary: RCT and cost effectiveness study of Hospital at home scheme and early discharge scheme. Found patients in the hospital at home group generated better outcomes. Unclear of what the 'rehabilitation at home' outcome is measuring. Methodological limitations: Unspecified risk of attrition, detection and caregiver performance biases. Level of evidence: 2b
Key economic elements	Economic study type: Cost-effectiveness analysis from the health service provider perspective. Dates on which data relate: November 1999 to 1st November 2000. Prices 2000. Modelling: None Link between effectiveness and cost data: The collection of resource use data were undertaken on same patient sample as used in the effectiveness analysis, and were collected

	prospectively.
Economic analysis	Direct costs: Resources and prices were reported separately: Direct resources: Only health care costs considered: 1) length of hospital stay 2) ER visits not requiring admission to hospital. 3) hospital outpatient visits to specialists 4) primary care physician visits 5) visits for social support 6) nurse visits at home 7) treatment prescriptions 8) phone calls 9) transportation services No discussion of how the dissemination of the new protocol was established, or what additional managerial support was required to ensure good inter-departmental relations. Prices were based on tariffs (in euros) The values are inferred from average tariffs for COPD patients in a public insurance company. Inpatient hospital stay 2220.62; ER visits 79.2; outpatient visits 39.85; primary care physicians visits 47.48; social support visits 8.75; nurse home visits 25.34; phone calls 9.02, transport 6.01. Average direct costs per patient home hospitalisation 1255.12 (95% CI 978.54-1568.04); conventional care 2033.51 (95% CI 1547-2556.81). Indirect costs: None considered Currency: units of costs expressed at 2000 prices using euros. No discounting rate was required as the study reported data from November 1999 to 1st November 2000. Statistical analysis of quantities/costs: None considered Sensitivity analysis: None performed
Economic Results	Costs results: The number of days in hospital was lower in home hospitalisations (1.71 versus 4.15). Synthesis of costs and benefits: Not attempted, as home hospitalisation was regarded as more effective and cheaper. Author's conclusion: Home hospitalisation is cost effective.
Economists commentary	Choice of comparator: Appropriate comparator (as is standard practice). Validity of estimates of costs: No concern for costs to patients and their carers, arguing that these have been shown to be small in other studies (page 64) comparing home hospitalisation with hospitalisation (Shepperd et al, BMJ 1998). Other issues: -The study is limited in that it only considers public health care costs.

	- Exclusion criteria: those with extremely poor social conditions.

Author, year	Gordois, 2001
Title	The cost-effectiveness of outreach respiratory care for COPD patients/Developing a nurse-led service for COPD patients.
Design	Cost minimalisation analysis/cohort study, no controls. OUTCOMES DOCUMENTED IN ECONOMIC EVALUATION. Duration of follow up: 7 months
Country and Setting	UK, two centres, hospital bases
Objectives clearly described	Y/N: Yes 'Whether the acute respiratory assessment service (by preventing unnecessary admission and facilitating early discharge) is more cost effective than a hypothetical scenario of treating the same patient in the absence of the scheme. Previously all patients would have been admitted to hospital.
Participants	Actual sample size: 218. Male 48% Actual age of study subjects: 70.3 yrs Actual severity of COPD in study subjects at recruitment: Mild 4%, moderate 23%, severe 76% (based on FEV1) Study eligibility specified? Yes Inclusion criteria: Uncomplicated acute exacerbations of COPD admitted at the ER of 2 hospitals. Exclusion criteria: Extremely poor social conditions or without phone.
Intervention	Components of intervention clearly described? Y/N: Yes Duration of intervention: ('intensity, frequency, maintenance phase): Intervention Group: 'what they called intervention' An acute respiratory assessment service (ARAS) Interventionist: 0.5 whole time equivalent respiratory nurse specialists, 1 whole time equivalent physician, 2.75 whole time equivalent nursing sisters, 0.5 whole time equivalent secretary. Referral: from GPS, A&E, acute medical assessment unit and medical wards. In addition patients can self-refer if they have previously used the service. Assessment: Streamlined decision-making regarding whether to admit patients or to provide treatment at home follows patient assessment. The team's guidelines for admission and treatment are based on published clinical evidence (refs given). Discharge to home: Where admission is required the team review the patient daily until he or she meets these discharge criteria. On discharge the patient is transferred home with a care package which may consist of 1-high dose inhaled or nebulised therapy, 2-Intermittent O2, 3-antibiotics, 4-Steroids, 5-Information sheets and contact numbers. Home visit: On discharge patients are visited regularly, by a dedicated specialist nursing team. At each visit patients undergo a clinical assessment to evaluate

	their response to treatment, to decrease visits to GP, provide education and support, improve continuity of care, achieve cost effective prescribing (nurse was able to prescribe). Patient monitors daily for first 3 days and thereafter at nurses discretion. Thereafter, the nursing team makes decisions regarding ongoing care, with reference to evidence-based clinical management protocols. On discharge from the service a pulmonary rehabilitation programme acts as an adjunct to medical treatment to improve patient's ability to cope with their symptoms. Out-of-hours cover: The ARAS service, available daily from 9am to 5pm. Care pathway for exacerbation: Comprehensive nurse guidelines. Clinical support to nurses: Not specified.
Key economic elements	Economic study type: Cost-minimisation from the health service provider perspective, on the assumption that the health outcomes are the same under ARAS and in the absence of ARAS. Dates on which data relate: Effectiveness and resources used: August 1999 to March 2000. Modelling: None Link between effectiveness and cost data: The collection of resource use was collected prospectively.
Economic analysis	Measure of health benefits: There was no measure of health status. Direct costs: Resources and prices were collected, and were reported separately: Direct resources: Only key health care costs considered: 1) bed days 2) staff 3) major therapeutic interventions 4) patient assessments (including spirometry tests) 5) home visits No discussion of how the dissemination of the new protocol was established, or what additional managerial support was required to ensure good inter-departmental relations. The additional usage was estimated. Prices were based on standard national costs (sterling) Published sources - Staff costs- based on a seven-month joint salary of the team members (£58,936). - home visits were based on specific travel budget - Spirometry/reversibility test was estimated to cost £4.39 based on staff time to perform the test. - Cost of medical inpatient bed day was £146.

	- Antibiotic course was estimated at £5.97. Indirect costs: None considered Currency: sterling, but dates of published sources not reported. Statistical analysis of quantities/costs: None considered Sensitivity analysis: None performed
Results	Estimated benefits used in the economic analysis: None Costs results: It was estimated that 1437 bed days were saved, 427 months of long term nebuliser therapy and 63 courses of antibiotics. Synthesis of costs and benefits: None Author's conclusion: ARAS minimises costs
Economists commentary	Choice of comparator: A lot of assumptions are made to obtain the estimates of improvements brought about by ARAS. This suggests the need for further studies to confirm these findings. Validity of estimates of costs: No concern for costs to patients and their carers, even though states that only 30% of patients wished to enrol on the rehabilitation programme. Other issues: -The study is limited in that it only considers public health care costs.

Author, year	Sala 2001
Title	Supported discharge shortens hospital stay in patients hospitalised because of an exacerbation of COPD.
Design	Parallel group study including pre-test post test analysis Duration of follow up: Not specified- study ran for 12 months- does not give average follow-up dates.
Country and setting	Spain, single centre, hospital based
Objectives clearly described	Y/N: Yes 1-To assess feasibility and safety of supported discharge program, 2-Its impact on length of stay, 3-Its effects on hospital resources.
Participants (all reported as interventio n group vs control group)	Sample size: 105 (male: female ratio not specified) v 100 (male: female ratio not specified) Age (mean years (sd)): 70 (10) vs 65 (11) Severity of COPD at recruitment: PaO2 mm Hg 57.1 (32-100) vs 56.7 (30-88), PaCO2 mm Hg 46.8 (23-90.7) vs 43.5 (23-81.9), arterial pH 7.39 (7.24-7.51) vs 7.40 (7.170-7.54), FEV1 % ref 45 (20-76) vs 46 (15-73) Were the groups similar at baseline regarding the most important prognostic indications? Yes Study eligibility specified? Yes Inclusion criteria: Patients admitted to respiratory ward with diagnosis of exacerbated COPD Exclusion criteria: Not responding to initial therapy started in ER.
Interventio ns	Intervention Group: 'Supported discharge' Duration of intervention: Mean duration of scheme 7.3 days (sd 3.8) (range 1-17 days), mean number of visits 4.8 (sd 2.5) (range 1-12), telephone calls between patient and nurse mean 2.3 (sd 2.0 (range 0-8)). Components of intervention clearly described? Y/N: Yes Referral: Not specified. Assessment: Not specified. Intervention After first few days of standardised hospitalisation. The day after hospital discharge, a specialised, hospital-based, clinical nurse visited them at home. Thereafter, home-visits were scheduled according to patients needs. Patients in the supported discharge programme were allowed to use nebulizers and/or continuous O2 therapy at home if deem ed necessary by the attending physicians At each visit at home, the nurse assessed the patients general condition, shortness of breath intensity and presence of cough or sputum production. Also vital signs, arterial oxygen saturation. Out-of-hours cover: Not specified. Exacerbation care pathway: If necessary, during regular working hours the nurse could be reached by the patient (or the nurse could reach the doctor in hospital) through a mobile phone. Likewise, if required,

	the nurse could send the patient back to hospital for immediate medical assessment by the pulmonary team (including new hospitalisation if necessary). Clinical support to nurses: The programme nurse had daily meetings with the pulmonologists in the hospital to coordinate home-care needs. At the end of the home support programme, a lung specialist in the pulmonary clinic visited their patient. Additional social support not reported. Both groups bar intervention had same treatment. Comparison Group: Usual care Precise details: Hospital standard care (same as initial treatment in supported discharge group)
Outcomes	Were outcome measures well described? Yes Primary endpoint: Length of stay, Number of patients hospitalised during supported discharge (HRA) and number hospitalised during first 2 weeks following discharge (ERA), and after 2 weeks (LRA) mean number of hospital beds utilised daily by respiratory patients. Number of nurse visits at home per patient number of and mobile calls.
Methods	Recruitment and follow-up dates given: Recruitment April 1999 to April 2000 Rationale for sample size: Not specified Randomisation: Not randomised Risk of care giver performance bias: Unknown Risk of attrition bias: Unknown Risk of detection bias: Unknown Statistical methods clearly described? Yes- mean and sd and range, t-tests and chi squared comparisons between the groups and pre test post test analysis.
Results (Reported interventio n vs control)	Numbers analyzed: Not specified Primary endpoint: Length of stay in days (range) 5.9 sd 2.8 (1-19) vs 8.0 sd 5.1 (1-30), p=0.001, number of hospitalisation during 12 months follow-up 134 vs 116 (78% were hospitalised once during 12 months of study), number of patients requiring hospitalisation before discharge from nurse scheme 1 (0.7%) vs NA, number of patients requiring hospitalisation during the first 2 weeks following discharge from nurse scheme 3 (2.2%) vs 2 (1.7%) p=ns, number of patients requiring hospitalisation after 2 weeks from discharge from nurse scheme 25 (18.7%) vs 14 (12.0%) p=ns Demand for hospitalisation in department before supported discharge programme was a total of 2256 patients and after it had started it was 2294 patients. The average length of stay before programme (in supported discharge programme. previous year) was 7.7 days compared to 6.4 during. Generalisability: All patients presenting within recruitment period

	were included if CCT of discharge to HaH after few days in hospital.
Reviewers conclusions and comments	Summary: Parallel controlled group study of early discharge scheme, no difference in subsequent readmission rates Limitations: Not an RCT. Unclear length of follow-up and attrition Level of evidence: 2b-.

Author, year	Skwarska, 2000
Study title	Randomised controlled trial of supported discharge in patients with exacerbations of chronic pulmonary disease.
Design	RCT and cost effective analysis. COST EFFECTIVENESS ANALYSIS REVIEWED SEPARATELY BELOW. Duration of follow up: 8 weeks
Country and setting	UK, single centre, hospital
Objectives clearly described	Y/N: Yes 1-What proportion of patients can be safely managed at home. 2-Are there any differences in recovery in terms of readmission and quality of life between home supported patients and comparable patients admitted to hospital, 3-Is patients satisfaction with the home support service as good as that for admitted. 4-Is a home supported discharge service economically viable?
Participants (reported as intervention Vs control group)	Sample size: 122 (male: female 63:59) vs. 62 patients (male: female 24:38). Age (mean years, range) 69.9 (51-86) vs. 68.5 (38-84) Severity of COPD at recruitment (mean): Respiratory rate (beats/min) 22.8 vs. 23.2, peak expiratory flow (l/min) 179.8 vs. 144.9 FEV1 (l) 0.77 vs. 0.66, oxygen saturation (%) 92.0 vs. 91.9 Were groups similar at baseline regarding the most important prognostic indications? Yes except for gender, although authors state not statistically significant. Study eligibility specified? Yes Inclusion criteria: Patients presenting to A&E on 5 days per week with a diagnosis of an exacerbation of COPD as the main reason for admission. Exclusion criteria: Patients with indicators of severe exacerbations of COPD (1) impaired level of consciousness, acute confusion, acute changes on radiography or an arterial pH of <7.35. Admitted at weekends.
Interventions	Duration of intervention: Average number of visits 3.8. Mean time to discharge from service was seven days. Components of intervention clearly described? Yes Intervention: 'Acute Respiratory Assessment Service' Referral to service: Not specified Assessment: In the admissions unit the ARAS nurses and reviewed by respiratory on call team (consultant and registrar) who made final decision on inclusion- weekday only service. Hospital discharge to scheme: Discharged home immediately with an appropriate treatment package arranged by the ARAS team (antibiotics, corticosteroids, nebulised bronchodilators and if necessary an oxygen concentrator on loan). Homes visits: Visited day after discharge from hospital by ARAS nurse and thereafter at intervals of 2-3 days until recovery when

	they were discharged. Out-of-hours cover: Available weekday 9-5pm Exacerbation care pathway: Medical advice available from the on call team Clinical support to nurse: Progress was assessed in consultation with the two ARAS nurses weekly at a review meeting with the consultant. Medical advice was available daily from the on-call respiratory medical team and changes in prescription could be obtained by consultation with patients GP. Additional support services: Not part of programme Comparison Group: Usual care Description: Admitted to hospital to respiratory unit. The treatment offered at home and hospital was prescribed and reviewed according to BTS guidelines and clinical judgement. Mean time to discharge was five days.
Outcomes	Were outcome measures well described? Yes Primary endpoint: Readmission rates before and after discharge, economic analysis on inpatients length of stay, drug use, GP costs. Time to discharge, respiratory function (spirometry), patient satisfaction (chronic respiratory questionnaire), GP satisfaction (short postal questionnaire), asked about any additional care services they needed. Outcome assessor blinded? Not specified
Method	Recruitment and follow-up dates given: November 1996 to May 1998, excluding Christmas. Rationale for sample size: given Randomisation sequence generation: Set of computer generated random numbers:, allocation concealment: Not specified Risk of care giver performance: High Risk of attrition bias: High Risk of detection bias risk: High Statistical methods clearly described? Yes- Mann-Whitney/t-tests and chi squared tests used, some were pre-test post test comparisons and some between group comparisons. Analysis done on intention to treat basis? Not specified
Results (reported as intervention Vs control group)	Numbers analysed: 79 v 28. Readmission rates before discharge from ARAS: Respiratory readmissions 9 (7%) Vs na, non-respiratory readmission 3 Vs na, Death: Before discharge 0 Vs 1, before final assessment 4 Vs 6. Readmitted before final assessment: For respiratory reason 23 Vs 19 p=ns, for non-respiratory reason 4 Vs 2, GP visits: between referral and discharge:

	Visits/100 patient-days 0.85 Vs na. GP visits: between discharge and final assessment: Visits/100 patient-days 0.70 Vs 1.07, Number of patients reporting increase in carer visits (%) 21 Vs 36 Mean changes in respiratory function between initial assessment and home discharge*: Respiratory rate (beats/min) -2.1 (p<0.001), -2.4 (p<0.001), Peak expiratory flow 40.3 (p<0.001, 21.9(P<0.01), FEV1 0.16 (p<0.001), 0.06=ns Oxygen saturation 2.8 (p<0.001), 1.4 (p<0.05) * initial mean minus discharge mean Mean change in respiratory function between discharge and final assessment: Respiratory rate 0.2=ns, -0.6=ns, Peak expiratory flow -12.6=ns, 10.3=ns, FEV1 0.06=ns, 0.14=ns Oxygen saturation -0.75=ns, 2.4 =<0.01. No significant differences between the groups on any dimension of the Chronic Respiratory Questionnaire: (data not shown in paper) at 8 week follow-up (QOL measure)- Patient satisfaction with service ONLY FOR INTERVENTION GROUP: Responses from questionnaire of patients treated at home was 69% of these 95% said they were 'completely satisfied' and 90% felt they had been cared for just as well or better at home than they would have been in hospital. GP satisfaction with service ONLY FOR INTERVENTION GROUP: 50% of GPs replied to postal questionnaire. All of them were satisfied with the decision to provide domiciliary support and the information they received on patients progress; 65% felt that managing the patient at home by the ARAS did not increase the demands on their practice; 33% reported decreased demands, 2% increased demands. Number presenting to emergency services with an acute exacerbation that participated: 26% (3% (n=24) refused –reasons not given)
Clinical effectiveness reviewers conclusions and comments	Summary: RCT and cost effectiveness analysis of Hospital at Home schemes (no overnight hospital stay). Found no difference in clinical effectiveness outcomes. Hospital costs were lower. Methodological limitations: High risk of attrition, detection and caregiver performance biases. Randomisation allocation concealment not specified. Level of evidence: 2b
Key economic elements	Economic study type: cost effectiveness. Dates on which data relate: Resources used from November 1996 to mid May 1998, excluding Christmas periods. Prices were estimated from financial year data for 1997-1998 and from published sources (Netten, PSSRU, 1997). Reported in pounds sterling, no apparent allowance for inflation was made nor discounting.

	Modelling: None Link between effectiveness and cost data: The resource use data and effectiveness data were collected from the same patient sample.
Economic analysis	Direct costs: Resources and prices were used separately in the analysis but not reported separately: Direct resources: Only health care costs considered: 1) inpatient stays based on length of hospital stay 2).drug use extracted from patient notes for a subset of patients 3) GP costs Prices were based on retrospective apportioning of costs -Average cost per bed-day in the respiratory unit - The Personal and Social Services Research Unit estimated GP units costs at Kent (Netten, PSSRU, 1997). Indirect costs: None considered Currency: pound sterling but not clear which year they were referred to (there is confusion given the different sources of the price estimates). Statistical analysis of quantities/costs: None considered Sensitivity analysis: None performed
Results	Estimated benefits used in the economic analysis: No significant differences between the groups on Chronic Respiratory Questionnaire. Attendance by GPs and carers did not differ significantly between the groups during the 8-week follow-up (based on patients reporting, page 910). GPs also commented on the use of their practice (50% replied to the questionnaire): 65% reported that home care did not increase the demands on the practice, 33% reported decreased demands and 2% reported increased demands. Costs results: The average cost per episode in control group was £1753. The average cost per episode in intervention group was £877. The mean cost of GP care between discharge and final assessment was slightly greater for the hospitalised patients than ARAS patients. Synthesis of costs and benefits: none Author's conclusion: Home hospitalisation provides an acceptable alternative to hospital admissions. This conclusion is based on the finding that home hospitalisation have similar quality of life measures (as measured by the Chronic Respiratory Questionnaire). In addition, home hospitalisation results in a lower average costs per patient, and did not appear to increase the costs of GP or other primary care services. The authors estimate that 23% of patients would be eligible for the home hospitalisation service (page 911).
Economists commentary	Choice of comparator: Appropriate comparator (as is standard practice) Validity of estimate of effectiveness: The study design seems

	appropriate to the hypothesis. The patients in the RCT were comparable and there were no statistically significant differences between these groups with regard to age, sex, smoking status or home circumstances. Validity of estimates of health benefits: There was no overall benefit measure, such as EQ-5D, but a disease specific measure which showed no difference between the groups. Other measures focus upon use of resources, which does not measure quality of care. The patient satisfaction measure is an imprecise measure of quality of care, since it is unclear how the patient can make comparisons about the care received at home and in hospital. Interesting no satisfaction for the control group is given, probably as this was also high! Validity of estimates of costs: The estimation of average costs overstates the saving from reduced bed-days due to the existence of fixed costs. However the authors note that had they reduced their estimate of average bed-days costs, to only 50% of inpatient costs, the intervention cost is still less expensive at £877 compared to £891 for the control. No concern for costs to patients and their carers. Other issues: -The study is limited in that it only considers public health care costs. Baseline comparisons were made with patients admitted on weekends (which were not included in the RCT study) and those admitted on weekdays, (which has the potential to be admitted to the study). A greater proportion of those presenting at the weekend were house-bound and more had worsening peripheral oedema ($p<0.01$), suggesting that these group may have been under-represented in the RCT.

Author, year	Flannigan 1999
Study title	An acute respiratory assessment service
Design	Descriptive, plus subgroup survey of satisfaction Duration of follow up: Not specified
Country and setting	UK, single centred, hospital base
Objectives	Describes development of an acute respiratory assessment service
Participants (All reported if given as intervention group vs control group.)	Sample size: 1216 Age of study subjects: Not specified Severity of COPD in study subjects at recruitment: Not specified Were the groups similar at baseline regarding the most important prognostic indications? Single group Study eligibility specified? Yes Inclusion criteria: Acute uncomplicated exacerbation of COPD Exclusion criteria: Not specified
Interventions	Components of intervention clearly described? Y/N Yes Duration of intervention: ('intensity, frequency, maintenance phase): The number of visits and the amount of time a patient stays under supervision by ARAS varies; each visit lasts approximately 30 minutes. Intervention Group: 'what they called intervention' Acute respiratory assessment service Description as detailed as possible: (weekday, office hours service) Referral: GP, accident and emergency, hospital based respiratory clinics, and latterly, directly from patients who have had previous contact with ARAS. Assessment: Patients are seen on the day of referral in the department of respiratory medicine. Local agreement with the Scottish ambulance service allows patients to be collected from their homes within one and two hours of referral and to be taken home promptly following assessment. Transportation can be by ambulance, with paramedic supervision and oxygen therapy if a patient's symptoms are severe enough. On arrival patients are seen by the respiratory nurse to be clinically assessed, patients may undergo a chest x-ray and an electrocardiogram if requested by the clinical team. The final decision on admission to scheme is by the clinical staff. Hospital discharge to scheme: Patients and carers receive verbal and written instruction on the use of the nebuliser and have their drug regimen fully explained before discharge. The initial findings of the assessment and patient's treatment plan are faxed to the GP. Home visits: The patient is seen the day after discharge by the same nurse seen in the hospital. An individualised care plan is developed based on a nursing model. Non respiratory problems are referred to the appropriate agencies, including social work and community nurses. The patient's clinical symptoms and vital signs

	are recorded by the nurse at each visit, as well as psychological well-being and response to treatment. Out-of-hours cover|: Not specified Procedure for clinical deterioration: transfer back to hospital for full assessment Clinical support to the nurse: medical staff in the respiratory unit Additional support services: Not part of service Comparison Group: usual care/other : Not applicable Description of control treatment:
Outcomes	Satisfaction evaluated by question in a random subgroup which consisted of twenty questions about the service and their condition.
Methods	Simple statistics
Results (intervention v control)	Recruitment and follow-up dates given: 1993 to 1994 Numbers analyzed: 150 questionnaires sent out by post, 116 returned (77%) Primary endpoint: Most patients were either very satisfied or satisfied with the care they had received, and 80% expressed a desire to have home care for any future exacerbation
Reviewers comments	Summary: Detailed descriptive cohort study with subgroup satisfaction survey which found overall satisfaction with service Limitations: Not a randomised controlled trial, subgroup analysis only Level of evidence: 4

Author, year	Gibbons, 2001
Study title	Developing a nurse-led service for COPD patients
Design	Pre-test, post test design Duration of follow up:
Country and setting	UK, single centre, hospital base
Objectives	Describe the development of a nurse led acute respiratory assessment service that reduced hospital admission rates, length of stay and readmission rates, increase patients education, improves continuity of care and achieves cost-effective prescribing.
Participants (All reported if given as intervention group vs control	Sample size: 218 (48% male) Age of study subjects: 703 yrs Severity of COPD in study subjects at recruitment: 76% severe disease as characterised by FEV1 Were the groups similar at baseline regarding the most important prognostic indications? Not applicable

group.)	Study eligibility specified? Yes Inclusion criteria: Uncomplicated exacerbation of COPD-standardised local guidelines were set Exclusion criteria: Adverse clinical signs, disorientated, unstable cardiac status, poor functionality
Interventions	Components of intervention clearly described? Y/N Yes Duration of intervention: ('intensity, frequency, maintenance phase): Intervention Group: 'what they called intervention' a nurse led acute respiratory assessment service (service daily, 9am to 5pm) Description as detailed as possible: Referral; Accepted from GP, accident and emergency, the acute medical admission unit and medical wards. Patients could also self refer once they had used the service. Assessment: Consisted of medical, nursing and clinical examinations. Hospital discharge to scheme: Patients transferred home with a care package which consisted of GP informed, high does inhaled or nebulised therapy, intermittent oxygen, antibiotics, steroids, information leaflets and contact numbers. Home visits: The nurse monitored progress daily for first three days. Thereafter, the frequency varied depending upon the complexity. Drug prescribing protocols enabled nurses to adjust regimens accordingly. Comprehensive home management guidelines based around objective clinical indicators directed decision making, allowing the nurse to select appropriate action. Out-of-hours cover: Not specified. Exacerbation care pathway: where medical assessment or admission was required this could be arranged directly by the nurse. Clinical support to nurses. Medical team. Following discharge patients were encouraged to maintain telephone contact to discuss any problems; Each patient was followed up at 6 weeks in clinic. Comparison Group: usual care/other Not applicable
Outcomes	Were outcome measures well described? In brief Primary endpoint: Length of hospital stay, range of bed days used, readmission rate, day of discharge.
Methods	Statistical methods clearly described? Simple statistics only
Results (Pre test v post test)	Recruitment and follow-up dates given: Yes Numbers analyzed: 218 Primary endpoint: Hospital stay pre test 8 days, post test 3.8 days, range of bed days 3-30 v 0-15, readmission rate 18% v 16%, discharge day 0 0% v 18%.
Reviewers comments	Summary: Pre test post evaluation of a acute respiratory assessment service, found outcomes were 'better' after introduction of service Limitations: Not a randomised controlled trial Level of evidence: 4

Author, year	Nicholson, 2001/undated
Title	Cost comparison of hospital- and home- based treatment models for acute chronic obstructive pulmonary disease/A pilot study comparing substitutable care at home with usual hospital care for acute chronic obstructive pulmonary disease.
Design	RCT-COST COMPARISON ANALYSIS REPORT SEPARATELY BELOW Duration of follow up: reviewed over 10-14 day period
Country and setting	Australia, two centre, hospital based
Objectives clearly described	Y/N: Yes 'To compare the resource use and costs of acute care at home, hospital at home, with inpatient care for acute COPD patients.'/'A subset of patients with acute exacerbations of COPD requiring hospital admission could be managed safely and effectively at home'.
Participants (All reported as intervention group v control group)	Sample size: 13 v 12 (gender distribution not specified) Age: Not specified Severity of COPD in study subjects at recruitment: Patients admitted with acute COPD and identified as requiring admission. Were the groups similar at baseline regarding the most important prognostic indications? Not reported Eligibility specified? Yes Inclusion criteria: Age 45 plus, documented diagnosis of COPD, current or ex smoker, FEV1<60% predicted, admission request by general practice or considered necessary by outpatient staff or ED staff, telephone at home, willing to give informed consent. Exclusion criteria: Unstable co-morbid conditions needing acute medical management, pneumonia on x-ray, hypoxia.
Interventions	Intervention Group: 'Integrated home based care model for acute chronic obstructive pulmonary disease'. Components of intervention clearly described? Y/N; Yes Interventionist: Received care from hospital medical staff in ED and outpatients, own GP, community nursing and Duration of intervention: Average number of nurse's visits was 6, average time spent with each patient was 38 minutes. A total of 15 GP visits, including 3 2nd home visits. 43 allied health professional visits were undertaken. Referral: Not reported, weekday only. Assessment: Not reported. Discharge to home intervention: not reported. Home visits: Patient's GPs was invited to participate in the trial, and the GP reviewed the patient at home between the 2nd and 4th day and to inform the respiratory registrar of the patients' status. The GP scored the HADS and notified the trial co-ordinator if psychology referral was needed. A second visit was at the discretion of the GP. Community nursing visits were mandatory for days 1,2,3 and 7

	and optional for days 4,5,and 6. Liaison with the supervising respiratory registrar was required to suspend care on the optional days. At each visit the nurse clinically assessed the patient, gave general comfort and agreed goals were reviewed. The registrar was update daily. Out-of-hours cover: Out-of-hours-hospital staff provided 24hr telephone support. Exacerbation pathway: 'Hot rescue' referral for trial patients who required re-admission (no details what hot rescue is). Clinical support to nurse: Hospital respiratory team. Additional support services: Patients were referred to community allied health professionals (dietician, occupational therapist, pharmacist, physiotherapist, and psychologist) as needed. All patients were reviewed in the respiratory outpatients clinic around 2 weeks into trial. Comparison Group: Usual hospital care Description: Not reported
Outcomes	Clinical outcomes including oximetry and spirometry, and a six-minute walk test. Quality of life measures including the Seattle Obstructive Lung questionnaire, the Hospital Anxiety and Depression Scale, the Carer Strain Index, Risk screening tool, and the Patient Specific Measure (that allowed patients to identify and measure their own goals). Non validated questionnaire were developed specifically for the project to evaluate health professional and patient satisfaction, items covered were communication and information sharing, collaboration, service delivery and clinician/patient impressions of patient care outcomes.
Methods	Randomisation: No details Statistical methods clearly described? Yes, analysis of variance with pair-wise comparisons subsequently using t-tests and chi – squared tests. Rationale for sample size: Yes Analysis done on intention to treat basis? No
Results (All reported as interventio n group v control group)	(Reported in unpublished paper) Risk of attrition bias: low. Risk of caregiver performance bias: unknown. Risk of detection bias: unknown Recruitment and follow-up dates given: recruitment October 1999 to October 2000. Numbers analyzed: 11 v 11 (3 were readmitted) Baseline comparatibility: No, home care group significantly less anxious and less depressed. Primary endpoints: No figures given for any outcomes. Anxiety-states 'there was a significant decrease in anxiety score in the home care managed group compared with the hospital managed group (p=<0.05)'. Lung function: There was an significant improvement in lung function- (FEV1) in the hospital managed group compared to the home managed group at follow-up (p=<0.05). Length of stay Not significantly different (unclear if this means length of hospital stay). Readmission rates states 'numbers were too small to draw

	statistical conclusions. Patient satisfaction states 'no significant difference' Health professional satisfaction does not reference any statistical testing. Concludes that all health professionals agreed that the model encouraged improved communication and information sharing, collaboration, enhanced delivery and improved care outcomes. 92% of patients in the home group required allied health intervention, result in 43 visits to 12 patients, more patients, ten, required physiotherapy than any of the other services.
Clinical effectiveness reviewers conclusions and comments	Generalisability: 25 patients out of 168 candidates were suitable, 5% declined, reasons not given, Represents 15% of hospital admissions. Summary: Trial reported in two papers; one published the other an unpublished reported assessable via the internet. Small sample size and difficult to judge quality of study as very little information provided on method and results, see economic extraction for further details Level of evidence: 2b-
Key economic elements of study	Economic study type: cost minimisation from the health service provider perspective. Prices for financial year 1999-2000. Modelling: None Link between effectiveness and cost data: Though the abstract links the resource use data with effectiveness data on same patient sample (i.e. improvement in lung function in hospital-managed group at outpatient review; decreased anxiety in the emergency department for the home-managed group and equal patient satisfaction with care delivery) , this effectiveness data is not outlined in the published paper.
Economic analysis	Measure of health benefits: None.. Direct costs: Resources and prices were reported separately: Direct resources: Only health care costs considered: 1) Emergency department (medical, nursing, case manager) 2).Outpatient department (including medical, nursing, administration and clinical co-ordinator) 3) GP costs. 4) Community nursing from three NGOs 5) Rehabilitation teams 6) Recurring costs not related to direct service provision (e.g. advertising, professional development, data management). 7) Clinical service management (i.e. time not related to a specific patient) includes client management/scheduling, in-service/team meetings, resource preparation and service liaison. 8) The telephone contact between the GP and community nurses and the Respiratory Register after each visit. All direct care, including community providers, was funded through

	the National Demonstration Hospitals Program and so could accurately measure any shift in costs from acute to primary providers. Prices were based on: Retrospective apportioning of costs (dollar) -Costs per day were identified for control patients using AR-DRGs (Australian Refined Diagnostic Related Group). -Emergency department costs were collected from individual patients. - Outpatient costs were modelled based on the weighted costs for Australian ambulatory health care (Cleary et al, 1998). Hourly rates - GPS costed at $91 per hour Indirect costs: None considered (note though the authors talk of including indirect costs, the costs that they refer to fall under direct costs in the CRD review). Currency: dollars. No discounting rate was required as the study reported data from one year. Statistical analysis of quantities/costs: None considered Sensitivity analysis: None performed
Results	Estimated benefits used in the economic analysis: An improvement in lung function in hospital-managed group at outpatient review; decreased anxiety in the emergency department for the home-managed group and equal patient satisfaction with care delivery: Costs results: The average costs per episode in control group was $2543 (based 12 observations; with 95% CI 1766-3321). The average costs per episode in intervention group was $745 (based 13 observations; with 95% CI 595-895). When considering the intervention alone, the main costs were community costs at 59% (based on community nursing (28%); community allied health costs (21%) and GPs (10%)) and 41% hospital costs. Synthesis of costs and benefits: none Author's conclusion: Home hospitalisation is less costly
Economist comments	Choice of compactor: Appropriate compactor (as is standard practice) Validity of estimate of effectiveness: The study design seems appropriate to the hypothesis. However, the requirement that there were no co-morbidities limited the recruitment (page 186) and so the sample is very small. No discussion is made of whether the groups were similar at baseline. Validity of estimates of costs: No concern for costs to patients and their carers, arguing that these have been shown to be small in other studies (page 184) comparing home hospitalisation with hospitalisation (Shepperd et al, BMJ 1998). But did collect information on carer strain (though this was not reported), Other issues: -The study is limited in that it only considers public

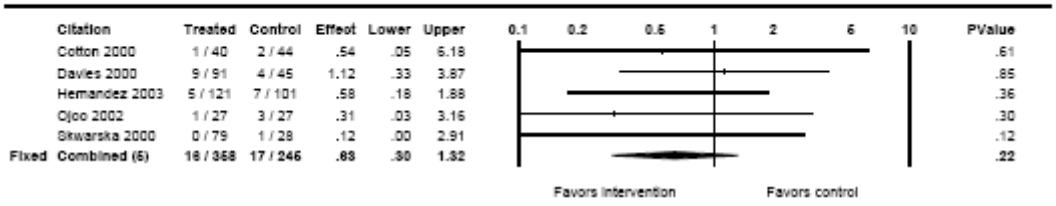
	health care costs. - exclusion of co-morbidities lead to a very small sample

Author, year	Ojoo 2002
Study title	Patients' and carers' preferences in two models of care for acute exacerbations of COPD: results of a randomised controlled trial.
Design	RCT Duration of follow up: 2 weeks
Country and setting	UK, single centre, hospital base
Objectives clearly described	Y/N: Yes 'Acceptability to patients and carers of Hospital at Home scheme
Participants (all reported as intervention group vs. control group)	Sample size: 30 (male:female 16:14) vs. 30 (male:female 15:15) Age: 69.7 vs. 70.1 yrs, Severity of COPD at recruitment (mean (SD)): FEV1 0.85(0.34) vs. 1.0 (0.38), FVC 1.83 (0.80) vs. 1.99 (0.77), symptom score on admission 63.6 (17.8) vs. 63.0 (1.3), total SGRQ score-67.6 (16.3) vs. 67.9 (10.7) Were the groups similar at baseline regarding the most important prognostic indications? Yes Study eligibility specified? Yes Inclusion criteria: COPD patients >18 yrs, FEV1/FVC ratio <70%, FEV1 reversibility to salbutamol <15% (obtained on a previous admission or clinic visit), worsening of symptoms with any combination of increased purulence and/or volume and worsening dyspnoea. Exclusion criteria: Concomitant medical conditions requiring admission, residence over 15 miles from hospital, complications of exacerbation: acidosis, cor pulmonales, and acute changes on chest radiograph, newly diagnosed type 2 respiratory failure, social exclusion was discretionary and depended on level of domiciliary support and performance status of the patient.
Interventions	Intervention 'Hospital at Home' Components of intervention clearly described? Y/N: Yes Duration of intervention: Daily monitoring duration not stated Assessment: of eligibility ran from Monday to Thursday: not stated by whom, reviewed day after admission. Discharge to home: within 48 hours of admission with a discharge package that included nebulised or inhaled bronchodilators, oral and inhaled steroids, antibiotics and oxygen as necessary. Homes visits: The nurses (two in team) monitored the patients daily and gave patient and carer education and reassurance. 24 hour cover: nurses available 9-5 (where they were accessible by phone) outside this time patients could obtain advice from medical chest clinic direct line. Exacerbation care pathway: Not specified. Clinical support: Not specified. Additional support services: Not specified

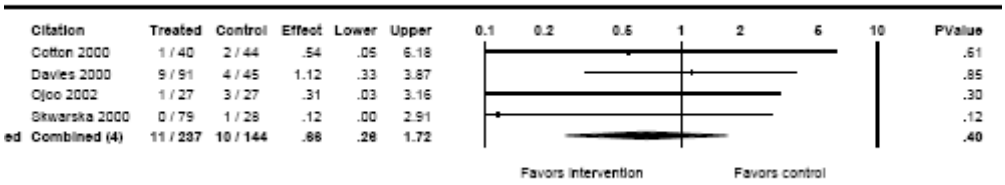
	Comparison Group: Usual care Precise details: Conventional inpatient care according to BTS guidelines, in addition they had twice daily visits by the interventionists to complete daily progress charts.
Outcomes	Were outcome measures well described? Yes Primary endpoint: Retrospective preference of site and satisfaction with care Other endpoints: Efficacy of care
Methods	Recruitment and follow-up dates given: May 1999 to February 2000 Rationale for sample size: No details given Randomisation sequence generation: Not specified, allocation concealment: Sealed envelopes Care giver performance bias risk: Unknown Attrition bias risk: Low for patient outcomes, moderate for carer outcomes. Detection bias risk: Unknown Statistical methods clearly described? Yes- (Fishers exact t test, Mann Whitney, 2 sample t test). Analysis done on intention to treat basis? No
Results (All reported as intervention group vs. control group)	Numbers analyzed: 27 v 27 Preference/satisfaction within 2 weeks of discharge (%): Preferred domiciliary care 26/27 (96.3) vs. 16/27 (59.3) p=0.001, carer preferred domiciliary care 17/20 (85.7) vs. 6/14 (42.9) p=0.01, satisfaction with care 91.7% vs. 88.1% p=ns, carers satisfaction with care 92.7% vs. 91.3% p=ns. Efficacy of care mean (SD) improvement: FEV1 0.16 (0.26) vs. 0.60 (0.27) p=ns. FVC 0.17 (0.55) vs. 0.12 (0.65) p=ns. Symptom score (%) 12.1 (17.3) vs. 11.6 (12.8) p=ns. Mean no of days in care 7.4 vs. 5.9 p=0.14. Mean (range) no of readmissions per patient at 3 months 0.4 (0-2) vs. 0.8 (0-3) p=ns. Readmission rate at 3 months (%) 33.3 vs. 44.4 p=ns. No (%) deaths at 3 months 1 (3.7) vs. 3 (11) p=ns Also looked at: 'There was no association between preferred site of management and age or sex of patient, treatment with maintenance steroids, home nebuliser or oxygen, frequency of admissions in the preceding year, symptom score at admission and whether the patient lived alone or had a partner. Number of patients in trial who presented with an exacerbation : 60/328 (18.3%) participated.

Appendix 7 Mortality and Readmission

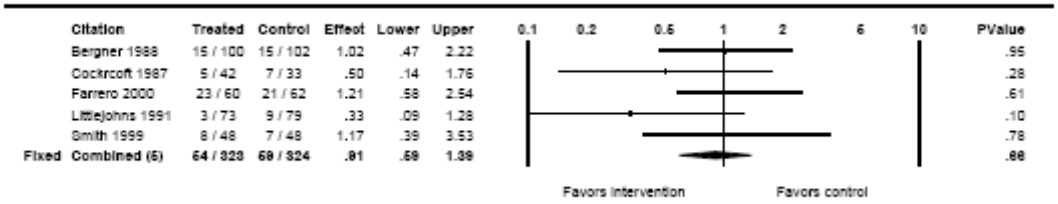
Mortality Acute Interventions (all studies, Peto odds ratio)



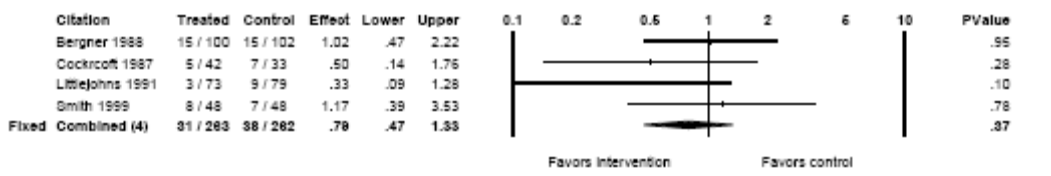
Mortality Acute Interventions (excluding Hernandez 2003, Peto odds ratio)



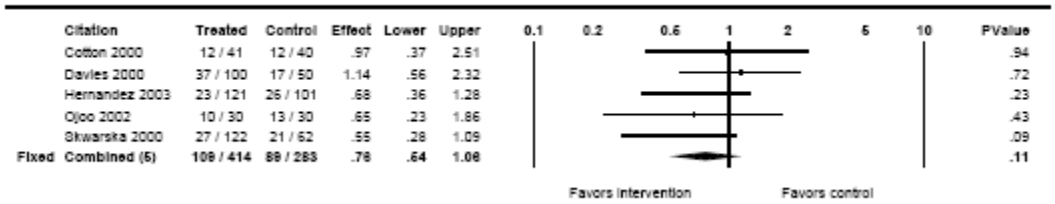
Mortality Chronic Disease Management Interventions (all studies, Peto odds ratio)



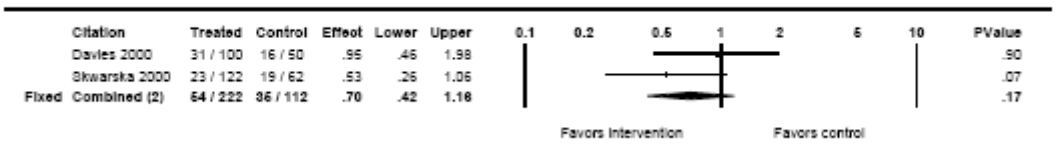
Mortality Chronic Disease Management Interventions (excluding Farrero 2000, Peto odds ratio)



Odds Ratio For Readmission During Follow Up For Acute Interventions (Peto OR)



Odds Ratio For Respiratory Readmission During Follow Up For Acute Interventions (Peto OR)



Appendix 8 Implementation issues: what do evaluative published studies and grey literature tell us about the implementation of nursing innovations for patients with COPD living in the community?

8.1 Introduction

One of the original aims of this project was to examine with what success innovations involving nurses for the care of people with COPD living in the community have been implemented within the NHS. In this appendix we explore what has been reported on implementation issues. By implementation issues we mean factors that may promote or impede the implementation of the innovations reviewed in Chapter 2. Our original hypothesis was that information on implementation issues might be a particular feature of the grey or unpublished literature.

8.2 Objectives

To describe what has been documented about the implementation of innovations involving nurses for the care of people with COPD from the published and grey literature identified in this review.

To determine the strength of the evidence about the implementation of these innovations from the published and grey literature identified in this review.

To identify any gaps in what is known about the implementation of these innovations.

8.3 Methods

Identifying implementation issues

Two researchers (one a respiratory nurse specialist) working independently reviewed all the published and unpublished literature eligible for inclusion in the main review. These included: peer-reviewed articles; published and unpublished grey articles; and Dutch literature identified from the search of the citation data bases for the main review (see chapter 2, for details on retrieval) and from material sent in from responders of our survey of health providers following a call for such literature

about their service (see chapter 3, for details on retrieval). Papers that described factors or arrangements that facilitated the delivery of the intervention, or that mentioned organisational problems during the set up or delivery, were included in this exercise.

Data extraction

Each reviewer documented the type of publication, and the intervention described for each included study. Implementation issues and their location in the text (e.g. in results or discussion sections) were recorded. Implementation issues identified by each reviewer were then compared and any disagreements were resolved by discussion.

Assessing the quality of the evidence on implementation

We aimed to assess, if appropriate, the quality of evidence on implementation in quantitative and qualitative studies as described in Chapter 2. To our knowledge there are no recommended checklists for assessing the quality of descriptive papers. For non-evaluative studies we intended to test the application of a framework, TAPUPAS, developed by the UK Centre for Evidence Based Policy and Practice, Queen Mary, University of London (Pawson, 2003). This framework is intended to be a tool for reflecting on the quality of a paper rather than a checklist for inclusion or exclusion in the review. It has seven main themes: transparency; accuracy; purposivity; utility; propriety; accessibility; and specificity. The TAPUPAS framework is operationalised by a series of questions, including was the knowledge generated open to outside scrutiny; was the knowledge generated by appropriate methods. However we were also aware that evidence relevant to implementation is likely to be documented, even in evaluative trials, in a wide variety of ways that may make assessing its value problematic and contested. Therefore our approach on assessing quality was open to adaption depending on what we retrieved.

Synthesising the evidence on implementation

To provide information on the scope of implementation information provided, the implementation issues arising were considered in relation to the overarching ‘generic’ themes arising from work by Griffith and Bryar (2003). Their themes for the successful development of community nursing practice were drawn from examination of a large number of practice development activities in community nursing and from the practice development literature (see Box 1).

Box 1 Generic themes from lessons learned about developing community nursing practice (Griffiths and Bryar 2003)

Planning
Identification of potential barriers
Identification of resources available
Securing the support of the organisation
Literature review and critique of evidence
Appointment of a facilitator
Use of networking at all stages
Inclusion of all staff from the outset

Other themes:
Team working
Involvement and empowerment of users and carers
Addressing needs of local community
Evaluation
Setting clear goals and outcomes
Preparedness for change stimulated by the service development
Dissemination

8.4 Results

Thirty-five studies were identified that documented information on implementing the intervention. See table 1 for details on studies identified. Most studies eligible for the review, whether they evaluated or simply described a specialist nurse respiratory service, did not document any implementation issues.

Where information on implementation was found

In papers that *did* include information on implementation, the exploration of implementation issues was never stated as an aim of the project, and information was often found in the discussion sections of descriptive or evaluative papers. Generally the information provided was brief. Implementation issues were mostly identified in papers describing innovations for acute exacerbations and commonly concerned facilitation. For the most common type of service found in the reviews survey (see chapter 3), an acute and chronic disease management service, we identified only one paper discussing implementation.

Table 1.1 Proportion of studies documenting implementation issues by type of intervention

Type of intervention in paper	Published in/total	Unpublished in/total
Acute	14/17	10/21
Chronic disease management	7/15	4/13
Specialist service	0/2	0/4
Comprehensive service	1/3	0/0
Total	21	14

Two papers were identified that did not describe or evaluate an intervention but did collect implementation information from health providers. One was a discussion paper describing initiatives that allow nurses to manage exacerbations of COPD at home (Angus 2001). This paper also documented key components of such services, including some that were related to implementation, which had been identified by health professionals at a British Thoracic Society workshop in 1999. The other paper described a telephone interview survey of respiratory consultants in 1999 that aimed to identify service models for acute COPD (Johnson 2001). The interviewers noted some organisational features related to implementation.

Application of the TAPUPAS criteria

We attempted to apply the TAPUPAS criteria to a subset of the descriptive papers, but found that poor reporting of methods made this, or any other, kind of formal appraisal of quality very difficult. Because of this we have included all the papers, regardless of quality.

Limitations of the publications around their discussion of implementation issues

We noted several limitations of the papers with regard to the data they provided on implementation:

None, apart from the paper that documented the workshop on acute services and the survey paper, devoted much space to

implementation issues, and none included implementation as a main focus of their paper or as part of a formal evaluation.

Sometimes, particularly in the grey literature, it was difficult to differentiate whether the issues raised came from the experience of implementation of the service described in the paper or were gathered from elsewhere.

In some of the grey literature published in the nursing journals implementation issues were documented by a journalist, who will have had his/her own objectives for what was included in the article.

Implementation issues identified in clinical trials may not be applicable to the implementation of a service that is not part of a research exercise.

Implementation issues may differ between countries where different medical practices exist and where health services are organised in different ways (see for example Iles and Sautherland, 2001).

Implementation themes

Comparison of themes generated by the two reviewers showed good agreement. Using Griffiths and Bryar's framework they are listed as follows:

Themes from Griffiths and Bryar	Corresponding implementation issues for nurse innovations for COPD from literature reviewed
Planning	Sufficient lead-time to ensure (1) the respiratory team are appropriately trained (2) health service departments and staff are aware of service, particularly those who will refer patients to the service, and (3) standards of practice are finalised and documented
Identifying/ addressing potential barriers	Lack of knowledge and interest by potential refers, particularly GPs, of type of service provision. Health professionals involved in the service need clinical knowledge and expertise in the speciality area. Need for clinical and medico-legal support from clinical respiratory team.

	Involvement of primary and secondary care health professionals, particularly clinical respiratory staff. Reviewing of service to be done jointly by primary and secondary care. Training of team and all involved in service. Protocol development to ensure standardisation of care.
Identification of resources available	None found
Securing organisational support	Support of healthcare management and respiratory and primary care clinical staff to enable the service to be recognised as part of mainstream health services thereby ensuring that it is offered to all eligible patients
Literature review and critique of evidence	None found
Appointment of a facilitator	Full time support members of the team required, such as a co-ordinator or administrator, to provide secretarial support, service co-ordination and assist in communication with liasing departments.
Use of networking at all stages	Communication pathways and good colleagueship developed within the team and with liaising departments including health professionals, support staff, health care managers and social services.
Inclusion of all staff from the outset	None found
Other themes (see box 4.1)	None found

Other issues were also highlighted in the BTS workshop as reported by Angus (2001). These were: that the minimum of two respiratory nurses is required to run an acute service to enable the service to sustain the necessary components of daily assessments and ongoing care at home, and the need for adequate space to accommodate patients, respiratory equipment and office equipment. In the survey by Johnson (2001) several respondents considered other organisation features as important to the service. These included: rapid access to social services when needed and the facility for direct fast-track admission or readmission.

Discussion

Overall we found little information on implementation; many published papers did not provide any information on implementation. Our initial hypothesis that grey or unpublished papers might constitute a rich source of information on implementation proved unfounded. We did not find it practicable to use the TAPUPAS framework on the grey publications in this area. Most of the information on implementation concerned innovations for acute exacerbations, but the paucity of information on how these statements on implementation had been generated in the included papers made it not possible to assess the quality of the evidence for the statements on implementation. Despite this, we did identify several statements relating to implementation - these most commonly related to helping the service become part of main stream health service by ensuring a good communication network is established services (such as sufficient lead time to introduce service and set up communication pathways and by employing support staff), and support of healthcare management and clinical respiratory team (to establish bone fide recognition of service, to provide ease of referrals to and from service and for clinical and medical legal support).

Examination of the themes from the COPD literature in the context of lessons from a wider body of practice development literature (Griffith 2003) demonstrates potential gaps that exist in the literature examined. While some material identified issues to be addressed, for example the need for sufficient time to be allocated to the planning process or the need to identify and address staff training needs, in general this information was patchy. One of the outcomes of the present review of literature on the most effective configuration of community based COPD services might be change within existing services and/or the development of new services so this lack of information on successful implementation strategies is of concern.

Strengths and weakness of this work

We are not aware of any previous published attempts to explore systematically the level of information on implementation provided in evaluative studies, unpublished studies and grey literature around a specific health care innovation. Although data extraction was done by two reviewers working independently, ultimately they had to make subjective decisions about what was, or was not an implementation issue. Similarly, subjective decisions were made when fitting our findings to Griffith and Bryar's themes. We also recognise that reasons why information

on implementation may be lacking include space limitations in published articles. There is also the potential problem that authors may be reluctant to air difficulties because of their personal investment in the success of project, or because the difficulties encountered related to a particular member of staff. While it was difficult to ascertain to what extent the information we gleaned was evidence based, it may still offer policy planners and health providers some useful pointers to facilitate implementation.

The lack of information on the implementation of service development issues is not unique to COPD services. Currently, the National Institute of Clinical Excellence is further developing its research and development strategy and has produced a document that identifies the complexities around the implementation of guidance and putting evidence into practice. (NICE, 2003) It suggests the need for an extensive programme of research to support implementation processes.

In conclusion, implementation 'advice' is an issue that needs to be recognised. It is not enough to know that the innovation 'works'. Researchers and health professionals need to log this information to help others implement similar initiatives. Information is also needed to know how, and in what circumstances it works (Pawson, in preparation). There is currently a deficit of well reported information around the implementation of the nurse innovations for COPD, even where the evidence suggests that innovations are effective.

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Published studies

Published studies identified mentioning implementation issues

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18- Porter-Jones. Running a nurse-led nebulizer clinic in a district general hospital? Implementation issues

19-Schwartzman K, Duquette G, Zaoude M et al. Respiratory day hospital: a novel approach to acute respiratory care. *Canadian Medical Association Journal.* 2001, 165: 1067-1071.

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Un-published

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2-*Author:* Anonymous. *Title:* Acute Respiratory Assessment Service. Pilot study report. *Type of paper:* unpublished report *Date:* undated

3-*Author:* Anonymous. *Title:* No title (describes COPD homecare scheme ran by the Lancaster Rapid Response District Nursing team. *Type of paper:* unpublished report *Date:* undated

4-*Author:* Anonymous. *Title:* Impact: integrated case management in primary and community teams. End of project evaluation report *Type of paper:* unpublished report *Date:* 2002

5-*Author:* Anonymous. *Title:* Haringey COPD service model outline specification and action plan. *Type of paper:* unpublished report *Date:* 1998.

6-*Author:* Anonymous. *Title:* Peterborough Hospital NHS Trust-Acute Respiratory Assessment Service. *Type of paper:* unpublished report. *Date:* 2002

7-*Author*: Barber. *Title*: Can patients referred to hospital with acute exacerbations of COPD be safely treated at home? *Type of paper*: Unpublished summary of a report. *Date*: undated.

8-*Author:* Braterman. *Title:* Integrated care for COPD-North Staffordshire Hospital Trust *Type of paper:* unpublished report *Date:* 2003.

9-*Author:* Crutchley. *Title:* Reduction of hospital re-admissions in COPD. *Type of paper:* unpublished report. *Date:* undated.

11- *Author:* Jones .*Title*: COPD project. *Type of paper:* unpublished paper. *Date:* undated.

12-*Author:* Oakley. *Title:* Respiratory Nurse Specialist Annual Report. *Type of paper:* unpublished article. *Date:* 2002

13-*Author:* Topping. *Title:* COPD homecare. *Type of paper:* unpublished article.

14-*Author:* Wood M, Gosling S. *Title:* COPD Hospital at home service. *Type of paper:* poster and PowerPoint presentation. *Date:* undated.

Appendix 9 Rapid review of other systematic reviews of specialist nurse innovations for patients living in the community with chronic diseases

We compared the findings of this review with the findings of systematic reviews of specialist nurse innovations for patients living in the community with other chronic diseases: congestive heart failure (CHF), Parkinson's disease, renal failure and diabetes mellitus (DM). These were identified in a rapid and pragmatic search for RCTs. The four conditions were selected on the advice of the Nursing Reference Group. The aim was to explore the components of the interventions for these conditions, the outcomes measured and any evidence on their effectiveness, and to compare these findings with those of the COPD review.

Methods

Databases searched

The four databases searched were: CINHAL , the Cochrane database of systematic reviews, DARE, and the Health Technology Assessment (HTA) database. The database search was much less extensive than the one used for the main review because of time limitations. However for CHF we also had access to the extensive literature retrieved during a recently completed Cochrane systematic review of disease management programs for patients with CHF which had been led by one of the reviewers (Taylor, 2003).

Search strategies

The search strategy used for CINHAL was based on the NHS Centre for Research and Development search strategy for systematic reviews (http://www.york.ac.uk/inst/crd/search.htm); the various disease terms used by the appropriate Cochrane Collaboration review groups (the renal group; metabolic and endocrine group; heart group; movement disorders group); and the terms used for specialist nurse innovations that were used in the main review, see Appendix 1, for this search strategy. As the other databases to be screened contained fewer references the search strategy was confined to the specific disease terms.

Eligibility criteria and screening for eligibility

Eligible reviews were SRs of either of the four chronic diseases which concerned nurse led or nurse co-ordinated interventions. One reviewer screened all the titles and abstracts retrieved for eligibility.

Data extraction, quality evaluation and synthesis

Data was abstracted from all the included SRs by one reviewer and checked by a second reviewer, any differences were resolved by discussion. The data abstracted included: the main findings of each SR and an assessment of quality based on the recommendations of the QUORUM statement on criteria for improving the quality of randomised controlled trials (Moher 1999). The findings of the SRs were weighted by our assessment of the quality of the reports using the QUORUM statement and were planned to be synthesised narratively.

Results

Five eligible reviews were identified, see **table 1** for the numbers of studies identified in each database. No systematic reviews were identified for Parkinson's disease or for renal failure. Four potentially eligible reviews were identified for patients with DM and after full text retrieval two remained eligible: one Cochrane SR (Loveman 2004) and one published in a peer review journal (Vrijhoef 2000), this study also reviewed interventions for COPD. No reviews of CHF innovations were identified from the database searches but three relevant SRs were identified from the available literature on CHF (Moser 2001a; Moser 2001b; Stewart 2001), these were all chapters in books on chronic disease management approaches.

The reviews included trials with various modes of delivery of the interventions, from phone support, home visits, clinic visits or discharge planning.

Table 1 Number of studies identified per database

Disease	Cochrane	Dare	HTA	CINHAL
Parkinson	134	25	27	6
Renal OR kidney	663	155	60	81
Diabetes	505	170	87	41
Heart	836	413	191	61

Quality evaluation

On applying the QUORUM statement quality checklist it was found that the review by Loveman provided sufficient details on the methodological process used (2004).

The four other reviews did not report all key methodological processes (Vrijhoef 2000; Moser 2001a; Moser 2001b; Stewart 2001). None provided details on how they data extracted and synthesised the data, not all provided a comprehensive search strategy (Moser 2001a; Moser 2001b; Stewart 2001). Since less reliance could be placed on these SRs because of the under reporting of key methodological processes, we planned to detail the findings of the SR by Loveman only. This SR explored the effectiveness of nurse specialist nurse interventions for patients in the community with Diabetes Mellitus. After indepth data extraction it was found that this SR did not inform the COPD review, in that the interventions evaluated were different and the main outcome measured in all trials were disease specific clinical outcomes, only one measured quality of life.

Data extraction

Table 2 contains data extraction on key characteristics for all SRs included.

Key findings in light of COPD review

In a rapid and pragmatic systematic review there was found an absence of good quality review evidence on the effectiveness for specialist nurse innovations in renal failure, Parkinson's disease and congestive heart failure.

One systematic review on specialist nurse interventions for chronic disease management of diabetes was identified that provided comprehensive details on all methodological process. This review identified five RCTs and one non randomised controlled trial. It found the interventions vary in content and intensity, in one trial the interventions involved telephone support only, in four it involved telephone support with clinic or home visits and in one it involved the addition of a nurse specialist to the primary care team (no details are provided on how the nurse delivers the intervention). Two involved formal educational components, all involved clinical assessments and

advice. The quality of the trial reported was of moderate to high risk of bias. Outcomes evaluated were clinical or related to health service use, one explored quality of life.

In comparison with the COPD review on nurse innovations this review: (1) differed in that not all interventions identified involved nurse home visits or nurse clinic visits; (2) The outcomes assessed, although the review reports main trial outcomes onlyl, were a narrower range than those assessed in the COPD trial. None assessed satisfaction or costs; (3) The effectiveness of the chronic disease management specialist nurse innovations for patients with diabetes also found no overall long-term benefit.

Table 2 Characteristics of reviews of community nurse interventions for diabetes mellitus and chronic heart disease

Author	Loveman 2003
Title	Specialist nurses in Diabetes Mellitus
Objective	To assess the effects of diabetes specialist nurse/nurse case manager in diabetes on the metabolic control of patients with type 1 and type 2 diabetes mellitus.
Search Strategy	Dated searched to 2002 on Medline, CINHAL, EMBASE, BNI, RCN journals database, Health STAR, BIOSIS, PSYCHINFO, Science and Social Sciences Citation Index and NNR. Provided documentation of their search strategy for Medline
Selection criteria	They included only controlled trials on the effects of specialist nurse practitioner on short and long term diabetic outcomes.
Data collection and analysis	Three investigators performed data extraction and quality scoring independently; any discrepancies were resolved by consensus.
Main results	Five RCTs, one CCT (Couper 1999) Two trials on adolescents (Marrero 1995; Couper 1999). Marrero's trial intervention was clinic and telephone based, in Couper's trial the intervention involved monthly home visits and telephone follow-up. Both involved clinical assessments and goal setting, one involved structured education (Couper 1999). Four adult trials (Piette 2000a; Piette 2001; Thompson 1999; Wilson 2001). Piette 2000a and Piette 2001 intervention involved an automated telephone system of structured messages from the nurses and provided system for patient to feedback self care and clinical assessments. Patient given option to participate in interactive self-education. Trials undertaken in different patient groups. In the Thompson trial the intervention involved individualised telephone contact with the diabetes nurse several times a week. The intervention in the Wilson trial involved the addition of a nurse care coordinator to a primary care system (2001). Main outcomes tested: Glycated haemoglobin (HbA1c) used in all trials. Other main outcomes were the number of hypoglycaemic episodes, hyperglycaemic incidents, emergency department visits and hospitalisation. One trial used quality of life (no data was presented in trial). Length of follow-up:Six to 18 months. Methodological quality:The five RCTS could be classified by their quality into moderate risk of bias (Thompson 1999; Piette 2000a; Piette 2001) and two with high risk of bias (Marrero; Wilson 2001). Effectiveness: Due to substantial heterogeneity between

	trials a meta-analysis was not performed. HbA1c was not found to be significantly different between the trial groups. Where reported no differences in emergency department visits or quality of life. In two studies explored hypoglycaemic episodes one found significantly fewer in the intervention group, the other found no difference. Again with hyperglycaemic incidents one trial report a significant fewer hyperglyceamic events in the intervention group, while the other found no significant difference.
Reviewers conclusions	The presence of a diabetes specialist nurse/nurse case manager may improve patients diabetic control over short periods, but from currently available trials the effects over longer periods of time are not evident. There were no significant differences overall in hypoglycaemic episodes, hyperglycaemic incidents or hospital admissions. Quality of life was not shown to be affected by input from a diabetes specialist nurse/nurse case manager.
Our conclusions and commentary	Aims of the review were stated and the inclusion criteria were defined in terms of the interventions, study design and outcomes. Details of the methods used to conduct the review were specified in the text. Several relevant sources were searched. Validity was assessed using defined criteria and only studies that met the minimum quality criteria were eligible for inclusion. Relevant data were extracted and tabulated. Statistical heterogeneity among studies was not statistically assessed, and the influence of study validity on the results was not examined. Information on the design of the individual studies was reported and details of what defined a good quality study. In general the trials identified were of poor quality.
Author	Moser, 2001a
Title	Community case management models (CCM) of heart failure care
Objective	To provide an overview of community case management models and describes one successful heart failure program in detail
Search Strategy	None given
Selection criteria	None given
Data collection and analysis	None given
Main results	Five evaluative studies, 4 RCTs, and one pre-test post test evaluation. (Covers some of the trials reported in

	Stewart 2001). In each of the studies described, the CCM approach produced positive outcomes (gives % only, no statistical test). The patients receiving the intervention experienced significantly fewer total and heart failure rehospitalisations, fewer hospital days when hospitalised, improved quality of life and lower health costs. States generalisability is good but does not discuss other quality features
Reviewers conclusions	Existing evidence suggests that when applied to appropriate high risk patent populations CCM is cost effective. The lack of studies comparing different heart failure health care delivery models makes it impossible to determine at this time whether CCM is more or less effective than other models, such as clinics, multidisciplinary disease management or telephone case management.
Our conclusions and commentary	The aims of the review were stated. No details are given on inclusion criteria or the methods used to conduct. Type of research methodology used for each study described was noted. Data were extracted on patient details, design, program components and outcomes. There are no details of what defined a good quality study, although they do point out that 3/5 of the studies were RCTS and only one was a pre/post intervention with historical controls. The author's conclusions should be interpreted with caution because key methodological processes are not documented.
Author	Moser
Title	Heart failure management: optimal health care delivery programs
Objective	To review the findings from heart failure disease management programs from 1980 to 'present'.
Search Strategy	Studies were identified from search of Medline and Cinhal from 1980 to 1999, using search terms for congestive heart failure with terms for nursing, economics and therapy, disease management, health services research, evaluation studies, patient care planning, treatment outcomes, managed care programmes, risk management, hospitalisation, readmission and multidisciplinary care team. The reference lists of studies reviewed were examined for any additional relevant articles
Selection criteria	All heart failure disease management studies included data on at least one of the following outcomes: 1-Quality of life, 2-Health care resource utilisation, 3-Costs of care, 4-Functional status or 5-Mortality. (Programs described all represent programs in which there is a significant departure from traditional episodic care delivery, in that patients receive additional heart

	failure attention using a disease management approach.)
Data collection and analysis	Disease management programs can be categorised broadly and were described in three categories; 1-Speciality heart failure clinics, 2-Speciality care that extends to home, 3-Increased access to primary care
Main results	1-Speciality heart clinics: 5 studies, only one evaluation was a RCT, all other evaluations were pre-test, post-test designs. Interventions: All involved nurses, 2 were nurse led and 3 involved nurse and doctor clinics. Common components found were 1-comprehensive care (attention to multiple aspects of heart failure care), 2-care under the direction of experienced heart failure cardiologists, 3-care either directed/managed or co-ordinate/assisted by a nurse practitioner or clinical nurse specialist, 4-optimization of medical therapy/and or attention to improving compliance to prescribed medications; and 5-increased patient access to health care providers and vigilant patient follow-up. In three studies patients received instruction on self-management and flexible use of diuretics in response to changes in weight. Effectiveness: Consistent finding that patients who received care in speciality clinics improved outcomes in terms of reduction in number of subsequent hospitalisations, hospital days, improvement in quality of life and functional status. They also note that the care appears cost effective, the increased costs of speciality heart failure clinic care being offset by reductions in rehospitalisation (statistical data not given). 2-Specility care that extends to home: 6 studies, 3 of which were RCTs. Interventions: These interventions were more diverse in components than heart failure clinics. Common components were 1-comprehensive care, 2-care either directed/managed or co-ordinated by a nurse, 3-optimisation of medical therapy and compliance, 4-increased access to health care providers and follow-up Effectiveness: All trials produced positive outcomes. Patients receiving care in these programs experienced significantly fewer total and heart failure rehospitalisations, fewer hospital days when hospitalised, improved quality of life and lower health costs. (statistical data not given). 3-Increased access to primary care: 1 study Intervention: RCT with nurse/doctor involvement. A lack components of other programs types reviewed. Effectiveness: Negative results
Reviewers conclusions	Taken together, these studies offer evidence that it is possible to reduce rehospitalisation rates, costs substantially, improve functional status and quality of life. However there are a number of limitations that must

	be considered when determining their clinical implications and their whole sale adoption into practice. These limitations include the following 1-design and generalizability issues, 2-lack of attention to behaviour change theory in designing programs, 3-disease management programs consisting of multiple components and 4-difficulty in translating findings into practice.
Our conclusions and commentary	The aims of the review were stated and the inclusion criteria were defined in terms of the interventions, study design and outcomes. No details of the methods used to conduct the review were specified in the text. Two relevant sources were searched. Validity was assessed using defined criteria and only studies that met the minimum quality criteria were eligible for inclusion. Relevant data were extracted. The data were synthesised narratively. There are no details of what defined a good quality study. The authors conclusions should be interpreted with caution.
Author	Stewart, 2001
Title	Specialist nurse intervention in chronic heart failure: a critical review
Objective	Critical overview of the evidence supporting the use of specialist nurse-led interventions in the management of heart failure following acute hospitalisation
Search Strategy	Studies between 1988 and 1999
Selection criteria	RCTs on non pharmacological interventions targeting a high proportion of patients with chronic heart failure (CHF) with the aim of reducing hospital use in CHF patients discharged from acute hospital
Data collection and analysis	None given. States scientifically sound (appropriately powered and with complete follow-up) trials
Main results	They report on eight trials and discuss various components of effective and ineffective interventions. Interventions included increased access to primary care nurses and GPs, discharge planning, home based education programme by specialist nurses, nurse led multidisciplinary intervention involving home visits, and clinic based care. One RCT evaluated increased access to primary care nurses and physicians, it found patients had greater number of readmissions but had greater patient satisfaction. Two trials were inconclusive, one on discharge planning and the other on home based educational programmes. Five trials were found to have positive results: in the first, a nurse home visit education and support scheme the intervention had beneficial

	effects on readmission, quality of life and cost of care, in the second and third trial a clinic based intervention found patients in the intervention were event free longer. The fourth and fifth the home based intervention was found to have positive outcomes on health care utilisation.
Reviewers conclusions	Specialist nurse-led interventions in heart failure, especially when incorporating an inter-disciplinary approach and home visits, are particularly effective in improving health outcomes among heart failure patients.
Our conclusions and commentary	The aims of the review were stated in brief and the inclusion criteria were defined in terms of the interventions, and study design. No details on the search strategy, data extraction or quality assessment of trials. The data were combined narratively. Information on the design of the individual studies was lacking. There are no details of what defined a good quality study other than that they were all RCTs. Hence, the authors conclusions should be interpreted with caution

Author	Vrijhoef, 2000
Title	Effects on quality of care for patients with type 2 diabetes or COPD when the specialised nurse has a central role: A literature review.
Objective	Explores the effects of models of care for patients with diabetes type 2 or COPD in which the specialised nurse has a central role. Two questions: 1-which outcomes are identified in publications about the effectiveness and efficiency of these models, and 2-are these models of care effective and efficient.
Search Strategy	Medline express searched for published studies between 1966 and January 1999. Details on the search strategy used were: the term 'nurse' combined with 'effectiveness outcome(s)' terms for clinical or randomised controlled trials of Dutch or English language papers on adult patients with diabetes type 2 or COPD. Papers were excluded if the intervention did not deal with nursing care as its main component.
Selection criteria	Dutch or English language papers, RCT or CCT, adult patients with diabetes type 2 or COPD, and intervention had to deal with nursing care as its main aspect.
Data collection and analysis	Main features identified, and related to 'expected' effects, statistically significant effects and four main task areas. These tasks were identified from preliminary work by researchers undertaking a nurse intervention, these were 'direct patient care' (clinical assessment and clinical advice), 'organisation and coordination of care for individual patient' (activities relating to continuity of care), 'consultation' and 'promotion of expertise' (education).
Main results	Ten trials were identified: six on COPD; two mixed illness; and two on diabetes. All interventions consisted of the nurse as the main healthcare provider. Trials were located in primary and secondary care. Type of interventions: All intervention dealt with chronic care but service location differed: primary care, outpatient, inpatient and combination of inpatient and outpatient. Components of the interventions were single task (promotion of expertise), or expertise plus consultation or expertise plus organisation and co-ordination. Outcomes: cites common outcomes as survival, clinical parameters, quality of life, self-care and knowledge, patient satisfaction, medical consumption. Quality of life measured in a standardised and validated way. Self care and patient satisfaction not always assessed using validated measurements. In all studies statistical effects found in at least one outcome and overall outcomes were

	mixed. Found most often were improvements in self care, 4/10 studies, and quality of life, 3/10 studies and an increase in medical consumption in intervention group 4/10 studies. No effect results are reported, but states 'no relation seems to exist between the length of the intervention or the frequency of planned contacts and the number of significant effects found'.
Reviewers conclusions	Interventions for patients with DM or COPD in which the nurse fulfils a central role do not seem to affect clinical parameters as often as expected. (expected indicated by the trialist choice of these outcomes). The authors also conclude: promotion of expertise improves self care, organisation and coordination of care by nurse affects medical consumption, and direct patient care improves quality of life.
Our conclusions and commentary	The aims of the review were stated and the inclusion criteria were defined in terms of the interventions, study design and outcomes. Some details of the methods used to conduct the review were specified in the text. One relevant source was searched. Validity was assessed using defined criteria and only studies that met the minimum quality criteria were eligible for inclusion. Relevant data were extracted. The data were combined narratively. Information detailing methodological features of the individual studies was lacking. There are no details of what defined a good quality trial. The author's conclusions should be interpreted with caution because key methodological processes are not documented.

Moher D, Cook DJ, Eastwoood S, Olkin I, Rennie D, Stroup DF, for the QUOROM Group. Improving the quality of meta-analyses of randomised controlled trials: the QUORUM statement. The Lancet, 1999: 354; 1896-1900.

Appendix 10 Breathe Easy consultation sheet

Barts and The London
Queen Mary's School of Medicine and Dentistry

RESPIRATORY NURSE SERVICES FOR PATIENTS WITH CHRONIC LUNG DISEASE: A PROJECT TO FIND OUT WHERE THESE SERVICES ARE AND IF THEY WORK

This information sheet is being delivered to over 1000 members of Breathe Easy. It summarises the initial findings of a research study that we introduced earlier this year to your Breathe Easy group. This information sheet also offers you the opportunity to give us your views on the findings, so that we can make our report even more useful to people with chronic lung disease.

Is this relevant to me?

Yes. It gives the initial findings of a project on specialist respiratory nurse services for patients in the community with Chronic Obstructive Pulmonary Disease (COPD), the overall name for a number of lung conditions that include chronic bronchitis and emphysema. While the project is specifically on COPD, many specialist respiratory nurses care for patients with a wide range of respiratory diseases whose care is often similar. These findings, therefore, are relevant to all patients with chronic lung disease.

Who usually treats patients with COPD?

Once diagnosed, the management of patients with COPD is generally undertaken within a GP surgery. Those with moderate/severe COPD may also be under the care of a respiratory hospital consultant, and any patients with a sudden severe increase in symptoms (an acute attack) of COPD may be treated in hospital.

New types of care

New types of care in the community for patients with COPD are being developed, and are often led by specialist respiratory nurses who have had additional training in respiratory care. The services they provide can be divided into those that care for a patient whose COPD is relatively stable, and those that care for patients who experience an acute attack of COPD. They usually include a clinic and/or regular home visiting.

How can these services help patients?

Specialist Respiratory Nurses can help doctors and nurses in general practice choose the best treatment for their patients. They can also help ensure that patients manage their disease as well as possible. Some nurse schemes use regular home visiting to support patients when they have an acute attack of COPD, enabling them to stay in their own homes rather than be admitted to hospital. Others have been set up to help patients return home earlier from hospital following an attack of COPD.

Why haven't we got a service, or a full service here?

There are likely to be several reasons why local health care managers have not developed a service:

These services have not been fully tested to establish whether they work.

The NHS does not require them to be provided everywhere.

There may be no health professionals in the area with the necessary skills.

About the project presented here

The project is being carried out by a group of doctors, nurses, researchers and a lay person. It is based at Queen Mary, University of London, and is funded by the NHS.

The main questions the team asked are:

What nurse services are there and where are they?

Do these services work?

What we would like you to do

After you have read the summary of our initial findings we would like you to comment on the findings as to whether these services work. For this purpose we enclose a yellow sheet with 3 questions for you to answer. We also enclose a Freepost envelope for you to return your answers to us.

Why do we want you to help?

Patients have a great deal of useful knowledge to offer health service researchers and planners. While you may not yet have any care from a specialist respiratory nurse, the number of services is growing. Your views can help ensure that these services are as well designed and helpful to patients as possible. You do not need to have COPD to contribute. Specialist

respiratory nurses care for a range of chronic lung disease (including asthma).

Will I find out the result of consulting Breathe Easy members?

We hope to have the opportunity to feedback a summary of the report in future Breathe Easy newsletters.

Will I find out what the NHS does with the report?

No, but this report will add to the growing pressure on the government to recognise the need for national recommendations for COPD services. The report should also help any new local services that are just being set up to be more effective.

FINDINGS SO FAR…
Where are the services?

We found 239 specialist respiratory nurse services in England and Wales. Below and on the next page are maps which show where they are located (each dot on the maps represents a service). As you can see, they are scattered.

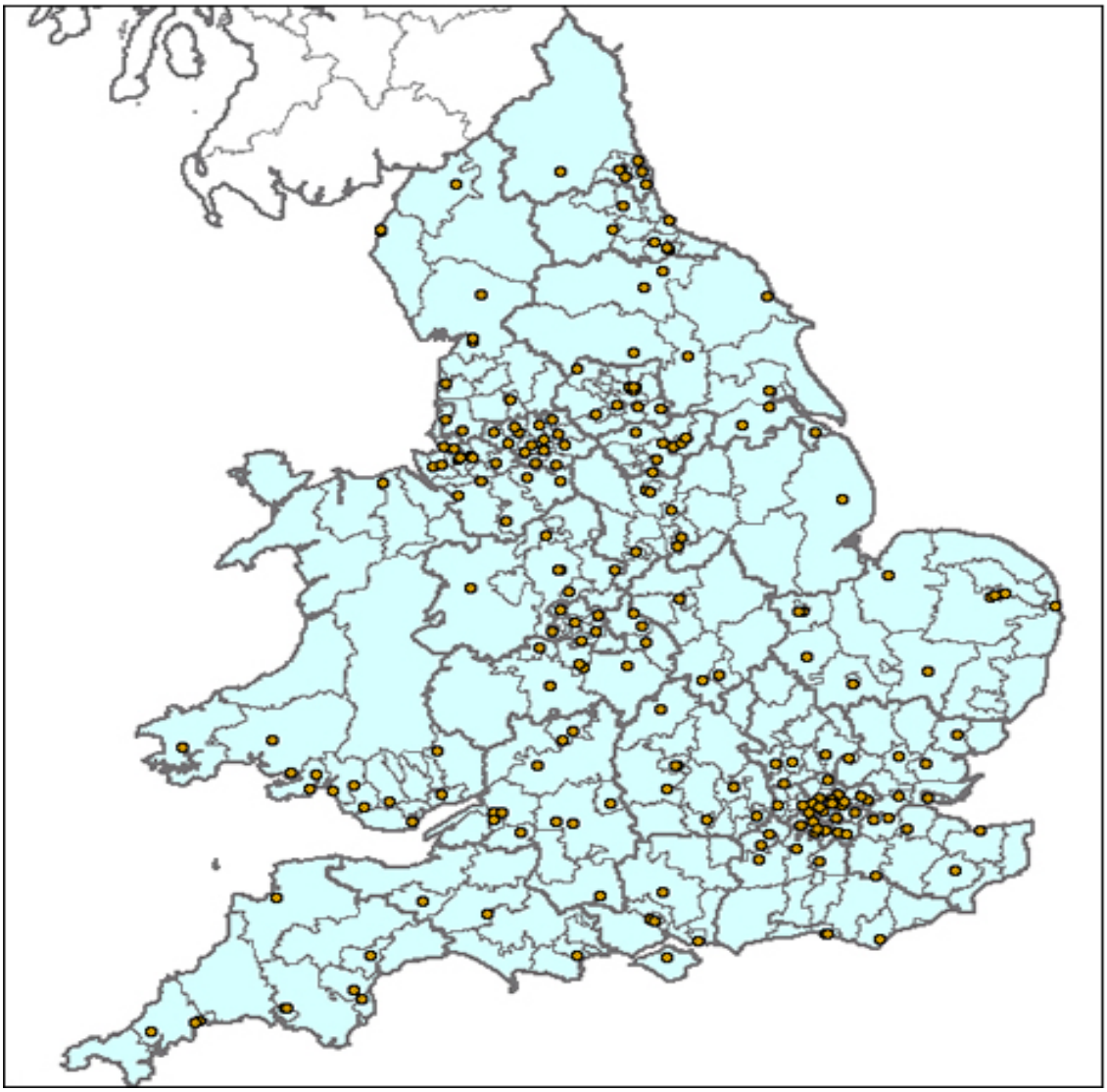
What do the services do?

Around two thirds (69%) of the services involve nurses visiting patients in the stable phase of COPD in their homes to provide advice, assessment and education.

Half (52%) of these services also involve support for patients at home during or following an acute attack of COPD.

Two thirds (60%) of all services include pulmonary rehabilitation services.

Map 1 Location of specialist nurse services for patients in the community with COPD



Have these services been tested to see if they work?

Yes, and 11 studies have used the best type of study design to test whether a service works. This is a randomised controlled trial.

We report the findings here of the randomised controlled trials on:

1-Nurse services for patients in the community with stable COPD.

2-Nurse services in the community for patients with an acute attack of COPD.

How do the studies test if these services work?

The studies examine the 'outcome' of providing the services. Most studies have looked at the number of hospital admissions after the patient had received the service. Some looked at whether lung function improved, and a few looked at whether the service improved a patient's quality of life and whether the patient was satisfied with the service.

Please note

We have looked at the quality of these studies and we believe that all the studies reported below have limitations that could affect their findings (for example some studies were very small).

Finding 1: What are the results of studies that looked at nurse home visits to patients in the stable phase of COPD?

We found 6 studies.

Overall the findings suggest that for the outcomes tested:

It is very unclear whether these services benefit the patient (the results of the studies differ).

See Table 1 for details of what they tested; please note none of the studies tested all outcomes listed.

Finding 2: What are the results that looked at nurse schemes to treat patients at home who have an uncomplicated acute attack of COPD?

We found 5 studies.

Overall the findings suggest that for the outcomes tested:

A quarter of patients (those with an uncomplicated attack) who experienced an attack of COPD could be safely treated at home.

See Table 2 for details on what they tested; please note none of the studies tested all outcomes listed.

How we would like you to give us your views

We would like you to give us your views on the yellow form enclosed with this information sheet or via the Breathe Easy member link on our website at: http://www.smd.qmul.ac.uk/gp/copdreview/copdreview.html. Either way, we would like you to answer three questions, as well as using the opportunity to tell us your general views on services for chronic lung disease.

Please note that all comments are anonymous; we do not ask for your name.

If you write your comments on the enclosed form, please return to: Bridget Candy, Research Officer, Centre for General Practice and Primary Care, Institute of Health Sciences, Medical Sciences Building, Mile End Road, London, E1 4NS. If you have any queries please contact Bridget on 020 7882 7944.

Table 1 Studies of services for patients with 'stable' COPD

Outcomes tested for:
Patient's and carer's quality of life
Lung function
Survival
Health service use
Patient being anxious or depressed
Patient's knowledge of disease
Cost
Patient satisfaction with care
GP and nurse satisfaction with care

Table 2 Studies on services for patients with an attack of COPD

Outcomes tested for:
Patient's quality of life
Patient's and carer's satisfaction with care
Lung function
Survival
Health service use
Patient's knowledge of disease
Patient self-management of COPD
Cost
GP satisfaction with care
Patient's and carer's preference of care

Appendix 11 Breathe Easy member consultation comments form

Name of Breathe Easy Branch:

Our questions to you:

Overall, the study results suggest to us that (A) it is unclear that specialist nurse services to patients in the community with stable COPD can benefit, and that (B) some patients with an attack of COPD can be treated as well at home as in hospital

1- Is this sort of research important to you?

……
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……..

2- Are the researchers, in the studies we found, testing for the right sorts of thing?

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……..

3-Should decisions on whether or not to provide services be based on this sort of evidence, or should decisions be based on, or take into account other things?

……
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……

If you need more space please use additional pages. Please also use additional pages to provide us with any other comments you may have on services for chronic lung disease. If you have any queries in answering these questions please call Bridget Candy on 020 7882 7944 or b.candy@qmul.ac.uk

Please return this form to: Bridget Candy, Research Officer, Centre for General Practice and Primary Care, Institute of Community Health Sciences, Medical Sciences Building, Mile End Road, London, E1 4NS either by post or email: b.candy@qmul.ac.uk

Thank for your time

Appendix 12 Provider consultation feedback form

We would be very grateful for your comments on this preliminary report. Your feedback will be incorporated into our final report and will help to shape it.

Please indicate what type of health professional you are (*tick box*):

Respiratory nurse consultant or specialist ☐ Respiratory consultant physician ☐ Practice nurse ☐

General practitioner ☐ Other nurse ☐ Other doctor ☐ Manager primary care ☐

Manager secondary care ☐

Other (*please specify*)…….

Please indicate whether or not you agree with the following statements by ticking the appropriate boxes:

1. Summarising the research evidence around nurse innovations for COPD in this way is important.

Strongly agree ☐ Agree ☐ No opinion/unsure ☐ Disagree ☐Strongly disagree☐

Comments:……
……
……
……
……
……
……
……

2. I was surprised by the findings or the survey and/or the preliminary summary of published evidence.

Strongly agree ☐ Agree ☐ No opinion/unsure ☐ Disagree ☐Strongly disagree☐

Comments:……
……

……
……
……
……
……
……

3. The researchers involved in the *individual* studies included in this report looked at the right sort of outcomes.

Strongly agree ☐ Agree ☐ No opinion/unsure ☐ Disagree ☐ Strongly disagree ☐

Comments:……
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3. I concur with the recommendations in this preliminary report.

Strongly agree ☐ Agree ☐ No opinion/unsure ☐ Disagree ☐ Strongly disagree ☐

Comments:……
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4. Decisions on whether or not to provide services should be based on this sort of evidence.

Strongly agree ☐ Agree ☐ No opinion/unsure ☐ Disagree ☐ Strongly disagree ☐

Comments:……………………………………………………………………………………
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If you have any queries regarding this feedback form please call Bridget Candy on 020 7882 7944.

Thank for your time

Appendix 13 Profession of respondents to provider feedback on interim report

Profession of respondents
Nurse consultant/specialist n=25
Practice nurse n=10
Other nurse n=11
Respiratory consultant n=4
GP n=8
Other doctor n=1
Primary care manager n=5

Appendix 14 First survey questionnaire and supporting letters

Letter (double sided, frequently asked questions on back):

Dear Nursing Colleague,

Re: Part One - Extended systematic review of specialist nursing innovations for patients with COPD

We have been funded by the NHS Service Delivery and Organisation research programme to do an 'extended' systematic review of innovations involving nurses for patients with chronic obstructive pulmonary disease (COPD) living in the community.

This project will bring together the evidence from different types of published research, audit studies and 'grey' literature (literature which has not been published in a journal or otherwise widely disseminated). We will consult users, carers and health care professionals about our preliminary findings and recommendations and build their feedback into the final report (due in early 2004).

We are also mapping the current provision of specialist nursing services for patients with COPD living in the community in England and Wales to go with our report. Further details of the project are given on the reverse of this letter.

We are writing to ask you to complete the enclosed one page questionnaire for two reasons:

To identify the contact details for any existing specialist nurses/specialist nursing services for COPD patients in the community in your locality.

To find out if you want to comment on our preliminary findings and recommendations (which will be circulated in early autumn 2003). These comments will then be fed into our final report, which has the potential to change policy on the provision of such services.

We would be most grateful if you could answer the following questions and return this sheet to us in the prepaid envelope. Please return the questionnaire by 14th April 2003.

Thank you very much for your help.

Yours sincerely,

Project officer Project lead

Frequently Asked Questions

Q. Who is involved in this research?

A. The research is being carried out by a group of researchers from Barts and the London School of Medicine and Dentistry, Queen Mary, University of London and St Bartholomew's School of Nursing and Midwifery, City University. The steering group includes a lay member with a users' and carers' perspective.

Q. What do you mean by 'nursing innovations'?

A. By innovations involving nurses we mean those services targeted at patients living in the community which are principally delivered by nurses, or which are led, or co-ordinated, by nurses and which are not universally available throughout the UK at present.

Q. Can you tell me more about the funding body, the NHS' Service Delivery and Organisation programme?

A. The SDO is one of the major NHS funding streams for research and development, further details of their remit and work can be found on their website: www.sdo.lshtm.ac.uk

Q. Does this study have ethical approval?

A. Yes, the study has been approved by the London Multiple Research Ethics Committee (MREC) (insert the MREC approval reference when MREC approval gained)

Q. Will I be able to have a copy of the final report from the study?

A. The final report will be sent to the funding body (the SDO) in early 2004. All those who contribute to the consultation on the

final report will be sent an executive summary. Details of the dissemination of the final report have yet to be finalised, and indeed there may be more than one version of this report to cater for different audiences. Ultimately we aim to have an electronic version of the full report available on the web.

Q. How can I find out more about this project?

A. Please contact us at the address overleaf or email Dr Stephanie Taylor: s.j.c.taylor@qmul.ac.uk

Q. Can I have an electronic copy of the questionnaire?

A. Yes, please email Linda Stephenson – Project Administrator: l.m.stephenson@qmul.ac.uk

First questionnaire:

Chronic obstructive pulmonary disease (COPD) Review Questionnaire

Your title and name:……...
……

Job title/ role:…… Phone no:……
Fax no:……..Email:……...
Your work address:…..……
……
……
……

Q1. Do you organise or provide a specialist nurse service for patients living in the community with COPD?
No □ Please go to Q2.
Yes □ Who would be the best person for us to contact for a description of this service?
Please contact me □ or Please contact:……....
Address:……
……
……
Phone no: (if known) ……Their email: (if known)……..……

Q2. Is there a specialist nurse service (not organised by you) in your area for patients living in the community with COPD?
No □
Yes □ ⟨ if Yes, please provide contact details
Name of contact person for service: (if known)……
Address:……..……..……..……..……..……
……
……
Phone no: (if known) ……Their email: (if known)……..……

Q3. In your area, is there any other special service for patients living in the community with COPD which is led by physiotherapists or respiratory technicians?

No □

Yes □

Q4. Would you be interested in commenting on the preliminary findings and recommendations of this review in Autumn 2003?

No □

Yes □ \ Please let us know how you would prefer us to contact you:

Letter □, Email □, Other……

Please return this questionnaire in the reply paid envelope enclosed by 14th April 2003 or send to: Bridget Candy Project Officer, COPD review, Department of General Practice and Primary Care, Medical Sciences Building, Queen Mary, University of London, Mile End Road, London E1 4NS.

Appendix 15 Second survey questionnaire and supporting letter

Letter (double sided, frequently asked questions on back):

Dear 'insert name'

Re: PART 2 - Extended systematic review of specialist nursing innovations for patients with COPD

We have been funded by the NHS Service Delivery and Organisation research programme to do an 'extended' systematic review of innovations involving nurses for patients with chronic obstructive pulmonary disease (COPD) living in the community. (*Further details of the project are given on the reverse of this letter.)*

This project will bring together the evidence from different types of published research, audit studies and 'grey' literature (literature which has not been published in a journal or otherwise widely disseminated). We will consult users, carers and health care professionals about our preliminary findings and recommendations and build their feedback into the final report (due in early 2004).

The report will also include a map of the current provision of specialist nursing services for patients with COPD living in the community in England and Wales. We understand that you are involved in the delivery of such a service and we are writing to ask you for some further details about your service.

We would be most grateful if you could spare the time to complete the attached questionnaire. If you do not feel you are the appropriate person to complete this questionnaire could you

please pass it on to the colleague whom you believe is the most appropriate person. (The questionnaire has been designed to be as quick and easy to complete as possible.)

The questionnaire includes a question inviting you to comment on our preliminary report which will be circulated in September 2003. In addition all respondents will, of course, be sent an executive summary of our final report in early 2004.

Please return the questionnaire by the end of May 2003.

We apologise if you have all ready received this letter and the enclosed pink questionnaire.

Thank you very much for your time and help.

Yours sincerely,

Bridget Candy
Project officer

Stephanie Taylor
Project lead

Frequently Asked Questions

Q. Who is involved in this research?

A. The research is being carried out by a group of researchers from Barts and The London School of Medicine and Dentistry, Queen Mary, University of London and St Bartholomew's School of Nursing and Midwifery, City University. The steering group includes a lay member with a users' and carers' perspective.

Q. What do you mean by 'nursing innovations'?

A. By innovations involving nurses we mean those services targeted at patients living in the community which are principally delivered by nurses, or which are led, or co-ordinated, by nurses and which are not universally available throughout the UK at present.

Q. Can you tell me more about the funding body, the NHS Service Delivery and Organisation (SDO) programme?

A. The SDO is one of the major NHS funding streams for research and development, further details of their remit and work can be found on their website: www.sdo.lshtm.ac.uk

Q. Does this study have ethical approval?

A. Yes, the study has been approved by the London Multicentre Research Ethics Committee (approval reference number MREC/03/2/011)

Q. Will I be able to have a copy of the final report from the study?

A. The final report will be sent to the funding body (the SDO) in early 2004. All those who contribute to the consultation on the final report will be sent an executive summary. Details of the dissemination of the final report have yet to be finalised, and indeed there may be more than one version of this report to cater for different audiences. Ultimately we aim to have an electronic version of the full report available on the web.

Q. How can I find out more about this project?

A. By visiting our website http://www.smd.qmul.ac.uk/gp/copdreview/copdreview.html or contacting us at the address overleaf or emailing Bridget Candy (Research Officer) b.candy@qmul.ac.uk or Dr Stephanie Taylor s.j.c.taylor@qmul.ac.uk

Q. Can I have an electronic copy of the questionnaire?

A. Yes, please email Linda Stephenson – Project Administrator: **l.m.stephenson@qmul.ac.uk**

Second Questionnaire:

Extended systematic review of specialist nursing innovations for patients with COPD

Your title and name……

Job title/role…… ….

Phone no…….

Fax no……

Email……

Your work address……...

……
……

Name of your Service
……

These questions are about your specialist nursing services for patients with COPD living in the community.

Q1 How long has your specialist nurse COPD service been established? ……Years

Q2 Where is your specialist nurse COPD service **based?** *Please tick one ✔*

- In primary care only ☐
- In secondary care or tertiary care (ie hospital clinics) ☐
- In both primary and secondary care or tertiary care ☐
- Other *(Please describe)* ☐……

Q3 Is your service funded from *Please tick ✔all that apply*

- Recurrent monies from secondary care ☐
- Recurrent monies from Primary Care Trusts ☐
- One-off/special project funding ☐
- Charitable monies ☐

Other *(Please state)* □……

Q4 How many 'Whole Time Equivalent' specialist nurses does your service for COPD patients employ? ……

Do these specialist nurses look after patients with a wide variety of respiratory conditions in addition to those patients with COPD? *Please tick ✔* **Yes** □ **No** □

If **'Yes'**, approximately what % their of time is allocated to COPD? ……

Q5 How are patients referred to your specialist nurse COPD service? *Please tick ✔all that apply*

By secondary care staff □

By primary care staff □

Self-referral □

By other means *(Please state)* □……

Q6 Are there any eligibility criteria for COPD patients referred to your specialist nurse service? *Please tick ✔all that apply*

Patients must live in a specific geographic area **Yes** □ **No** □

Patients must belong to a specific Primary Care Organisation/s **Yes** □ **No** □

Patients must attend a specific secondary care hospital/s **Yes** □ **No** □

Patients must have COPD of a certain degree of severity **Yes** □ **No** □

If **Yes,** please expand……..

Adult patients of any age are eligible for the service **Yes** □ **No** □

If **No,** what is the age cut off point:……..

Other criteria not listed above **Yes** □ **No** □

If **Yes,** please expand……

Q7 Please describe the nature of your specialist nurse service for COPD patients living in the community.

EITHER by ticking all the descriptions that describe your service from the provisional typology we have developed of possible components of these services (and describe below any components of your service not covered in this typology).

See opposite page

OR ALTERNATIVELY you may wish to write your own description of your services. **(*please continue on a separate sheet if needed)***

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Description of possible components of your service: *Please ✔tick box for all components that describe your service*	**This column describes a service where the patients mainly (or exclusively) have COPD** ↓	**This column describes a service for patients with a mixture of respiratory conditions, some whom have COPD** ↓
Respiratory nurse specialist/s care for patients in their own homes.	☐	☐
Respiratory nurse specialist/s led or respiratory nurse specialist-run	☐	☐

outpatient clinics.		
Respiratory nurse specialist/s led or respiratory nurse specialist-run clinics in general practice.	□	□
Outpatients clinics which include respiratory nurse specialists (but which are not led by them).	□	□
Respiratory nurse specialist/s-led discharge planning programmes or initiatives.	□	□
Respiratory nurse specialist/s with an on-going 'caseload' of patients living in the community.	□	□
A respiratory nurse specialist/s-led or nurse run 'hospital at home scheme' to facilitate the early discharge of patients following admission to secondary care.	□	□
A respiratory nurse specialist/s-led or nurse run 'hospital at home scheme' to avoid the admission to secondary care of patients with an acute exacerbation of their respiratory condition.	□	□
Respiratory nurse specialist/s who provide or are involved in a formal pulmonary rehabilitation service for patients.	□	□
Respiratory nurse specialist/s who provide a formal smoking cessation service for patients.	□	□
Respiratory nurse specialist/s led or co-ordinated self-help groups for patients.	□	□
Respiratory nurse specialist/s provide specific psychological intervention/s for patients e.g. anxiety management programmes.	□	□
Respiratory nurse specialist/s-led diagnostic service to identify patients (e.g. spirometry, reversibility test).	□	□
Respiratory nurse specialist/s provide on-going follow up of domiciliary long term oxygen therapy (LTOT)	□	□
Respiratory nurse specialist/s-led education service for Primary Care Professionals	□	□

Please turn over the page →

Q8 Does your specialist nurse service have a framework or philosophy of care or a set of explicit aims and objectives?

Please tick ✔
Yes □ **No** □

If '**Yes',** please attach any relevant documents if possible

Q9 Please could you indicate whether your specialist nurse service for COPD patients in the community has been the subject of any of the following:

Please tick ✔

Peer reviewed journal publications **Yes** □ **No** □

If '**Yes',** please send us a copy or supply a reference if possible:
……

Conference/meeting/forum abstracts arising from poster presentations or/ and oral presentation. **Yes** □ **No** □

If '**Yes',** please send us a copy or supply a reference if possible:
……

Unpublished audit reports* **Yes** □ **No** □

Unpublished evaluations* **Yes** □ **No** □

Unpublished patient/ carer/ health professional satisfaction studies/ reports* **Yes** □ **No** □

Other unpublished studies/ reports*. *Please describe*
……
……
……
……

**We may contact you to see if we could obtain a copy*

Q10 Are you aware of any other unpublished studies or reports on specialist nurse innovations for COPD patients in your locality or any other area. If Yes, please supply details. **Yes** □ **No** □
……
……
……

Q11 In Autumn 2003 would you be interested in commenting on the

Please tick ✔ box
No □

preliminary findings and recommendations of this review?

Yes □ \ Please let us know how you would prefer us to contact you:

Letter □ Email □ Other □.....

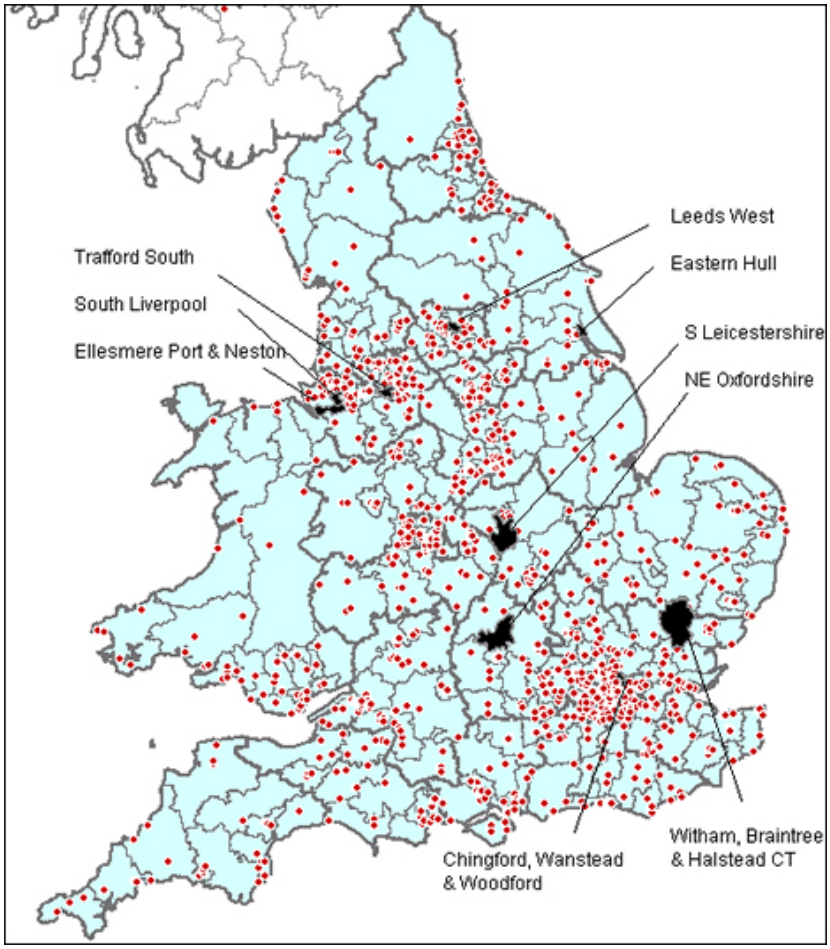
.....

Please return this questionnaire in the reply paid envelope enclosed by the end of May 2003 or send to: Bridget Candy, Project Officer, COPD Review, Department of General Practice and Primary Care, Medical Sciences Building, Queen Mary, University of London, Mile End Road, London E1 4NS. Telephone No 020 7882 7944

*********THANK YOU FOR YOUR ASSISTANCE**********

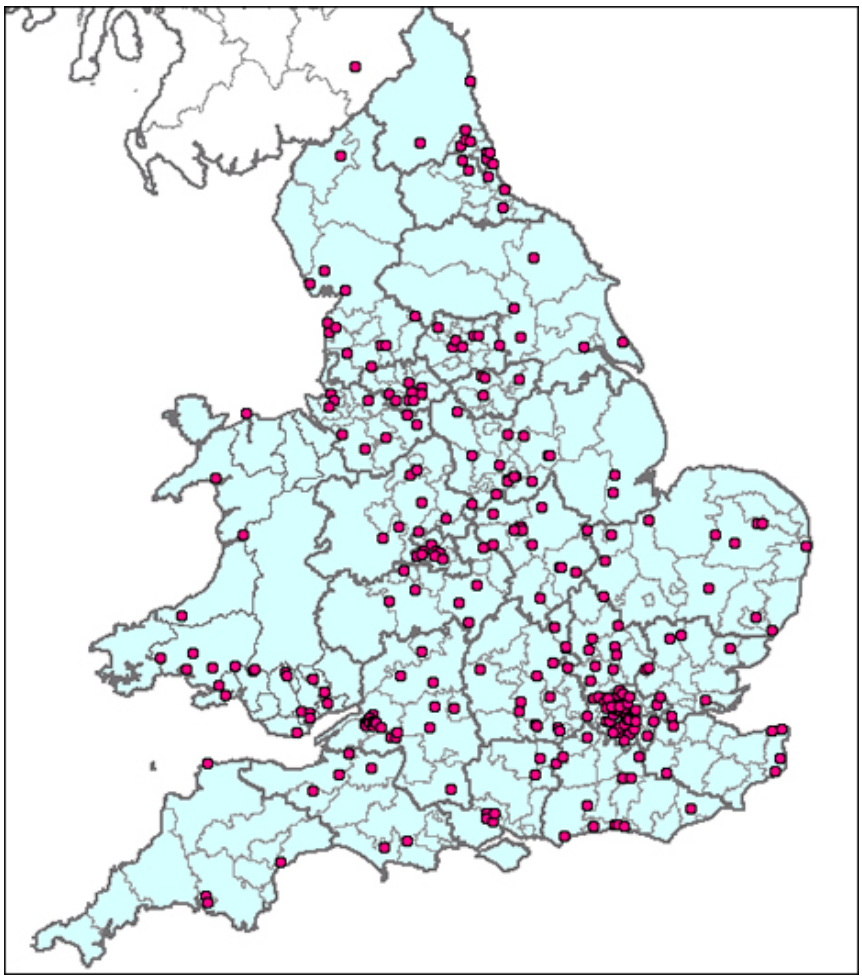
Appendix 16 Map of response to first survey by PCT boundary

Dots represent the location of a responder (many dots are clustered together). Black areas are PCT where no one in the survey responded.

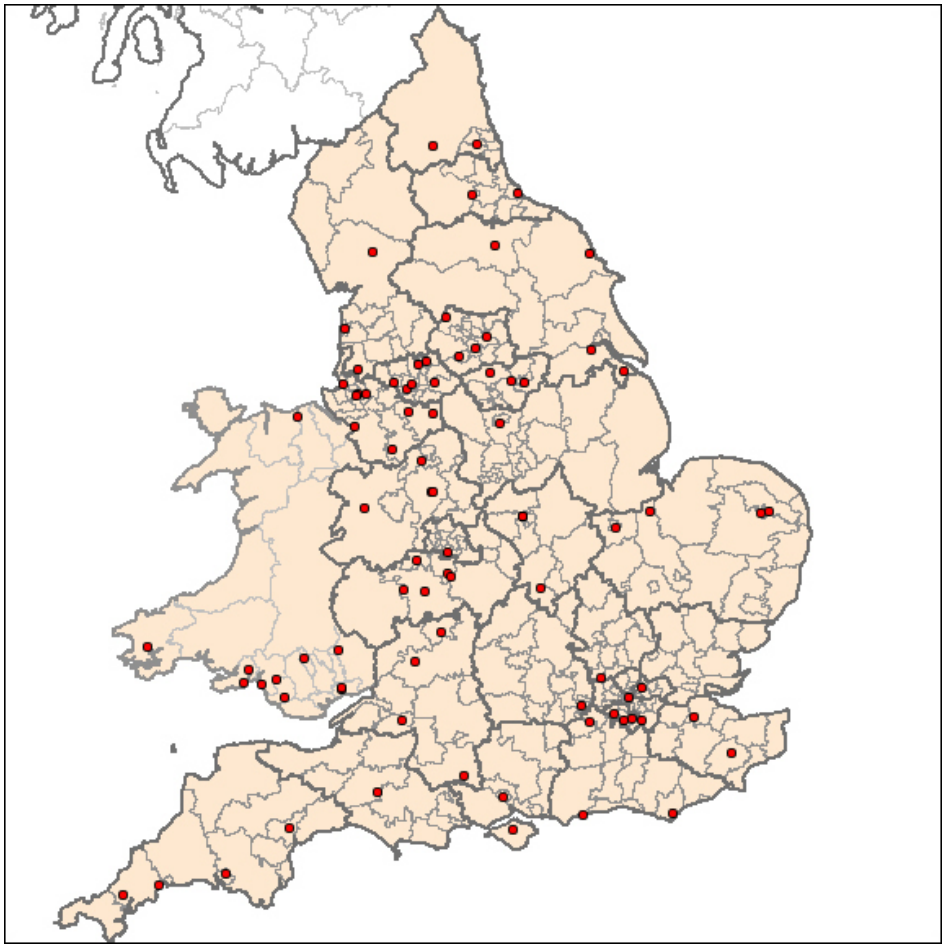


Appendix 17 Physiotherapy and respiratory technician services

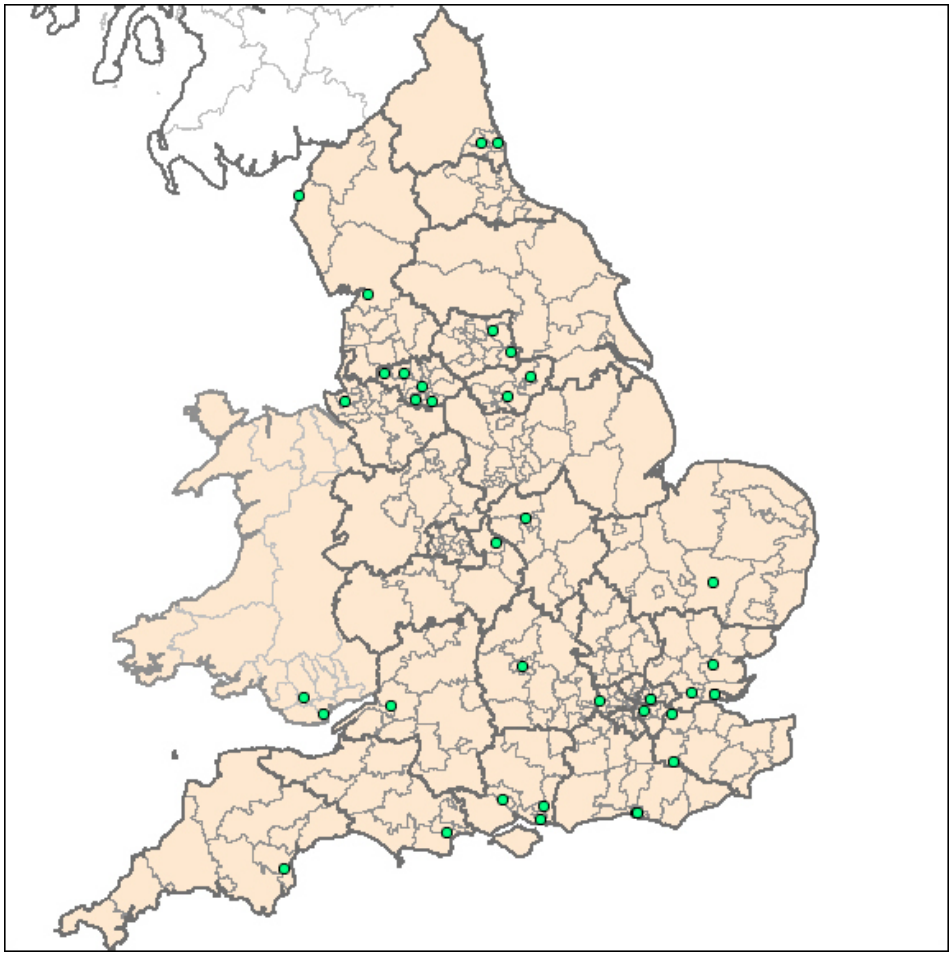
Each dot represents location of respondent who identified a local physiotherapy or respiratory technician service.



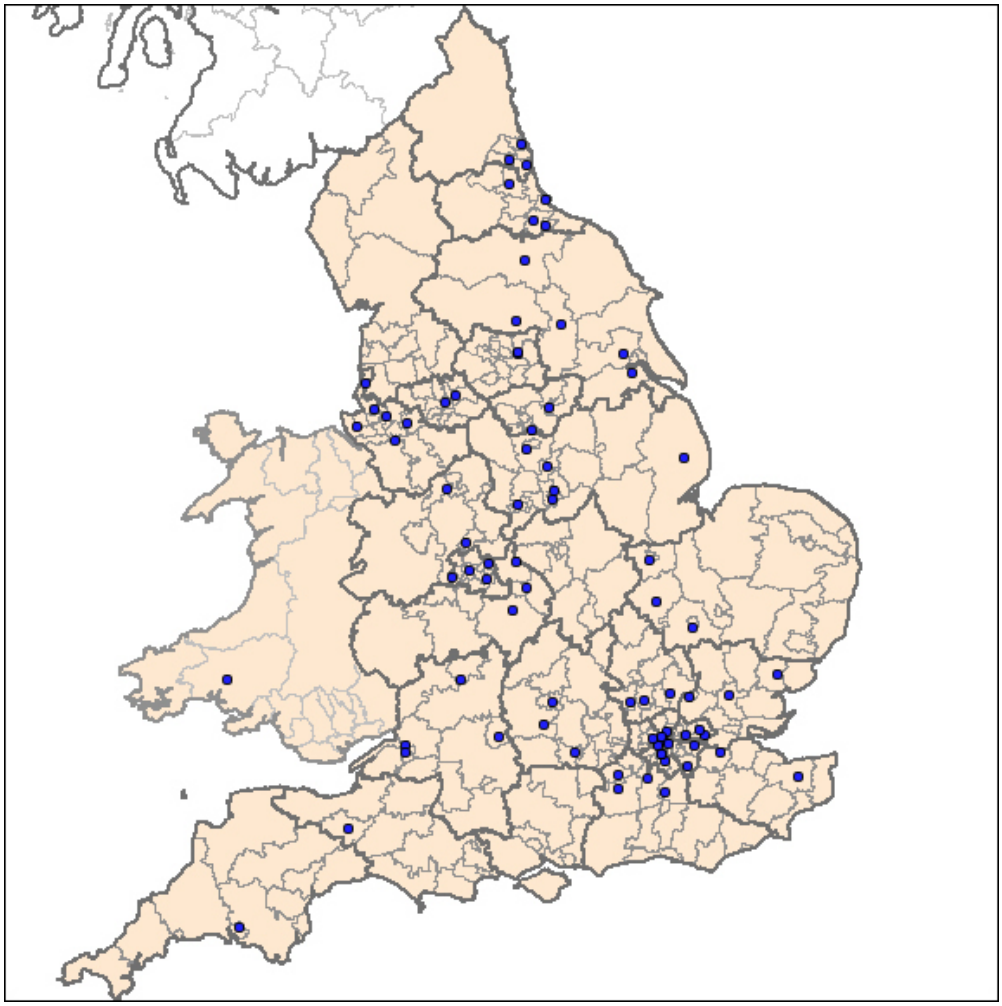
Appendix 18 Map of location of COPD nurse community chronic disease management services



Appendix 19 Map of location of nurse services for an acute exacerbation of COPD



Appendix 20 Location of COPD nurse community acute care and chronic case management services



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Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.

Addendum:

This report was amended on 3rd October 2011 to update the correct copyright statement and/or correct the publication date. The content of the report has not been changed.