Factors that facilitate the implementation of interventions to reduce preventable hospital admissions with a focus on cardiovascular or respiratory conditions: an evidence map and realist synthesis

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Abstract

Background: In 2012 a series of systematic reviews summarised the evidence regarding interventions to reduce preventable hospital admissions. While intervention effects were dependent on context, the reviews revealed a consistent picture of reduction across different interventions targeting cardiovascular and respiratory conditions. We sought to provide an in-depth understanding of how interventions that have been shown to reduce admissions for these conditions may work with a view to supporting their effective implementation in practice.

Objectives: To map the available evidence on interventions used in the UK NHS to reduce preventable admissions for cardiovascular and respiratory conditions and to perform a realist synthesis of implementation evidence related to these interventions.

Methods: For the mapping review, we searched six databases for studies published between 2010 and October 2017. Studies were included if they were conducted in the UK, USA, Canada, Australia or New Zealand; recruited adults with a cardiovascular or respiratory condition; and evaluated or described an intervention that could reduce preventable admissions or readmissions. We produced a descriptive summary of key characteristics of the included studies.

The studies included in the mapping review helped to inform the sampling frame for the subsequent realist synthesis. We also engaged with the wider evidence base through supplementary searching. Data extraction forms were developed using appropriate frameworks (an implementation framework, intervention template and realist logic template). Following identification of initial programme theories (from the theoretical literature, empirical studies and insights from the PPI group) the review team extracted data into evidence tables. Programme theories were examined against the individual intervention types and collectively as a set. The resultant hypotheses functioned as synthesised statements around which we developed an explanatory narrative referenced to the underpinning evidence base. Additional searches for mid-range and overarching theories were performed using Google Scholar.
Results: A total of 569 publications were included in the mapping review. The largest group originated from the USA. The included studies from the UK showed a similar distribution to that of the map as a whole but there was evidence of some country-specific features such as the prominence of studies of telehealth.

In the realist synthesis, we found that interventions with strong evidence of effectiveness overall had not necessarily demonstrated effectiveness in UK settings. This can be a barrier to using these interventions in the NHS. Facilitation of the implementation of interventions was often not reported or inadequately reported. Many of the interventions were diverse in the way they were delivered. There was also considerable overlap between interventions. The role of specialist nurses was highlighted in several studies. The five programme theories identified were supported to varying degrees by empirical literature but all provided valuable insights.

Limitations: The research was conducted by a small team and time and resources limited our ability to consult with a full range of stakeholders.

Conclusions: Overall, implementation appears to be favoured by support for self-management by patients and their families/carers; support for services that signpost patients to consider alternatives to seeing their GP when appropriate; recognition of possible reasons why patients seek admission; support for health professionals to diagnose and refer patients appropriately; and support for workforce roles that promote continuity of care and coordination between services.

Future work: Research should focus on understanding discrepancies between national and international evidence and the transferability of findings between different contexts; design and evaluation of implementation strategies informed by theories about how the intervention being implemented might work; and qualitative research on decision-making around hospital referrals and admissions.
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**List of abbreviations**
ACSC  Ambulatory care sensitive condition
CCG  Clinical Commissioning Group
CCM  Chronic care model
CHD  Coronary heart disease
CR  Cardiac rehabilitation
COPD  Chronic obstructive pulmonary disease
HCP  Health care professional
HS&DR  Health Services & Delivery Research
MDT  Multi-disciplinary team
NACR  National Audit of Cardiac Rehabilitation
NHRPP  Northumberland High-Risk Patient Programme
NHS  National Health Service
NIHR  National Institute for Health Research
NRCT  Non-randomised controlled trial
PAAP  Personal asthma action plan
PARIHS    Promoting Action on Research Implementation in Health Services
PPI      Patient and public involvement
PRISMA   Preferred reporting items for systematic reviews and meta-analyses
PT       Programme theory
RCT      Randomised controlled trial
TIDIER   Template for Intervention Description and Replication
Plain English summary

Unnecessary admissions to hospital are damaging for patients and expensive for the health service. Different methods (interventions) have been recommended to make sure patients are looked after as well as possible to reduce unnecessary admissions. These include helping people to manage their condition themselves, having a named health professional to coordinate a patient’s care, electronic communication between patients and health professionals and using exercise programmes to help patients recover after a spell in hospital.

The aim of this research was to use a review of published research literature to improve our understanding of what makes these interventions work more or less well. We looked at interventions used to help patients with heart or lung problems. We started by making a map of the interventions that are used by the NHS to help manage these conditions and the research supporting the effectiveness of each. We then investigated factors that may contribute to these interventions being successfully used in the NHS.

We found that interventions recommended after considering all relevant research may not be supported by evidence that they work well in the UK. This can be a barrier to using these interventions in the NHS. Our research suggests that programmes to reduce unnecessary hospital admissions can be best supported by:

- Support for self-management by patients and their families/carers, including ability to recognise when they need to seek further help
- Support for services that signpost patients to consider using less familiar services when appropriate rather than treating GP appointments as the default option
• Recognition of reasons why patients may seek admission, for example the need for security and reassurance

• Support for GPs and other health professionals to diagnose and refer patients appropriately and with confidence.

• Support for workforce roles, commonly filled by specialist nurses, that promote continuity of care and co-ordination between services.

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Scientific summary

Background
Admissions to hospital increasingly contribute to pressure on health system resources internationally. In the UK National Health Service (NHS), changes to commissioning arrangements have increased the focus and drive to reduce hospital admissions. Despite this, overall emergency admissions continue to increase each year, increasing by 9.3% from 2013-14 to 2016-17. In 2016-17, there were 5.8 million emergency admissions, up by 2.1% on the previous year, and 24% of these were admissions that NHS England considers could be avoidable. The number of bed days used by people admitted in an emergency admission increased from 32.41 million in 2013-14 to 33.59 million in 2016-17. This is a 3.6% increase, which is less than the 9.3% increase in emergency admissions during the same period. The National Audit Office calculated that the real terms cost of emergency admissions increased by 2.2% since 2013-14, from £13.4bn to £13.7bn in 2015-16. This situation poses a significant challenge to health services delivery.

Unplanned hospital admission rates vary between geographical areas from 90 to 139 per 1,000 population and variation in emergency admission rates is even higher. The existence of such variation across the NHS indicates that there is potential to reduce hospital admission rates. The way in which emergency admissions are recorded also varies between institutions and this makes it more difficult to get an accurate picture of the current situation.
Interest in reducing admissions focuses in particular on a group of ambulatory care sensitive conditions (ACSCs), defined as those for which hospital admission could be prevented with care delivered in the primary care setting. These include asthma, chronic obstructive pulmonary disease (COPD), diabetes, epilepsy, hypertensive disease, dementia and heart failure.

In 2012 a series of systematic reviews by Purdy et al summarised the evidence regarding interventions that had exhibited success in reducing unplanned hospital admissions. In terms of services to reduce admissions Purdy and colleagues found evidence of effectiveness for education, self-management, exercise and rehabilitation, and telehealth in certain patient populations, mainly respiratory and cardiovascular. Specialist heart failure services and end-of-life care were also reported to reduce these admissions. However, case management, specialist clinics (other than for heart failure), care pathways and guidelines, medication reviews, vaccine programmes and hospital at home did not appear to reduce preventable admissions. The reviews found insufficient evidence on the role of combinations or coordinated system wide care services, emergency department interventions, continuity of care, home visits or pay-by-performance schemes.

Thus, while the pattern of findings was mixed, Purdy’s systematic reviews revealed a consistent picture of reduction across different interventions targeting two particular types of condition, namely cardiovascular and respiratory conditions. For this interpretative review the NIHR HS&DR programme asked us to consider these as “proven interventions” and seek to provide an in-depth understanding of how interventions that have been shown to reduce admissions for cardiovascular and respiratory conditions work in practice.

**Objectives**

The aim of this research is to fill a gap in the evidence base around successful implementation of admission reduction programmes by focusing on understanding what works for whom, why and in what contexts. We first investigated interventions that are currently used within the NHS to manage cardiovascular or respiratory conditions using a
systematic mapping approach. We then used a realist approach to identify and explain factors that contribute to successful implementation of interventions to reduce preventable hospital admissions, looking at responses to interventions that involve different mechanisms and different contexts.

Methods
The overall review comprised two main phases:

(i) Systematic mapping of cardiorespiratory intervention studies for reducing preventable admissions
(ii) Realist review of implementation evidence

The overall review commenced with the decision, agreed with the NIHR Programme Team, to focus exploration on those conditions revealed by the 2010 Purdy review to demonstrate effective interventions to prevent inappropriate hospital admissions. Consistently a positive effect or positive indication was found for cardiorespiratory conditions and this was a focus for systematic mapping of studies.

Based on these included studies four complementary activities were conducted:

(i) Generation of IF-THEN-LEADING TO statements from a conceptually rich set of empirical studies and theoretical papers and selection of candidate programme theories;
(ii) Analysis of Implementation studies to identify intervention components using an abbreviated version of the TIDieR checklist;
(iii) Analysis of Implementation Studies using the PARIHS Framework
(iv) Comparison of PARIHS Templates with shortlisted programme theories.

Mapping review
For the mapping review, we searched six databases for studies published between 2010 and October 2017. Studies were included if they were conducted in the UK, USA, Canada, Australia or New Zealand; recruited adults with a cardiovascular or respiratory condition; and evaluated or described an intervention that could reduce preventable admissions or readmissions. We produced a descriptive summary of key characteristics of the body of

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included studies. Summary tables were developed using the search, cross-tabulation and reporting functions of EPPI-Reviewer 4.

**Realist synthesis**

The studies included in the mapping review helped to inform the sampling frame for the subsequent realist synthesis. We also engaged with the wider evidence base (using supplementary searches) through systematic reviews, opinion pieces and direct reference to individual study reports, particularly where authors themselves establish a connection to the UK context. We developed explicit inclusion criteria for our sampling frame to ensure consistent study selection by the review team across the different intervention types. Purpose-designed data extraction forms were designed using appropriate frameworks as structures by which to interrogate the theoretical literature and the empirical evidence.

In summary, data extraction comprised use of:

(1) an implementation framework, PARIHS, as a structure for examining how interventions are delivered;

(2) an intervention template, TIDieR-Lite, as a format for describing intervention components; and

(3) a realist logic template, IF-THEN-LEADING TO, to elicit programme theory on how interventions might work.

The initial programme theories were tested from the theoretical literature, empirical studies and, insights from the PPI group. Programme theories were examined against the individual intervention types and collectively as a set. Following identification of the initial programme theories the review team extracted data into evidence tables. The resultant hypotheses functioned as synthesised statements around which we developed an explanatory narrative referenced to the underpinning evidence base. Additional searches for mid-range and overarching theories were performed using Google Scholar.
Our EPPI-Reviewer map, reference management database and accompanying data extraction spreadsheets collectively offer a comprehensive evidence base relevant to interventions to reduce unplanned hospital admissions.

Results

Mapping review
A total of 569 publications were included in the mapping review. Unsurprisingly, the interventions identified by Purdy et al. as having the best evidence of effectiveness (or no effect) were well represented in the map. The largest group of studies originated from the USA and differences between healthcare systems mean that care should be taken in extrapolating the results of such studies to the UK setting. The included studies from the UK showed a similar distribution of studies by intervention and population to that of the map as a whole but there was evidence of some country-specific features such as the prominence of studies of telehealth. The studies coded for the mapping review and stored in EPPI-Reviewer 4 represented a broad sampling frame for use in the accompanying realist synthesis.

Realist synthesis

Implementation framework
Within the PARIHS framework, successful implementation is represented as a function of the nature and type of evidence (to be examined from the mapping review), the qualities of the context in which the evidence is being introduced, and the way the process is facilitated (to be extracted from included UK studies, both quantitative and qualitative). We found that interventions with strong evidence of effectiveness overall had not necessarily demonstrated effectiveness in UK settings; that the large majority of the evidence came from the USA, where the context for delivery of healthcare is very different from that of the UK; and that facilitation of the implementation of interventions was often not reported or inadequately reported in UK studies, which generally focused mainly on effectiveness or qualitative evidence of patient and health professional experience of service delivery.
Descriptive framework
The TIDieR-Lite framework provided a useful descriptive framework for recording key elements of the interventions and their delivery. Many of the included interventions were highly diverse in the way they were delivered, the main exceptions being cardiac and pulmonary rehabilitation. There was also considerable overlap between interventions in terms of their key components. The role of specialist nurses in providing continuity of care and links between primary and secondary care was highlighted in multiple studies.

Programme theories
We identified five programme theories to explain why interventions might work to reduce avoidable hospital admissions (see box).

Box A – Programme theory components

| People with chronic conditions are frequently admitted to hospital when hospital is not the optimal destination for them. They may have symptoms that could be self-managed or anxieties that could be addressed by patient education or information [PT1]. |
| People with chronic conditions lack knowledge about alternative health provision and therefore draw disproportionately upon well-signposted channels such as their GP or the emergency department [PT2]. Alternatively, patients perceive that presentation to an emergency department holds relative advantage (e.g. quality, ease of access, response etc.) over GP-based or other primary or community care services [PT2]. Patients pressure health professionals to admit them to hospital. |
| Health professionals lack confidence in their own diagnoses or may lack confidence in, or knowledge of, alternative sources of healthcare provision and so may refer people with chronic conditions or admit them direct to hospital. Health professionals feel under pressure to admit people with chronic conditions directly to hospital [PT3]. |
People with chronic conditions use health services inappropriately; delaying their presentation to health professionals or hospital [PT4] because of perceptions of the service either anticipated or based on the past experience of either themselves or others.

GPs and other health professionals are influenced by the wider context of the healthcare system and the availability or otherwise of support and incentives may influence their adoption of interventions and pathways designed to avoid preventable referrals and admissions to hospital [PT5].

The programme theories, expressed as scenarios, were refined and endorsed by our public involvement group. We found evidence to support programme theory PT1, which suggests that hospital admissions could be reduced by optimal self-management. Considering PT2, we did not find substantive evidence to suggest that patients may seek hospital admission primarily on the basis of relative advantage. It seems that concerns associated with anxiety and risk may constitute a more important driver, hospitals being seen as safe places that can offer security and reassurance. However, the presence of perceived, implicit or indirect pressure cannot be ruled out. Programme theory PT3 relates to clinicians’ confidence in their own diagnoses and ability to refer appropriately to services that might avoid admission. In the context of cardiovascular and respiratory disease, this is relevant to patients with symptoms such as breathlessness that could result from various underlying causes. Supporting evidence for PT3 was found in studies of heart failure services.

Direct evidence for PT4 (admissions resulting from patient delay in seeking treatment) was limited in our sample of studies. Finally, PT5 (influence of the broader health system context) addressed the limitations on rational decision-making around hospital admissions. This was reflected in our studies. For example, heart failure care delivered across multiple services, confusion about eligibility for specialist care and relational/managerial discontinuity of care increased the likelihood of suboptimal management and unplanned admissions.

Mid-range and overarching theories
In addition to the programme theories, we found numerous examples (both descriptive and empirical studies) of mid-range theories relevant to the interventions under review. The largest group focused on the patient, for example factors influencing adherence to recommended interventions, but theories related to health professionals’ behaviour and the overall health system were also located. Some theories were cited in relation to several interventions (for example, Bandura’s self-efficacy theory) but it is unclear whether this reflects their greater utility or simply their higher profile and more pervasive influence in the literature. The overarching theories may be considered as more exploratory than the programme and mid-range theories.

Conclusions
Avoidable hospital admissions for chronic cardiovascular and respiratory conditions are common and costly for both the health service and the patient/family involved. Systematic reviews have identified interventions with strong evidence of effectiveness in reducing avoidable admissions. However, the synthesised evidence may not be supported by evidence of effectiveness in a specific setting or how best to implement the intervention in routine practice. Our mapping review and supplementary searching indicated that this was the case for some interventions widely recommended and employed in the UK health system. The subsequent realist data extraction and synthesis used diverse frameworks and levels of theory to examine how interventions might work and factors that support or hinder their implementation. The TIDieR-Lite framework proved useful in characterising interventions and indicated that interventions with different names often contain the same or overlapping components. The programme theories we developed from the literature were supported to varying degrees by empirical evidence but all provided valuable insights.

Overall, implementation of interventions to reduce avoidable admissions for cardiovascular and respiratory conditions appears to be favoured by:

- Support for self-management by patients and their families/carers, including ability to recognise when they need to seek further help
- Support for services that signpost patients to consider using less familiar services when appropriate rather than treating GP appointment/referral as the default option
- Recognition of possible drivers leading patients to seek admission, for example the need for security and reassurance at a difficult time
- Support for GPs and other health professionals to diagnose and refer patients appropriately and with confidence. This includes creation of a supportive background context and set of incentives in the health system
- Support for workforce roles, commonly filled by specialist nurses, that promote continuity of care and co-ordination between different services across primary, secondary and community care.

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Chapter 1: Background

Admissions to hospital increasingly contribute to pressure on health system resources internationally. In the UK National Health Service (NHS), changes to commissioning arrangements have increased the focus and drive to reduce hospital admissions. In 2016-17, there were 5.8 million emergency admissions to hospitals, costing approximately £13.7 billion. This situation poses a significant challenge to health services delivery. Contributing factors to health service pressures include the high, rising unit costs of unplanned hospital admission compared to other forms of care, increasing admissions of older people and the disruption emergency admissions cause to elective health care, most notably in-patient waiting lists, and to the individuals admitted.

Unplanned hospital admission rates vary between geographical areas from 90 to 139 per 1,000 population and variation in emergency admission rates is even higher. The existence of such variation across the NHS indicates that there is potential to reduce hospital admission rates. The way in which emergency admissions are recorded also varies between institutions and this makes it more difficult to get an accurate picture of the current situation.

Interest in reducing admissions focuses in particular on a group of ambulatory care sensitive conditions (ACSCs), defined as those for which hospital admission could be prevented with care delivered in the primary care setting. These include asthma, chronic obstructive pulmonary disease (COPD), diabetes, epilepsy, hypertensive disease, dementia and heart failure.

The terminology in this field is complex. Terms such as unplanned admissions, inappropriate admissions, unnecessary admissions, preventable admissions and avoidable admissions are...
widely used but not always in a consistent way. Unplanned admissions may be defined as admissions or readmissions involving an overnight stay in hospital that were not previously planned or defined as ‘elective’\textsuperscript{1}. The term avoidable admissions is often used to refer to admissions via emergency departments which could potentially be avoided through interventions in the urgent and emergency care system. The focus of this evidence synthesis project is on preventable admissions, defined as those for ACSCs and other long-term conditions that could potentially be prevented by provision of appropriate care and services in primary care and community settings. However, the two categories are not completely mutually exclusive and some interventions to reduce preventable admissions or readmissions may be delivered in pre-hospital, emergency department or other hospital settings.

Over more than a decade the NHS has explored community, population and policy level interventions aimed at reducing preventable hospital admissions but these have had little impact on admission rates\textsuperscript{2}. In 2012 a series of systematic reviews by Purdy et al summarised the evidence regarding interventions that had exhibited success in reducing unplanned hospital admissions\textsuperscript{1}. In terms of services to reduce admissions Purdy and colleagues found evidence of effectiveness for education, self-management, exercise and rehabilitation, and telehealth in certain patient populations, mainly respiratory and cardiovascular\textsuperscript{1}. Case management, community interventions and specialist clinics showed effectiveness for heart failure only. However, case management and specialist clinics overall, care pathways and guidelines, medication reviews, vaccine programmes and hospital at home did not appear to reduce preventable admissions. The reviews found insufficient evidence on the role of combinations or coordinated system wide care services, emergency department interventions, continuity of care, home visits or pay-by-performance schemes\textsuperscript{1}.

Thus, while the pattern of findings was mixed, Purdy’s systematic reviews revealed a consistent picture of reduction across different interventions targeting two particular types of condition, namely cardiovascular and respiratory conditions\textsuperscript{1}, some of the interventions being disease-specific. By way of comparison one of the quality measures for accountable care
organisations under the US Affordable Care Act is to reduce preventable emergency admissions for three chronic medical conditions: COPD, congestive heart failure, and asthma\(^6\). For this interpretative review the NIHR HS&DR programme asked us to consider these as “proven interventions” and seek to provide an in-depth understanding of how interventions that have been shown to reduce admissions for cardiovascular and respiratory conditions work in practice. This will include both (i) how the interventions work to reduce unplanned admissions and (ii) how they seek to ensure that admissions that are avoided are, in fact, unnecessary. The intention is also to identify some potentially transferable lessons that might enlighten how to achieve comparable success in other conditions or, at least, help in understanding factors that potentially explain when comparable success is not realised outside these two focal conditions.

The aim of this research is to fill a gap in the evidence base around successful implementation of admission reduction programmes by focusing on understanding what works for whom, why and in what contexts\(^7\). We first investigated interventions that are currently used within the NHS to manage cardiovascular or respiratory conditions using a systematic mapping approach\(^8\). We then used a realist approach\(^7\) to identify and explain factors that contribute to successful implementation of interventions to reduce preventable hospital admissions, looking at responses to interventions that involve different mechanisms and different contexts. To the best of our knowledge this is the first example of a realist-based approach exploring these aspects of implementation.
Chapter 2: Methods

Overall review strategy
The overall review comprised two main phases:

(i) Systematic mapping of cardiorespiratory intervention studies for reducing preventable admissions
(ii) Realist review of implementation evidence

The overall review commenced with the decision, agreed with the NIHR HS&DR Programme Team, to focus exploration on those conditions revealed by the 2010 Purdy review to demonstrate effective interventions to prevent avoidable hospital admissions. Consistently a positive effect or positive indication was found for cardiorespiratory conditions and this was a focus for systematic mapping of studies.

Based on these included studies four complementary activities were conducted (Table 1):

(iii) Generation of IF-THEN-LEADING TO statements from a conceptually rich set of empirical studies and theoretical papers and selection of candidate programme theories;
(iv) Analysis of Implementation studies to identify intervention components using an abbreviated version of the TIDieR checklist;
(v) Analysis of Implementation Studies using the PARIHS Framework
(vi) Comparison of PARIHS Templates with shortlisted programme theories.

Finally, the Results and Discussion sections provide the opportunity to integrate the diffuse review outputs.

The remainder of this chapter provides fuller details of the mapping and realist reviews.
Table 1: Overview of review strategy

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Mapping review

The objective of the mapping review was to identify and map the literature on interventions that could be used to reduce preventable hospital admissions in the NHS, with a particular focus on cardiovascular and respiratory conditions. The included studies were to be used as a sampling frame, allowing the realist synthesis to examine the underpinning mechanisms that explain how the interventions work in practice, for whom and in what circumstances.

Inclusion criteria

Studies were included in the mapping review if they met the following criteria:

- Published in 2010 or later in English
- Conducted in a relevant country (UK, USA, Canada, Australia or New Zealand). Canada, Australia and New Zealand were included as the countries with the most similar health systems to the UK, while the USA was included because of the high volume of good-quality health research conducted there. We took a pragmatic decision to exclude as far as possible studies from other European countries because of differences in health service organisation. We recognised that this could involve excluding potentially relevant studies from some countries but considered that the impact on the structure of the evidence map was likely to be relatively minor
- Recruited adults with a cardiovascular or respiratory condition (not cancer)
- Evaluated or described an intervention that could reduce preventable hospital admissions or readmissions. Based on the work of Purdy et al., the following interventions of interest were specified in advance: case management; specialist clinics; community interventions (not fitting into any other relevant category); patient education; self-management; pulmonary rehabilitation; cardiac rehabilitation; and telehealth. Programmes involving combinations of these interventions were also eligible for inclusion
• Reported admissions/readmissions or prevented admissions as an outcome and/or reported on implementation of the intervention (e.g. barriers and facilitators, qualitative studies of staff or patient views/experiences) in the context of reducing admissions.

The main study designs of interest were experimental studies (e.g. randomised and non-randomised trials), controlled and uncontrolled observational studies, qualitative studies and systematic reviews. We attempted to exclude editorials, letters, study protocols, papers discussing study rationale and design, and other papers not reporting substantive data. Given that inclusion was based on titles and abstracts, published conference abstracts were eligible for inclusion.

**Literature search**
A formal bibliographic search of MEDLINE, CINAHL, HMIC, EMBASE, Web of Science and the Cochrane Library were conducted in September and October 2017. The search was developed from initial scoping searches and previous systematic reviews with search terms adapted for each information source. The search comprised terms for ambulatory care sensitive conditions combined with intervention terms and terms around admissions, implementation and research dissemination. The MEDLINE search is documented in Appendix 1. The ambulatory care sensitive conditions included the following: angina, hypertension, COPD and asthma. Intervention terms were derived from the King’s Fund report, *Avoiding hospital admissions What does the research evidence say?* The search was limited to studies published from 2010, the date of the Purdy report, to July 2018 and research published in English language. Focusing on this narrower year range is further justified by the specific focus of this review on implementation; an implementation context is a continually mutable backdrop within which to evaluate the introduction of a complex intervention.

Recent initiatives and, specifically, those that have been evaluated within a UK context were privileged. Nevertheless, the review methodology preserved the potential to engage with the...
wider literature through coverage of reviews that extend the time and geographical limits beyond the formal sampling frame. The UK focus was strengthened by examination of the catalogues of the Health Service Management Centre at the University of Birmingham, the King’s Fund Library and Health Management Online (NHS Scotland).

Screening of search results and coding of included records
Bibliographic records identified by the literature research were imported into EPPI Reviewer 4 (EPPI Centre, University of London, UK) for screening and data extraction. Records were screened for inclusion or exclusion by one reviewer, with a 10% sample being screened by two reviewers to check for consistency. Screening of search results was based on information in database records (title or title and abstract) only; we did not systematically screen study full texts.

Data extraction (coding) was performed by one reviewer in EPPI-Reviewer 4 using a mixture of tick-box selection and manual data entry. Table 2 summarises the extracted data items. We did not extract study findings or authors’ conclusions because the purpose of the review was to map interventions and not to evaluate their effectiveness.

Mapping review synthesis
We produced a descriptive summary of key characteristics of the body of included studies as reported below. Summary tables were developed using the search, cross-tabulation and reporting functions of EPPI-Reviewer 4.
<table>
<thead>
<tr>
<th>Data to code</th>
<th>Options</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Include or Exclude</td>
<td>Include; Exclude; Query</td>
<td>Initial code set</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Include if:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Published 2010 or later in English</td>
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<tr>
<td></td>
<td></td>
<td>- Conducted in relevant country (UK, USA, Canada, Australia or New Zealand)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Adults with a CV or respiratory condition (not cancer)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Refers to a relevant intervention (see below)</td>
</tr>
<tr>
<td>Study ID</td>
<td></td>
<td>Included studies only</td>
</tr>
<tr>
<td>Study design</td>
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<td>Author year EN number</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Broad categories for simplicity</td>
</tr>
<tr>
<td>Population/Condition</td>
<td>CHD; Heart failure; Hypertension; Asthma; COPD; Multiple; Other cardiovascular; Other respiratory</td>
<td>CHD includes angina and post-MI</td>
</tr>
<tr>
<td>----------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>Sample size</td>
<td>Number of participants</td>
<td>Community interventions = those that don’t fit into other relevant categories (Purdy et al). This is based on Purdy’s findings of interventions with evidence of positive effect; can be added to if necessary</td>
</tr>
<tr>
<td>Intervention</td>
<td>Case management; Specialist clinics; Community interventions; Patient education; Self-management; Pulmonary rehabilitation; Cardiac rehabilitation; Telehealth; Multiple; Other; Unclear</td>
<td></td>
</tr>
<tr>
<td>Comparator</td>
<td>Alternative intervention; Usual care; Baseline; Not applicable; Unclear/not reported</td>
<td>Who acts as ‘gatekeeper’ for the intervention?</td>
</tr>
<tr>
<td>Country</td>
<td>UK; USA; Canada; Australia; New Zealand; Multiple countries; Not applicable; Unclear/not reported</td>
<td></td>
</tr>
<tr>
<td>Access route</td>
<td>GP; Other general practice staff; Emergency department; Paramedic; Telephone advice; Outpatient appointment; Hospital discharge; Community service; Patient-initiated; Other; Unclear/not reported</td>
<td></td>
</tr>
<tr>
<td>Data type</td>
<td>Quantitative; Qualitative; Mixed</td>
<td></td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Outcomes assessed</th>
<th>Admissions/readmissions¹; Prevented admissions²; Patient-reported; Staff-reported; Costs/cost-effectiveness; Workforce outcomes; Health system outcomes; Qualitative outcomes; Other</th>
<th>Statistical data¹; Audit/judgement on specific cases²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length/period of study</td>
<td>Length of study</td>
<td>Years/months</td>
</tr>
</tbody>
</table>
Realist synthesis
The mapping review revealed the coverage by journal literature of each of the main intervention types identified by Purdy\(^1,2\), including the existence of systematic review evidence and UK-based quantitative and qualitative studies. This helped to inform the sampling frame for the subsequent realist synthesis. In contrast to a conventional systematic review a realist synthesis is not required to examine a comprehensive and exhaustive sample from the literature; instead it explores a judiciously and purposively selected sample favouring richer more informative data.

The practical focus of this review required exclusion of evidence with limited transferability to the NHS, such as avoidable admissions in low- and middle-income countries. Through systematic review-level evidence we accessed four countries in addition to the UK, namely the US, Australia, Canada and New Zealand. We also engaged with the wider evidence base (using supplementary searches) through systematic reviews, opinion pieces and direct reference to individual study reports, particularly where authors themselves establish a connection to the UK context. Explicit inclusion criteria were implemented within our sampling frame to ensure consistent study selection by the review team across the nine intervention types.

Data extraction
In contrast to the mapping review, data extraction for the realist synthesis was based on the full text of each item. Purpose-designed data extraction forms drew upon appropriate frameworks as structures by which to interrogate the theories and the empirical evidence. We used an experimental methodological development, previously tried in another NIHR HS&DR realist synthesis\(^9,10\) which combined use of realist synthesis methods with elements of best fit framework synthesis. Best fit framework synthesis involves identification of an appropriate “good enough” framework to operate as both a vehicle for data extraction and, subsequently, as an analytical lens for examination of extracted data\(^11\). Best fit framework
synthesis is believed to expedite the data extraction process\textsuperscript{12} with a majority of the data being handled deductively using the framework before a subsequent inductive phase to code data not explained by the categories derived from the original framework\textsuperscript{13}.

The focus of this realist synthesis on implementation encouraged the review team to focus on frameworks or models specifically derived in an implementation, knowledge translation or evidence-based healthcare context. Instead of embarking on an extensive parallel process of framework identification, typically the case in previous uses of best fit framework synthesis\textsuperscript{14}, the team used the sourcebook, \textit{Models and frameworks for implementing evidence-based practice: linking evidence to action}\textsuperscript{15}, and rapidly reviewed the pictorial models and accompanying textual descriptions for “fit” to the purpose and context of the review. A short list of candidate models was subsequently narrowed down to the Promoting Action on Research Implementation in Health Services (PARIHS) framework. Within the PARIHS framework, successful implementation is represented as a function of the nature and type of evidence (to be examined from the mapping review), the qualities of the context in which the evidence is being introduced, and the way the process is facilitated\textsuperscript{16} (to be extracted from included UK studies, both quantitative and qualitative).

Previous experience of realist synthesis within complex service delivery contexts had also revealed the value of using the Template for Intervention Description and Replication (TIDieR) as a formal framework for identifying and describing the components of included interventions\textsuperscript{17}. We therefore decided to use a version of this template, abbreviated in recognition of both the time constraints and the generic level at which interventions have been characterised, as a structure for describing the nine intervention types. The 12 item TIDieR checklist (brief name, why, what (materials), what (procedure), who provided, how, where, when and how much, tailoring, modifications, how well (planned), how well (actual)) was therefore abbreviated in the form of the five item “TIDieR-Lite” (By Whom, What, Where, To What Intensity, How Often). Importantly, this was to be used to summarise the generic characteristics of each intervention type across multiple intervention reports although
significant areas of variation across each generic type were prompted for identification by the framework.

Finally, data relating to programme theory was extracted using an “IF-THEN-LEADING TO” realist logic structure, pioneered by other research teams and used in previous reviews by team members. This enabled generation of multiple programme theory statements (ultimately five in number – PTs 1-5, see below) to be used to examine data from included empirical studies and to communicate programme logic to stakeholders in the form of narrative scenarios.

In summary, then, data extraction comprised use of:

1. an implementation framework, PARIHS, as a structure for examining how interventions are delivered;
2. an intervention template, TIDieR, as a format for describing intervention components; and
3. a realist logic template, IF-THEN-LEADING TO, to elicit programme theory on how interventions might work.

Initial logic model
The team deliberated whether logic models would be required for each intervention type, ultimately concluding that the focus on mechanisms, as opposed to outcomes, would facilitate a single inclusive logic model which could explain multiple points within the overall complex adaptive system. Using barriers and facilitators identified from a rich subset of the literature, supplemented by input from team members and from the PPI group (see below) the team identified three systemic “problem points”.

(i) Patient uncertainty about appropriate admission. This would have a direct effect on patient-centred interventions such as self management but also a secondary
effect on health-professional mediated interventions as patients attempted to resolve their initial uncertainty;

(ii) Health professional uncertainty about appropriate admission. This revolves around the health professional’s gatekeeper role and may relate to the severity of patient symptoms, the risk averse culture within which health professionals might operate and awareness of alternative service provision.

(iii) Structural barriers to appropriate admission. Patient or health professional current or previous experience of health service delivery may impact upon the decision pathway. For example, if patients or health professionals have previously experienced delays in arrival of ambulance transport they may factor in such delays by initiating call out earlier than the patient’s symptoms might otherwise justify.

Based upon these three potential problem points the teams mapped the different interventions to those points that each sought to address. For example, telehealthcare may offer a “feedback” loop to a patient on whether their current physical signs or symptoms should trigger admission and/or can offer more data to the health professionals to help them make a more informed and “real time” referral judgement. This map of barriers and the mechanisms by which interventions might address them became the initial logic model and contributed to the development of programme theories focusing on how inappropriate admissions may be facilitated or prevented at the three problem points listed above.

**Programme Theory Development**

Five programme theory components were identified following a review of published barriers, consultation with the PPI group and analysis of a rich subset of intervention studies for preventable admissions [Box 1]. These are expressed in the form of hypotheses to be tested against the empirical data.

**Box 1 – Programme theory components**

| People with chronic conditions are frequently admitted to hospital when hospital is not the optimal destination for them. They may have symptoms that could be self-managed or anxieties that could be addressed by patient education or information [PT1]. |

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People with chronic conditions lack knowledge about alternative health provision and therefore draw disproportionately upon well-signposted channels such as their GP or the emergency department [PT2]. Alternatively, patients perceive that presentation to an emergency department holds relative advantage (e.g. quality, ease of access, response etc.) over GP-based or other primary or community care services [PT2]. Patients pressure health professionals to admit them to hospital.

Health professionals lack confidence in their own diagnoses or may lack confidence in, or knowledge of, alternative sources of healthcare provision and so may refer people with chronic conditions or admit them direct to hospital. Health professionals feel under pressure to admit people with chronic conditions directly to hospital [PT3].

People with chronic conditions use health services inappropriately; delaying their presentation to health professionals or hospital [PT4] because of perceptions of the service either anticipated or based on the past experience of either themselves or others.

GPs and other health professionals are influenced by the wider context of the healthcare system and the availability or otherwise of support and incentives may influence their adoption of interventions and pathways designed to avoid preventable referrals and admissions to hospital [PT5].

**Synthesis**
Following identification of the initial programme theories the review team extracted data into evidence tables. The resultant hypotheses operationalised synthesised statements around which we developed an explanatory narrative referenced to the underpinning evidence base. Additional searches for mid-range theories (conceptual models or frameworks relevant to one or several of the interventions covered by the review) and overarching theories (theories
relevant to the phenomenon of inappropriate admissions as a whole) were performed using Google Scholar. The aim of searching for these higher level theories was to elucidate how previous researchers have understood factors underlying inappropriate admissions and their prevention at a relatively high level of abstraction. Our EPPI-Reviewer map, reference management database and accompanying data extraction spreadsheets collectively offer a comprehensive evidence base relevant to interventions to reduce unplanned hospital admissions.

**Testing and refining the programme theory**

Searches for programme theories relevant to avoidable admissions were conducted using Publish or Perish 6™ software. This desk-based tool offers an auditable interface to searching of the Google Scholar resource as well as allowing construction of semi-complex search strategies.

The first set of Google Scholar searches combined the term “ambulatory sensitive” with terms for preventable admissions and different programme theory terms. The second set of searches combined the term “preventable admissions” with “hospitalisation or hospitalization” and different programme theory terms. Full details of the search terms used for each individual search and the number of results retrieved are provided in appendix 2.

Papers retrieved from the programme theory searches were reviewed by one reviewer with experience of harvesting programme theories. Prioritising conceptually and contextually rich papers the reviewer drafted preliminary IF-THEN-LEADING TO statements19 (known technically as Context-Mechanism-Outcome (CMO) configurations) for discussion within the review team. The aim of this process was not to generate an exhaustive list of possible explanations but to generate a selection of theories of change operating variously at patient/carer, health provider and health system levels. Where several programme theory components seemed to be interrelated these were combined into a more overarching explanation.
From the papers retrieved from the programme theories searches and from the papers included in the mapping review we developed 5 programme theories to guide the realist review. Details of the generic programme theories are given in Box 1. Details of the programme theories expressed as IF-THEN-LEADING TO statements and the likely types of evidence identified by the team by which programme theories might be supported or negated are provided in Table 3. In Chapter 4 the programme theories are considered within the specific context of each of the included interventions.

Table 3: Details of the programme theories and the types of evidence that could support them

<table>
<thead>
<tr>
<th>Programme Theory</th>
<th>Types of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>PT1 – IF Patients are equipped with knowledge/information for self-management, including seeking help as appropriate, THEN they will access Hospital/Health Services as required LEADING TO appropriate utilisation of health resources and a reduction in unplanned admissions</td>
<td>• Self Management Interventions&lt;br&gt;• Patient Information Interventions&lt;br&gt;• Patient Education Interventions&lt;br&gt;• Qualitative Studies on Self-Management</td>
</tr>
<tr>
<td>PT2 - IF Patients feel confident and satisfied with non-secondary care health provision THEN they will not consider it necessary to access/request secondary care services LEADING TO appropriate utilisation of health resources and a reduction in unplanned admissions</td>
<td>• Primary Care located Interventions&lt;br&gt;• Patient Satisfaction &amp; Surveys&lt;br&gt;• Outcome Studies</td>
</tr>
<tr>
<td>PT3 – IF GPs/primary care staff feel confident in their own ability to diagnose and/or refer patients appropriately and have confidence in</td>
<td>• Qualitative studies on GPs diagnostic and referral skills</td>
</tr>
</tbody>
</table>
and knowledge of services available within primary and community care **THEN** they will not refer patients to hospital **LEADING TO** an increase in use of self-management and non-secondary care health service provision and a reduction in unplanned admissions.

<table>
<thead>
<tr>
<th>PT4 - <strong>IF</strong> Patients Delay/Are Delayed in accessing health services <strong>THEN</strong> Patients may experience exacerbation of symptoms <strong>LEADING TO</strong> a higher level of clinical input or resource use when they finally access health care and an increase in unplanned admissions.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>•</strong> Outcome studies from referrals</td>
</tr>
<tr>
<td><strong>•</strong> Outcome studies from non-hospital based alternative services</td>
</tr>
<tr>
<td><strong>•</strong> Qualitative Studies on Delayed Presentation</td>
</tr>
<tr>
<td><strong>•</strong> Outcome Studies on Delayed Presentation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PT5 - <strong>IF</strong> clinicians and other health service staff perceive that the wider health system provides appropriate support and incentives <strong>THEN</strong> they will feel confident in implementing (and evaluating) interventions that involve changes to practice and professional roles <strong>LEADING TO</strong> appropriate utilisation of health resources and a reduction in unplanned admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>•</strong> Primary studies or reviews evaluating interventions involving changes to practice, patient pathways or services</td>
</tr>
</tbody>
</table>

The initial programme theories were tested from the theoretical literature, empirical studies and insights from the PPI group. Programme theories were examined against the nine individual intervention types and collectively as a set. A subsequent activity involved seeking to map the elements of the programme theory to potential mid-range theories that might add greater transferability to review findings. Mid-range theories could be identified serendipitously, when reviewing the empirical evidence, but more typically were identified...
from Google Scholar searches that combined the intervention e.g. “case management” with terms relating to models or theories (i.e. theor* or model* or framework* or concept*)21.

Public involvement
Members of the pre-existing Sheffield HS&DR evidence synthesis centre public involvement advisory group provided input to the study at various stages including exploration of the study parameters, discussion regarding the meaning and interpretation of the study findings, drafting of the plain English summary, and help with disseminating the findings and maximising the impact of the research. The group comprised nine members, mainly from the Yorkshire and Humber region but with two members from other regions of England. Members were recruited by contacting other existing public involvement groups and via a public involvement website.

The project was discussed at three meetings of the advisory group. At the first meeting, the researchers introduced the topic and also provided a brief introduction to the concept of a realist review. We then discussed pathways that could potentially lead from a patient perceiving a problem to an avoidable admission or avoidance of admission. Advisory group members gave their perspective on factors that could influence patient behaviour at various stages of the pathway (e.g. ‘Patients lack confidence in their ability to self-monitor and self-manage their condition’ and ‘Patients perceive that they need to be treated in hospital’). This discussion was helpful to the research team in developing programme theories for analysis in the realist synthesis.

Before the second meeting, the researchers ‘translated’ aspects of the programme theories into ‘scenarios’ (see Appendix 3) and discussed these with the advisory group. Group members provided input on both the credibility of the scenarios and the appropriateness of the language used to describe them. Some scenarios were significantly modified as a result and this was reflected in a change in the researchers’ understanding of the corresponding programme theory.
The third advisory group meeting coincided with near-completion of the draft final report. The main findings were presented and the advisory group members discussed the draft plain English summary and channels for disseminating the research and achieving wider impact.

**Changes to protocol**

Time and resource constraints meant that we were not able to engage with health professional stakeholders to the extent outlined in the protocol. Since we did not invite health professionals to participate in interviews or focus groups, we did not need to obtain ethical approval as envisaged in the protocol.
Chapter 3: Results of mapping review

Screening of literature search results
Figure 1 (adapted from the standard PRISMA flow diagram) summarises the results of the screening process. A total of 569 publications were judged to meet the inclusion criteria (based on title and abstract) and were coded in EPPI-Reviewer 4. Total numbers in the following sections do not always add up 569 because of studies being coded for more than one item within a category or because studies could not be fully coded with the information available in the abstract.

Populations
The most commonly studied conditions were heart failure (238 studies) and COPD (212). Other conditions with significant numbers of studies were asthma (65), hypertension (44) and CHD (25). Thirty-two studies were coded as covering multiple (generally three or more) conditions. Some of these studies included patients with chronic conditions outside the main focus of the mapping review, e.g. diabetes.

Interventions
The largest groups of interventions were those coded as self-management (122 studies) and telehealth (119). Patient education (72 studies) was frequently linked with self-management. Pulmonary rehabilitation (53 studies) was more commonly studied than cardiac rehabilitation (24). A large group of studies (87) evaluated multiple interventions, notably those characterised as transitional care programmes. There were 50 studies of community-based interventions and 37 of case management.
Figure 1: Flow of studies through the mapping review

*Irrelevant, not country or date range of interest, or additional duplicates
**Nature/volume of evidence**

The number of included studies coded by intervention for each condition is listed in Table 4 (see below). In general, the frequency of included studies reflected the findings of Purdy et al. Interventions and populations where Purdy et al. found evidence of positive effects were generally well represented in the map as illustrated in Table 4. Examples were patient education and telehealth for heart failure (46 and 66 studies, respectively), self-management of asthma (37) and pulmonary rehabilitation for COPD (59). Interventions considered to have evidence of no effect (as distinct from no evidence of effect) were less well represented: we included 15 studies of case management for COPD but only three of community interventions for CHD and two of specialist asthma clinics.

Interventions not rated by Purdy et al. but covered by substantial numbers of studies (20 or more) in the mapping review included self-management for heart failure (44 studies, although many of these also included patient education) and community interventions (24 studies) and telehealth (57 studies) for COPD.

Literature reviews (including systematic reviews, narrative reviews and some conceptual or discussion papers based on literature reviews) were the most common type of literature included in the mapping review (156 studies), followed by experimental studies (randomised and non-randomised controlled trials (117)) and uncontrolled observational (115) studies. We also identified 47 controlled observational and 61 qualitative studies. As this was a mapping review, the quality of individual studies was not assessed. In the following section, we briefly describe the composition of the main groups of included studies.
<table>
<thead>
<tr>
<th></th>
<th>Case management</th>
<th>Specialist clinics</th>
<th>Community interventions</th>
<th>Patient education</th>
<th>Self-management</th>
<th>Cardiac rehabilitation</th>
<th>Pulmonary rehabilitation</th>
<th>Telehealth</th>
<th>Multiple</th>
<th>Other</th>
<th>Unclear</th>
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</thead>
<tbody>
<tr>
<td>Coronary heart disease</td>
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<td>3</td>
<td>2</td>
<td>3</td>
<td>12</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Heart failure</td>
<td>18</td>
<td>10</td>
<td>16</td>
<td>46</td>
<td>44</td>
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<td>2</td>
<td>66</td>
<td>37</td>
<td>14</td>
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<tr>
<td>Hypertension</td>
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<td>6</td>
<td>7</td>
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<td>0</td>
<td>11</td>
<td>4</td>
<td>2</td>
<td>0</td>
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<tr>
<td>Asthma</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>9</td>
<td>37</td>
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<td>0</td>
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<td>1</td>
<td>4</td>
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<tr>
<td>Other cardiovascular</td>
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<td>0</td>
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</tr>
<tr>
<td>Other respiratory</td>
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</tbody>
</table>
Yellow = evidence of positive effect; green = evidence of no effect¹
Evidence by study design

Key systematic reviews included in the mapping review are listed in Table 5. Up-to-date (2016 or 2017) systematic reviews were found for most key combinations of condition and intervention. Several were Cochrane reviews or overviews of reviews, which use standard methods and are likely to be of high quality. While some reviews focused purely on effectiveness of interventions, others attempted to assess which features were most essential to intervention effectiveness or to identify barriers and facilitators to implementation. This latter group of reviews was most useful for the realist synthesis.

Experimental studies generally compared an intervention with ‘usual care’. Usual care was generally not defined at all in the abstracts that we used for coding, making it difficult to compare studies. A few studies compared different interventions, although these tended to be variations of a common intervention (e.g. more vs. less intense or different durations) rather than distinctly different interventions. The distribution of experimental studies across conditions/interventions broadly reflected that of the whole group of included studies.

Table 5: Key systematic reviews

<table>
<thead>
<tr>
<th>Condition</th>
<th>Key reviews</th>
</tr>
</thead>
</table>
| Coronary heart disease | Cardiac rehabilitation: Anderson (2016)\(^{22}\) Anderson (2014)\(^{23}\) Huang (2015)\(^{24}\) Karmali (2014)\(^{25}\)  
|                     | Telehealth: Huang (2015)\(^{24}\)               |
| Heart failure       | Case management: Huntley (2016)\(^{26}\) Van Spall (2017)\(^{27}\)  
|                     | Specialist clinics: O'Neill (2017)\(^{28}\) Thomas (2013)\(^{29}\)  
|                     | Community interventions: Coffey (2017)\(^{30}\) Health Quality Ontario (2017)\(^{31}\) Van Spall (2017)\(^{27}\)  
|                     | Patient education: Casimir (2014)\(^{32}\) Gavgani (2015)\(^{33}\) |
Controlled observational studies were less frequent in the map than experimental studies, with no combination of condition/intervention having more than seven such studies. Similar to the experimental studies, the majority of this group compared the intervention with a ‘usual care’ control group. By contrast, most uncontrolled observational studies (65) used baseline values as a comparator, although 14 such studies also included a ‘usual care’ group.

Qualitative studies are an important source of evidence for understanding the implementation of interventions in practice, as the views and perceptions of health professionals and patients have a strong influence on whether and how interventions work in practice. The 61 qualitative studies included in the map covered the range of relevant populations and interventions, the largest single group being studies of pulmonary rehabilitation for COPD (13 studies). Other populations and interventions were covered by up to seven qualitative studies. Studies using recognised methods of qualitative analysis, such as thematic analysis, were included in this group, although the quality of individual studies was not assessed.
Setting
The largest number of studies were conducted in the USA (207 studies), followed by the UK (103), Canada (46) and Australia (43). Just two studies from New Zealand were included. There were 91 studies, primarily literature reviews, where the concept of study country was considered to be not applicable and 59 studies conducted in multiple countries. Finally, the country was coded as unclear/not reported for 23 studies where the reviewer’s judgement was that the setting was likely to be one of the countries included in the map. We did not systematically check full text of included studies to identify the authors’ country of origin, so it is possible that this group includes a few studies from outside our defined settings of interest.

In terms of how patients accessed the intervention, the largest single group was studies in which the access route was not reported or judged as unclear (213 studies). The most common identified ways of accessing interventions were via community-based services (134 studies) and at the time of hospital discharge to reduce risk of readmission (122 studies). GPs or equivalent primary care doctors were the access route in 45 studies and other general practice staff in 22. Less frequent ways of accessing interventions were outpatient appointments (24 studies), emergency department (15), paramedic and telephone advice (two studies each). There were no included studies where access to the intervention was initiated by the patient.

UK evidence
We included 102 studies from the UK. The majority of these focused on a small number of interventions: self-management of COPD (12 studies), pulmonary rehabilitation for COPD (15) and telehealth for COPD (26) and heart failure (15). Almost half of the included UK studies (49) dealt with interventions classified as telehealth, primarily remote monitoring and consultation. This concentration on telehealth probably reflects strong backing for the technology from the Department of Health through initiatives such as 3 Million Lives and the...
Whole System Demonstrator trial\textsuperscript{69}. Interventions classed as effective by Purdy et al. but with limited evidence from the UK included cardiac rehabilitation and telehealth for CHD (one study each), case management (one), specialist clinics (none), community interventions (two) and patient education (two) for heart failure, and self-management of asthma (six studies).

**Outcomes**

We mapped two measures of effect on admissions: admissions (or readmissions) per se, based on aggregated data from trials or routinely collected data; and prevented admissions, based on audit of individual cases. These outcomes were reported in 311 and three studies, respectively. This suggests that in most included studies there was an implicit assumption that admissions were prevented appropriately (i.e. the intervention did not lead to patients not being admitted when admission was the most appropriate course of action) but this was not investigated directly.

Other commonly reported outcomes were patient-reported outcomes such as quality of life (211 studies); health system outcomes such as length of stay or ED visits (91 studies); qualitative outcomes (themes identified by qualitative analysis (85 studies)); and costs or cost-effectiveness (73 studies). Other outcomes, including mortality, were reported in 133 studies.

**Summary of findings**

The mapping review allowed identification and description of a large number of studies relating to interventions to reduce preventable hospital admissions for people with cardiac or respiratory conditions. A limited number of descriptive outcomes are reported here but the features of EPPI-Reviewer allow the data to be analysed in a wide variety of ways.

Unsurprisingly, the interventions identified by Purdy et al. as having the best evidence of effectiveness (or no effect) were well represented in the map. The largest group of studies originated from the USA and differences between healthcare systems mean that care should be taken in extrapolating the results of such studies to the UK setting. The included studies...
from the UK showed a similar distribution of studies by intervention and population to that of
the map as a whole but there was evidence of some country-specific features such as the
prominence of studies of telehealth. We excluded studies from non-UK European countries
based on lack of similarity between most countries’ health systems and the UK NHS. This
means that some studies of interventions that could be implemented in the UK were omitted
from the mapping review. However, it is unlikely that this would have led to any significant
intervention being omitted from the mapping review altogether. Furthermore, studies from
European countries were included indirectly via the inclusion of relevant systematic reviews
in our mapping review.

Mapping reviews use systematic methods to identify, screen and code studies but a mapping
review is not a systematic review. Mapping reviews generally omit some standard features of
systematic reviews, for example study quality assessment, and do not attempt to assess
effectiveness. The role of mapping reviews is to provide a descriptive account of the
published literature and this should be taken into account when assessing the findings of this
part of the overall evidence synthesis

The studies coded for the mapping review and stored in EPPI-Reviewer 4 represent a broad
sampling frame of UK studies for use in the accompanying realist synthesis. In view of the
number of studies screened for inclusion and included we cannot rule out the possibility that
some studies were included or excluded in error. Inclusion decisions were taken on the basis
of information in the title and abstract only and in some cases important information, e.g. the
study country, was not available. However, it is unlikely that any errors regarding study
inclusion or exclusion would have a major effect on the overall shape of the evidence map.
Chapter 4: Analysis of UK studies

4.1: Case management

Summary
Exploration of case management reveals that the role of the specialist nurse is key to its success. The impact of the role is determined by issues relating to responsiveness (as seen in response times) and availability (as seen in the demand for 24 hour access), which themselves can be moderated by the size of the nursing caseload and the competing demands of the administrative workload. A tension may be identified between the intrinsic advantages of continuity of care, as especially evidenced in a knowledge of the patient’s symptoms, and the need to provide round the clock coverage to patients with more severe manifestations of cardiorespiratory conditions. Case management is therefore seen to require substantive re-engineering of the health system in which it is intended to operate.

Definition
Case management is a generic term, with no single definition, described as ‘the process of planning, co-ordinating and reviewing the care of an individual’. The Case Management Society of America (CMSA) defines it as ‘a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual’s and family’s comprehensive health needs through communication and available resources to promote quality cost-effective outcomes’ (www.cmsa.org, accessed 4th April 2019). This definition was operationalised by Purdy and colleagues within their series of NIHR reviews1. The literature reflects confusion between case management as “an ongoing programme of individualised care aimed at keeping people well” and as “an intensive, personalised and time-limited intervention aimed at preventing a specific occurrence or event – usually an emergency hospital admission”70.
Case management within the NHS has been largely configured as community-based programmes, set up and funded by primary care trusts (PCTs), and typically (but not always) staffed by community matrons. In recent years UK initiatives have focused on multidisciplinary team-led case management but have demonstrated little or no reduction in use of secondary care. Increasingly, attention has focused on the “added value” of benefits for patients and professionals. Interest in case management has been revived by the new models of care initiatives with their focus on integrated care.

**Intervention Components**

Rather than constituting a single intervention, case management typically describes a package of care which covers activities that vary widely between programmes; it is described as a “prototypical example of a complex intervention”. Such variation makes case management both difficult to describe and challenging to evaluate. TIDIER-Lite components of self-management interventions are summarised in Table 6.

Several commentators identify the following core components as particularly important to case management programmes:

- case-finding
- assessment
- care planning
- care co-ordination (usually undertaken by a case manager within the context of a multidisciplinary team), including but not limited to:
  - medication management
  - self-care support
  - advocacy and negotiation
  - psychosocial support
  - monitoring and review.
  - case closure (in time-limited interventions).
Case management can include such components as self-management, patient education and disease management programmes making it more challenging to distinguish this intervention from others reviewed in this report. Case management may be delivered in diverse ways that vary according to intensity (frequency and duration of the contacts), degree of embeddedness in the local care network, the background and training of case managers, the extent to which they work alone or within a team. Further variation is exhibited in whether the case manager is supported through reflexive group meetings with peers or supervisors, how the target population is identified and how the case management intervention is initiated.

Table 6: TiDIER-Lite characteristics for case management

<table>
<thead>
<tr>
<th>By Whom</th>
<th>Health care professionals, typically specialist nurses with medical support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• case-finding</td>
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<tr>
<td></td>
<td>• assessment</td>
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<td></td>
<td>• care planning</td>
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<td></td>
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<td></td>
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<td></td>
<td>o monitoring and review</td>
</tr>
<tr>
<td></td>
<td>o case closure (in time-limited interventions).</td>
</tr>
<tr>
<td></td>
<td>May also include self-management, patient education and disease management programmes.</td>
</tr>
</tbody>
</table>
Where | May be delivered face-to-face in a patient’s home or in a clinic setting or via the telephone
---|---
To What Intensity | Frequency and duration of contacts varies according to need
How Often | At intervals determined by case manager, may also be patient initiated.

**Number and Type of UK Studies identified**

The effectiveness review by Purdy drew upon only one UK study of case management\(^76\). This RCT in a COPD population in West London found no difference between case management and usual care in terms of numbers of hospital admissions. Indeed the primary impact of the intervention seemed to be a reduced need for unscheduled primary care consultations. For every one COPD patient receiving the intervention and self-management advice, there were 1.79 fewer unscheduled contacts with the GP\(^76\).

The mapping review identified two further quantitative UK studies (three papers) of case management for cardiovascular or respiratory conditions published since 2010. One study examined a COPD population in a single general practice\(^77\) while the remaining study\(^71, 78\) presented data on twenty ambulatory sensitive conditions. The six conditions of relevance to this review included asthma, atrial fibrillation, coronary heart disease, COPD, heart failure, and hypertension.

Three UK qualitative studies were identified (four papers/reports). One of these studies examined patients with heart failure and staff involved in their care\(^79\) while the other two initiatives targeted case management in “high risk” populations including conditions eligible for this review.

Details of the studies included in the analysis are presented in Table 34 (see Appendix 4).
Operating Programme Theories

PT2 proposes that **IF Patients feel confident and satisfied with non-secondary care health provision THEN they will not consider it necessary to access/request secondary care services LEADING TO appropriate utilisation of health resources and a reduction in unplanned admissions.** Case management affects the patient’s perceived capability for staying in their own home. Crisis situations can be anticipated, if not averted; this is particularly important in the context of exacerbations as with COPD.

However, because of its personalised tailored nature and the involvement of multiple health and social care professionals case management may be resisted as overly intrusive. Others report that the case manager was perceived as an impediment to accessing their GP. Furthermore, if the patient feels supported they are less likely to feel a need to access sources of support from within secondary care. One patient with respiratory problems reported past and likely future occasions when her needs might best be met in hospital. This patient perceived the hospital as a means for meeting not just her medical needs but also her holistic needs; making her feel safer and therefore, less anxious or by increasing opportunities for social interactions. Other participants described their ‘confidence’ in local hospitals should circumstances arise when they feel that some of their needs may be better met in hospital.

Case management also engages with PT3 that states that **IF primary care staff (in this case the case manager) feel confident in their own ability to refer patients appropriately and have confidence in, and knowledge of, services available within primary and community care THEN they will not refer patients to hospital LEADING TO an increase in use of self-management and non-secondary care health service provision and a reduction in unplanned admissions.** In this context the detailed knowledge of the patient’s condition and circumstances and the holistic perspective on their care enables the case manager to calibrate and negotiate appropriate thresholds for secondary care intervention. Previously, the Evercare evaluation found that as Advanced Primary Nurses’ knowledge of available services
increased over time, they referred their patients to an increasing range of resources for support\textsuperscript{82}. Gowing and colleagues (2016) report that some patients may be content to trust the case manager’s judgement and yet others may resolutely insist that hospital is the best place for them\textsuperscript{72}. A major issue was the lack of adequate social care support although isolated instances of providing overnight care, following hospital discharge, were reported\textsuperscript{72}.

An important contextual variable is the need for adequate training to strengthen the case managers’ self-efficacy and confidence in the appropriateness of their situational assessments\textsuperscript{80}. This confirms that as case managers become more experienced, GPs are likely to spend less time liaising with other services and case managers are able to provide more patient care themselves\textsuperscript{83}. One potential unintended consequence of case management is increased levels of case finding resulting in a non-reduction in hospital admissions\textsuperscript{83}.

Detailed knowledge of a patient’s condition and circumstances (embracing both clinical and social contextual factors) also mitigates against operation of action according to PT4, that is the patient does not perceive a need to delay presentation to secondary care services; they feel empowered to elicit information from their case manager as and when required. The triad of case manager, patient and informal carer only perceive a need to escalate action when the personalised threshold has been exceeded. A key contextual factor here relates to case manager caseload; if a case manager holds responsibility for an excessive number of cases then they will be unable to determine appropriate personalised thresholds and will either admit a patient unnecessarily or cause/contribute to delays in seeking treatment. Delays in accessing services have been shown to lead to deterioration in patients’ health and are a likely cause of future hospital admission. Lack of available community-based services constitutes a major challenge to effective case management\textsuperscript{82, 84}.

\textit{Description of Putative Mechanisms}  
Possible mechanisms for case management are summarised in Table 7. In theory, case management seeks to increase efficiency by reducing unnecessary contacts with the health system\textsuperscript{85}. Such contacts include fragmented routine contacts, as well as emergency contacts.
caused by potentially preventable exacerbations. The goal of case management is “to better co-ordinate care, offering individually-tailored contacts and care planning”\textsuperscript{85}.

The case management model is predicated on the presence of so-called ‘super-utilizers’; ‘high-risk’, high need patients, typically with multiple health conditions, who utilize a disproportionate amount of healthcare resource (high cost)\textsuperscript{86}. The idea behind case management is that by targeting additional and individually tailored primary care at these patients, more costly secondary care admissions (particularly emergency admissions) can be avoided\textsuperscript{87}.

However, research suggests that case management does not meet its primary aims for the patients involved, although it is associated with increased patient satisfaction \textsuperscript{88, 89}. In practice, MDT case management tends to target those identified as ‘high risk’ using a selected statistical algorithm that is validated to predict patients who are likely to have substantial future healthcare use\textsuperscript{78}. These tools generate a heterogeneous group of patients, and it may be that there are subgroups for which the direct effects of the intervention are more effective. However, as papers by Stokes\textsuperscript{71, 78} reveal it can be extremely challenging to identify so-called “super-utilizers” both in terms of the “safe” margin of those who can be appropriately managed in primary care and, equally, in terms of those for whom the complexity of their comorbidities renders secondary care an appropriate option.

Systematic review evidence identifies continuity of care as an important influence on admissions for long-term conditions\textsuperscript{90}. Commentators seek to distinguish continuity of relationship (a continuous caring relationship with clinicians) from continuity of management (all aspects of integration, coordination and sharing of information). Both mechanisms can be considered important within the context of preventable admissions. A patient must feel that they can trust the judgement of the health professional and that the health professional has a sufficient understanding of their unique personal circumstances. Practically, continuity of
management is important within the context of 24-hour care and delivery of services across organisational and professional boundaries.

Case management is centred on the premise that “targeted, proactive, community-based care is more cost-effective than downstream acute care”. Delivering such care requires that intervention is integrated across care providers to avoid overlap and to ensure each care provider knows and realizes what each other care provider does. Wagner’s Chronic Care Model (CCM) has been proposed as a framework to restructure the health system towards integrated, proactive, consistent and continuous care, and thus, anticipate acute exacerbations or lessen their consequences. The CCM draws on six interacting elements: links with the community, the health system, self-management support, tailored delivery system design, help for decision support and adequate clinical information systems. Case management for people with complex care needs offers a potential strategy for delivering this type of integrated care.

Time-limited case management targets those with the greatest risk of emergency admission. A stepped approach means that people at lower risk of admission can be targeted with disease management programmes or supported in self-management. Case management shares the patient-orientation of self-management (See below). Indeed, patients in the study by Gowing and colleagues reported being able to take a more active role in their own planning and care thereby promoting independence. However, independence appears context-dependent; a respiratory patient in the same study described being given a rescue pack for chronic obstructive pulmonary disease and struggling with her own judgement about when to use it.

Previous evaluations report that policy makers assumed that case management would stimulate “service redesign beyond the introduction of case management itself”. However, evidence of wider local re-engineering of primary and secondary care for older people has proved challenging to establish.
Conceptually, case management can be understood within the context of integrated care. The six dimensions of services integration suggested by the National Collaboration for Integrated Care and Support (2013)\(^93\) comprise:

- Consideration of patient and family needs
- Communication with the patient and between health care providers
- Access to information
- Involvement in decision-making
- Care planning
- Transitions between various health professionals.

Roland and colleagues advance possible explanations as to why using case management to improve care integration is not guaranteed to improve outcomes\(^94\). The first is a potentially faulty underlying programme theory i.e. e.g. because supply induced demand increases appropriate admissions and does not simply decrease inappropriate admissions. Alternatively, the implementation of case management interventions may be wanting – an explanation on which Goodwin\(^95\) and Ling\(^96\) draw to explain suboptimal achievement of effects.

**Table 7: Putative mechanisms for case management**

<table>
<thead>
<tr>
<th>Intervention Components</th>
<th>Contextual Factors (Enabling)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Accurate case-finding; identification of top 2% at risk patients on at risk register</td>
<td>• Knowledge and motivation of health and social care staff</td>
</tr>
<tr>
<td>• Single point of assessment</td>
<td>• Clarity of Role</td>
</tr>
<tr>
<td>• [May use MDT to case manage]</td>
<td>• Access to Training</td>
</tr>
<tr>
<td>• Joint care planning</td>
<td>• Optimised caseload levels (may not be achieved)</td>
</tr>
<tr>
<td>• Care co-ordination</td>
<td>• Regular and longer contact/visits</td>
</tr>
</tbody>
</table>

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- Contact between case manager and patient/caregiver
- Regular monitoring
- Knowledge of referral options
- Incentives
- “Green tape”: clear guidelines and algorithms relating to resource allocation by patients.
- *[Self Management]*

<table>
<thead>
<tr>
<th>Potential Mechanisms (HCPs)</th>
<th>Potential Mechanisms (Patients and Carers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accountability of individual or team to patient (named case manager)</td>
<td>Confidence in personalised thresholds</td>
</tr>
<tr>
<td>Confidence in ability to determine appropriate personalised thresholds</td>
<td>Belief in capability for self care and remaining at home</td>
</tr>
<tr>
<td>Identification of barriers to patient remaining at home and primary, community and social care resources required to address them</td>
<td>Prompt and open communication to HCP of exacerbations or barriers to self care.</td>
</tr>
<tr>
<td>Reduced fragmentation among services</td>
<td>Acceptance of care and services offered</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Leading To</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Efficacy (HCP)</td>
<td>Improved functional status</td>
</tr>
<tr>
<td></td>
<td>Improved quality of life</td>
</tr>
</tbody>
</table>
• Self Efficacy (Patient/Informal Caregiver)
• Increased case finding
• Changes to medication (to avoid adverse effects) in conjunction with GPs
• Case management seen as another add-on service competing for NHS resources
• Patients reluctant to be discharged from case management

Efforts to strengthen coping capability are closely linked to the self-efficacy theories propounded by Bandura (1977)\textsuperscript{97} [See under Self-management].

\textbf{Contextual Factors}
In common with other complex interventions case management studies generally lack contextual detail. As a complex intervention, case management includes various components interacting in a nonlinear way to produce outcomes that are highly dependent on context and variables across settings. Attention should focus on analysing not only if and how CM works for frequent users of healthcare services but also in what contexts.

\textbf{Role of Patient Preference}
Several studies reveal that patients are generally satisfied with individual case manager-led case management approaches\textsuperscript{85, 98, 99}. Patients particularly appreciate increased contact with health professionals and greater proactive input\textsuperscript{83, 100} and reassurance that care was being coordinated\textsuperscript{100}. In their qualitative study of the NHRPP Gowing and colleagues record that patients were generally unaware of the exact composition of the programme but, nevertheless, observed such individual features as a named GP, regular review and the occurrence of multidisciplinary team meetings\textsuperscript{72}.
Sheaff et al (2009) report that patients and carers valued case management for improving access to health care, increasing psychosocial support and improving communication with health professionals. They also report that “patients were often anxious that no-one should ‘take their nurse away’ and were often reluctant to be discharged from case management”.

Role of Culture
This section refers primarily to organisational culture within the healthcare system. See also the section on leadership below.

In most cases case management requires significant cultural change. In fact much of the relative lack of attributed success relates to the inability of case management approaches to stimulate the radical scale of change required in order to realise its full benefits. Ross and colleagues observe that “Case management works best as part of a wider programme of care in which multiple strategies are employed to integrate care. These include good access to primary care services, supporting health promotion and primary prevention, and co-ordinating community-based packages for rehabilitation and re-ablement. Where these features are not present case management may not demonstrate effects on emergency admissions.” In their thematic analysis of key factors of case management interventions, Hudon and colleagues highlight how the scale of innovation must be achieved across multiple levels, including organisational culture.

Role of Leadership
Leadership and culture are closely linked so this section should be considered in conjunction with the previous one.

Good leadership skills are required in order to secure the support of other members of the multi-disciplinary team for the case management model. In their thematic analysis Hudon and
Role of Evaluation/Measurement
Many individuals undergo repeated monitoring and review as well as further assessment and care planning until they are fit to exit the case management system (note previous discussion about time-limited versus ongoing definitions of case management). A well-written care plan enables case managers to monitor and review whether an individual is receiving an appropriate package of care. Frequency of monitoring will depend on the individual’s level of need; either daily, weekly or monthly, and directly, in the individual’s home, and/or through remote monitoring (e.g. by telephone or through telemetry of blood pressure or other vital signs). Such monitoring can be undertaken by a multi-disciplinary team.

Care plans must be constantly reviewed and changed where necessary. The Northumberland High Risk Patient Programme (NHRPP) incorporated a key area of monitoring; patients were to be followed up promptly within three days of discharge from hospital. It should be recognised that telephone contacts are likely to be under-reported because of the burden of recording.

Role and characteristics of Facilitation
The case manager typically operates within a multi-disciplinary team. It is vital that those in the team, and beyond, are engaged in the programme. Primary care professionals and social care staff generally welcome the role of case managers once they have a better understanding of what they do. They particularly appreciated the role of the case manager in:

- regular monitoring of patients
- making diagnoses and changes to medication regimens
- addressing patients’ social isolation by spending time with them
- co-ordinating the overall care process
- providing a link between primary, secondary and social care.

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Case managers need to work proactively with diverse health and social care professionals, requiring good working relationships and effective communication\textsuperscript{104}. Qualitative research supports personal aspects of the case manager role; community matrons were typically perceived as a “friend” community matrons in a case manager role\textsuperscript{81}. This finding corresponds with data from corresponding roles where empathy and compassion are regarded as important attributes.

Case management facilitates access to support and care as and when required. The patient, and their informal caregiver if present, feels able to call for adequate and appropriate help\textsuperscript{80}. There is evidence of case managers (specifically, community matrons) conducting low-skill roles initially but with the aim of these being delegated to other professionals in time or absorbed within self care\textsuperscript{81}. If, on the other hand a patient feels uncertain about their capability to remain at home, notwithstanding the information with which they have been provided, they feel empowered to access relevant secondary care-based help. Initially, the case manager occupies a role as a facilitator and gatekeeper to accessing appropriate help. Over time, however, the patient and informal care giver feel increasingly able to assess when a personalised threshold for accessing secondary care services has been crossed.

**Role/skills of Implementation Facilitators**

Care planning includes many components and may cross multiple settings rather than be episode-based. Fragmentation of care remains a persistent threat given the need to coordinate care plans for patients with complex chronic health conditions across multiple care contexts and professional groups. Given the frequent lack of consensus among professionals, relatives, carers and clients about the proposed care plan, good negotiation and communication skills are essential.

In addition to the pivotal role of the case manager, the care plan is typically seen as an essential component of the case management process. The initial assessment is translated into the development of a care plan and then facilitated and coordinated by the case manager.
Published studies, while agreeing on the importance of this component, typically lack detail on how this process should be undertaken.

Case management as an intervention may display considerable variation in the intensity with which it is delivered. Resource provision and the expertise of the case managers in their facilitation role are important contextual variables that may impact upon the success of the intervention. Further important variables include the balance of the case managers’ time between co-ordinating health and community-based services and interacting directly with the patient, the time spent on administrative tasks as opposed to direct work with patients, caseload size and role conflicts associated with combining the case-management role with other clinical responsibilities.

Crucial to the effective implementation of case management is case manager control over the form and content of the services provided. Does the case manager exert some control over the supply or availability of services or other resources? Alternatively, are resources allocated on a team basis or is the success of the intervention dependent upon referrals to other services. This latter “brokerage model” has been considered insufficient on its own to exert the requisite influence and thus to achieve effectiveness. However, even case management programmes with relatively more budgetary control may achieve only limited success when delivered within a wider resource-constrained environment105.

**Supporting Evidence**

This is a brief summary of evidence from systematic reviews, concentrating on hospital (re)admission as the outcome of interest. Key results from UK studies included in this analysis are also presented.

Case management is an area rich in systematic reviews and evidence syntheses. Small numbers of systematic reviews briefly addressed enabling factors of successful case management (CM) interventions in the discussion section of their paper. In a review on the
effectiveness of CM among frequent emergency department users, Kumar and Klein noted that “frequency of follow-up, availability of psychosocial services, assistance with financial issues and active engagement of the case manager and the patient were important characteristics of CM interventions”106.

Huntley and colleagues conducted a systematic review to identify observational studies conducted at a practice level that describe factors and interventions that impact on levels of utilisation of unscheduled secondary care107. Their review was limited by the challenges of trying to review across different health systems in different contexts. They found a benefit from seeing the same health professional thus informing debates about continuity care. Proximity to healthcare provision was another major factor. However, they found it difficult to determine factors impacting upon quality of care.

Huntley and colleagues subsequently conducted a systematic review and meta-analysis of case management interventions for heart failure. They included case management within a hospital context and also studies targeting nursing homes and long term care settings. None of their included UK studies therefore met our tighter inclusion criteria. They identified four studies of community-initiated CM versus usual care (2 RCTs and 2 Non Randomized Controlled Trials (NRCTs)) with only the 2 NRCTs showing a reduction in admissions107.

Stokes and colleagues conducted a meta-analytic review of 36 studies. Meta-analyses showed no significant differences in total cost, mortality, utilisation of primary or secondary care. They found small significant effects for case management in terms of self-reported health status and patient satisfaction. Interestingly their secondary analyses indicated that “the effectiveness of case management may be increased when delivered by a multidisciplinary team, when a social worker was involved, and when delivered in a setting rated as low in initial 'strength' of primary care” 85.
In an effectiveness review that included ten studies, none from the UK, Joo & Liu report that three studies documented statistically significant reductions in hospital readmissions. Two of these statistically significant studies fell within our 2010-2018 time period. Melton and colleagues report a nurse led CM intervention group of participants with multiple chronic illnesses demonstrated lower 30-day and 60-day hospital readmission rates than among participants in the control group (P < 0.05; P = 0.01). Chow & Wong similarly report that a nurse-led CM focused on older adults with chronic illnesses in China, demonstrated a significant reduction in hospital readmission rates in the intervention group over the control group (P = 0.018). The characteristics of these interventions indicates potential overlap within this review with the intervention labelled “specialist clinics”, with such clinics typically being nurse-led.

Joo & Liu (2018) conducted a qualitative evidence synthesis, using thematic synthesis, to review ten qualitative studies published between 2007 and 2016 for attitudes of individuals with chronic illnesses and their caregivers towards case management. Access to healthcare resources, health status supports and emotional aid were identified as facilitators of case management. Low information about case management and time constraints were identified as barriers. A complementary synthesis by Joo & Huber looked at barriers perceived by case managers when implementing case management. This thematic synthesis of ten qualitative studies (2007-2016) identified five barriers to implementation: unclear scope of practice, diverse and complex case management activities, insufficient training, poor collaboration with other health-care providers, and client relationship challenges.

In summary, there is little recent evidence to suggest that case management is effective across multiple diverse contexts. The UK research is limited in both quantity and rigour and suggests that such interventions are very context-specific with the surrounding environment playing a major role in the effect of the case management intervention. The intervention is well-liked by patients and, generally, by staff although concerns persist about caseload and the ability to deliver care in a timely and accessible manner. Economic evaluations are
relatively rare and it would seem that the performance of case management depends very much on how wide the evaluation framework is cast in terms of both costs and benefits.

**Potential Enhancements of Intervention/Implementation**

Commentators on case management consistently point out that, although the case manager role is pivotal, ultimately success is determined by the support available to back up the initial management. This does not only depend upon available primary care resources but also upon further social care involvement. A further consideration is the availability of a case manager. Optimally, 24-hour access to case management can combat the uncertainties that arise when the patient is unable to contact necessary advice and assistance. Below this very intensive level of provision, uncertainties about whether help is available and what to do when it is unavailable serve to subvert the very mechanisms by which case management achieves its success. Complementing availability concerns, comes anxieties about responsiveness. Critical to a timely response are issues relating to the overall caseload of the case manager, the level of dependency of patients within that caseload and the amount of time shared with other duties, for example administrative responsibilities. So, specifically in connection with community matrons in a case manager role, Brown and colleagues reported concern at the ability of community matrons to be able to respond within the patient’s perceived timescale.

While opportunities to co-create care plans with members of the primary care team are generally welcomed by patients and family members this requires sufficient time to prepare for care planning and to discuss those plans. It is therefore essential to make this planning process feel meaningful to the patient. Some patients felt that, by articulating their views and voicing concerns on behalf of other patients they could advocate for those who felt unable to take an active role.

Case management is a complex activity that operates over multiple care settings. Some commentators suggest that greater integration of IT systems, including shared electronic medical records and access to resource directories and clinical guidelines, could lead to improved patient outcomes (e.g. Lynch et al, 2000). However, this may be an artefact of
earlier evaluations and may now be offset, to a substantive degree, by technological developments in electronic health records, care plans and remote servers accessed through user authentication and secured, encrypted transmissions.

Previous evaluations emphasise the need for care pathways to be interpreted flexibly because patients do not fit into standard care pathway approaches. At a practical level this meant that “rigid eligibility criteria and cumbersome administrative procedures often led to delays in services being provided”82. Another reason for system failure was that nurses did not always have adequate access to alternatives to admission.

In a novel attempt to bring external theory to bear on the case management phenomenon Swanson & Weissert explore the Principal Agent Framework and Street Level Bureaucratic Theory114. They conclude that incentives, as well as "green tape", clear rules, guidelines, and algorithms relating to resource allocation among patients would impact upon the greater effectiveness of case management.

Evaluations have found little evidence of the systematic redesign of care aspired to by many case management programmes. The Evercare evaluation observed “poor integration between primary and secondary care, and out of hours services were not focused on keeping patients out of hospital”82. It concluded that more radical system redesign is needed to achieve a greater impact on admissions. Such radical system redesign has not generally been achieved, notwithstanding the potential offered by new models of care initiatives10, 115.

4.2: Patient education
Summary
Patient education is seen as a key component to several interventions designed to reduce preventable admissions and, given demands on general practitioner time, the role of the nurse is seen as critical delivery of such information. Three particular factors can be seen to mediate the success of patient education-based interventions; patient education is delivered in anticipation of exacerbations or other health incidents and so patients may not see the direct relevance of the information at the time provided or may forget it completely; patient education needs to be situated within the relative experience of individual patients (e.g. if your exacerbation is worse than the last one then… etc.) rather than in some impersonal absolute for all patients; for many patients self-efficacy is the issue not education retention. Many patients experience anxiety about their own ability to manage a situation and to make a correct decision. Unless this anxiety is alleviated then they will always seek a second opinion for reassurance.
**Definition**

A minimal definition of patient education is: “The teaching or training of patients concerning their own health needs”. In their report Purdy and colleagues distinguish “traditional patient education” which offers information and technical skills from “self-management education” which teaches problem-solving skills. From this perspective self-management education complements traditional patient education in supporting patients to live the best possible quality of life with their chronic condition\(^{116}\). Nevertheless, such a distinction is not implemented consistently throughout the literature making the co-existence of both patient education and self-management as separate intervention categories within this report particularly problematic. Self-management of multiple chronic illnesses, educating patients to monitor their own health and being able to recognise illness severity feature in current healthcare policy. The boundary between providing patient information and delivering patient education may also be difficult to perceive.

Controversy within the literature surrounds whether adult education is an appropriate model for patient education, particularly given that patients’ health needs are contingent to particular time periods or stages within a disease or treatment pathway. The above definition conveys formality, contrasting with the “teachable moment”, the idea that a health professional may harness any opportunity during their therapeutic encounter to impart some education that meets a patient’s health needs\(^{117}\). Key to this process is recognition of what health needs are – a patient may not know what they need to know while a health professional may not be able to time their education intervention to a point where a patient is most attentive, receptive or responsive to a particular message.

Kongstvedt defines patient education as "the process by which health professionals and others impart information to patients that will alter their health behaviours or improve their health status"\(^{118}\). This concept of behavioural change, very visible in the literature of the “teachable moment “is fundamental to contemporary views of patient education.
NICE guidelines for heart failure recommend that people with chronic heart failure should be offered “personalised information, education, support and opportunities for discussion throughout their care to help them understand their condition…”\(^{119}\). The reference to “personalised information” is particularly significant in this context; patients need to be able to situate the information that they have received within their own context of symptoms and disease progression.

Key challenges for patient education as an intervention relate to the fact that patient education is often an adjunct to other interventions that might be used to manage preventable admissions e.g. cardiac rehabilitation, self-management, telehealth and so it may be challenging to separate patient education as a discrete intervention/intervention component. The Cochrane review on *Patient education in the Management of Coronary Heart Disease* does attempt to separate the educational component from other aspects of cardiac rehabilitation\(^{120}\). Furthermore, patient education may constitute an ongoing iterative process that takes place over frequent patient-clinician interactions and therefore may be difficult to quantify.

**Intervention Components**

The key components of patient education interventions as reflected by UK studies identified for the mapping review are summarised in Table 8. As mentioned above a key challenge relates to how to operationalise the concept of patient education. Within a research context the Cochrane Review definition\(^{120}\)requires the presence of all four of the following elements: instructional activities organised in a systematic way; inpatient, outpatient or community setting; structured knowledge transfer about CHD for secondary prevention; and face-to-face (group or 1:1) or interactive delivery.

**Table 8: TiDIER-Lite characteristics for Patient Education**

<table>
<thead>
<tr>
<th>By Whom</th>
<th>By a health professional to patient with or without significant others.</th>
</tr>
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© Queen’s Printer and Controller of HMSO 2019. This work was produced by Chambers et al. under the terms of a commissioning contract issued by the Secretary of State for Health. This document may be freely reproduced for the purposes of private research and study and extracts may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.
What | Instructional activities organised in a systematic way involving personal direct contact including structured knowledge transfer about condition, causes, treatments or methods of secondary prevention.
---|---
Where | Delivered as inpatient, or outpatient in a community-based intervention setting or programme in a face-to-face format, in groups or on a one-to-one basis. May also include alternative delivery such as 'telehealth'.
To What Intensity | Intensity varies
How Often | Frequency varies

**Number and Type of UK Studies identified**
The mapping review identified 3 UK quantitative studies of patient education for cardiovascular or respiratory conditions. One study examined patients admitted with acute asthma\(^{121}\), a further study explored COPD patients with breathlessness\(^{122}\) while the remaining study\(^{123}\) examined multiple conditions including the cardiac and respiratory conditions that are the focus of this report.

Five UK qualitative papers were identified. Four of these reported findings from the HoldFAST study\(^{124, 125, 126, 127}\) with some of these identified not from the mapping review but from supplementary follow up of citations and references. The HoldFAST study was a multicentre study coordinated across Bristol, Oxford and Keele Universities and funded by the National Institute for Health Research. It aimed to explore the experiences of patients with heart failure from “multiple standpoints using ethnographic methods, combining observations, interviews and documentary data sources” \(^{126}\). It therefore offers a rich source of data on the experience of heart failure patients and particularly their experience of interventions that were commonly encountered in their ongoing care, e.g. patient education and specialist nurses. The remaining study\(^{128}\) examined the experience of patients who have encountered an exacerbation of chronic obstructive pulmonary disease, particularly in relation to fear and anxiety.
Details of the studies included in the analysis are presented in Table 35 (see Appendix 4).

*Operating Programme Theories*

People with chronic conditions are frequently admitted to hospital when hospital is not the optimal destination for them. They may have symptoms that could be self-managed or anxieties that could be addressed by patient education or information [PT1]. However, patients not only lack information about heart failure and self-care but, most importantly within this context they also lack knowledge on when to seek help. Patients may often, but not always, comprehend the information with which they have been provided, particularly if it is given in a standardised format. However, what they may typically lack is situational knowledge i.e. how to relate the information they have previously been given to the signs and symptoms which they are experiencing. Patients may feel confident about self-management of their medication in general and yet not feel confident about their actions in an “emergency” situation.

Access to written or verbal advice from a health professional, delivered remotely via technology and without presenting for face to face consultation or admission, may offer one route by which to address patient symptoms and concerns. However, there is increasing recognition that such information is only effective if the patient is receptive and the information is received at the time of need. If such information is not available, or if the patient perceives that it is not readily accessible, they may resort to easier channels of access such as a telephone call to their GP. There is substantial evidence to indicate that human sources of information are considered more accessible than other information sources in most contexts. Increased facility to look up information, for example on the Internet, may change perceptions about accessibility, particularly during out of hours, but this raises associated questions about whether such information is authoritative and credible and concerns that such information is not typically tailored to the context-specific needs of the individual patient. Glogowska documents how education messages were not always received and acted upon by patients, which could lead to unplanned admissions.
Patients may find it particularly challenging when first experiencing symptoms (e.g. coughing in relation to COPD) or when symptoms possess a severity not previously encountered or when symptoms include a new and unfamiliar feature for a patient to assess whether they have reached a legitimate trigger point. Patients may therefore delay seeking help (“I’ll just wait to see if the symptoms get better (or worse) before seeking further help”) or they may respond to the novelty or unfamiliarity of the symptoms (“I’ve not had one of these before, it must be bad”). Being unable to normalise their symptoms against their own experience patients may need to normalise what they are encountering against the experience of others, either as encountered through self-help groups or second-hand via their nurse or doctor.

People with chronic conditions could lack knowledge about alternative health provision and therefore draw disproportionately upon well-signposted channels such as their GP or the emergency department. Similar concerns relate to information required for directional purposes, as opposed to information required to manage a clinical problem. Directory type information may not be easily accessed or navigated and may not be maintained and kept up-to-date. If the credibility of such a source is damaged, albeit in a minor way a patient may find themselves pursuing channels that are more likely to yield a successful response.

Where patients have a good relationship with their GP they may perceive that they are more accessible to an appointment or a home visit. Other patients may feel guilty if they have to call the GP. As a consequence, they may leave the decision to the agency of another; a carer or family member. Having missed the initial window for timely non-hospital intervention they may find themselves at a point where they are too late to avoid hospital admission.

If patients do not have written or verbal information on when to telephone for an ambulance they may be less likely to use emergency services appropriately. One possible approach is to include such information within a written self-management plan. Both primary and
secondary care physicians in the HOLDFast study acknowledged that they were unsure about what services were available or that there were few services upon which they could call127.

People with chronic conditions may also use health services inappropriately; delaying their presentation to a GP or hospital [PT4] because of perceptions of the service either anticipated or based on the past experience of either themselves or others. Some patients may also feel a reluctance to seek medical advice if they perceive that their previous actions may have contributed to their condition (as in the case of smoking and COPD129).

Description of Putative Mechanisms
As noted by Fry et al.124, Bury (1982) describes the effects of chronic illness as ‘biographical disruption’ to everyday life131. Disruption extends beyond the patients themselves to impact upon their families and wider social network. In response, patients and their families may look for information, support, and the most effective strategies to manage their symptoms, hoping to minimise potential future disruption.

Symptom unpredictability reportedly leaves patients feeling helpless and completely dependent on those around them. This in turn can lead to a lack of control of the illness and an increased burden on family and the healthcare system (Morris et al, 2011132). Implications for carers are that responsibility for care may shift from the patient to their spouse or immediate family. Commentators suggest these factors may precipitate a patient to adopt the ‘sick role’, relying on their family for support both with their illness and previous responsibilities133.

Table 9: Putative mechanisms for patient education
**Intervention Components**

- Instructional activities organised in a systematic way
- Personal direct contact
- Structured knowledge transfer (e.g. condition, causes, treatments or methods of secondary prevention).

**Contextual Factors (Enabling)**

- Health professional knows patient’s personal circumstances, including co-morbidities
- Relaxed environment within which patient has “control”
- Patients whose first language is not English,
- Patients too ill to benefit from education
- Patients in denial about their condition,
- Patients attributing their condition to growing older,
- Patients with learning difficulties
- Patients experiencing cognitive decline
- Patients living with addictions.

**Potential Mechanisms (HCPs)**

- Good communication
- Tailoring of knowledge transfer to capacity and needs
- Sufficient time to allow tailored explanations

**Potential Mechanisms (Patients and Carers)**

- Good communication
- Good situational knowledge of their condition and appropriate responses to exacerbations
<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Leading To</th>
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<tbody>
<tr>
<td>• Challenging of “sick role”</td>
<td>• Decreased utilisation of health services</td>
</tr>
<tr>
<td>• Increased self sufficiency</td>
<td>• Development of “expert patient role”</td>
</tr>
<tr>
<td></td>
<td>• Possible development of a resource for similar patients</td>
</tr>
</tbody>
</table>

Negative contextual factors: red font

**Contextual Factors**

The HoldFAST study found that, notwithstanding almost universal recognition of the importance of providing education to patients to help them manage their condition among secondary care physicians (specialists) and general practitioners, both found that time pressures during consultations restricted their contribution to patient education.

Participants acknowledged that not all patients would take up the education offered. Patients who find the information difficult to assimilate would find self-management difficult. These patients were more likely to be those with English as a second language, those too ill to benefit from education or in denial about their condition, people with learning disabilities, and those experiencing cognitive decline or living with addictions. The specialist heart failure nurses felt that it was necessary to adapt the education they offered patients to the individual’s ability to receive it. They tried to identify issues of importance to patients as a way of personalising the information. The nurses stressed that even when patients were able to understand information, it would still be necessary to repeat those messages regularly.\(^{124}\)
Role of Patient Preference
All respondents in a HoldFAST study expressed positive views about the role within patient education of specialist heart failure nurses. Specialist nurses were perceived to have more time to dedicate to patients. Their role in explaining the illness and providing support, was greatly appreciated by the respondents. This additional time allowed for greater patient education on how to identify symptoms that could indicate a worsening of their illness.

GPs expressed the view that their personal patients would be likely to receive a different response than if someone else, lacking a knowledge of patient values and clinical circumstances, handled their care. Continuity of care is, by implication associated with appropriate targeting of healthcare facilities and resources. Other situational factors, not catered for by generic patient education, include where families are struggling to manage patients at home or patients are living alone without sufficient support.

While recognition exists of the increasing role that specialist heart failure nurses and community matrons could play in supporting patients at home this was accompanied by acceptance that they could not provide round-the-clock services and that symptoms like breathlessness required careful management in the community.

Role of Culture
Fry and colleagues (2016) emphasise the importance of continuity of care as an organisational backdrop against which to deliver effective patient education. This theme is specifically picked up in detail in a paper focusing on organisational management of heart failure. An initial barrier relates to the initial diagnosis and labelling of the condition with clinicians euphemistically referring to an ageing heart or a stiff heart in order to alleviate the impact of the stark term “heart failure” and its connotations with terminal illness. Many patients then found the level of supporting information and education unsatisfactory, often having to rely on leaflets available in the clinic or on explanations on their discharge papers. In contrast, where a specialist heart failure nurse was involved explanations were felt to be more complete and satisfactory.
Clinicians highlighted how the organisational culture of a busy hospital was not conducive to the provision of appropriate explanations of heart failure\(^\text{126}\); within hospital and community-based heart failure specialist nursing teams, patients reported more positive experiences. Overall, the study revealed that a lack of patient information and education was a strong theme in our study and a key barrier to the development of patient self-help strategies to help prevent readmissions (links to Section 4.3. Self-Management, below). Healthcare participants emphasised that patients need to be given information and guidance as part of an “ongoing conversation”. Use of the term “ongoing” here links this to the wider theme of continuity of care with heart failure specialist nurses and GPs being seen to be key to the success of this process.

Patient education is typically perceived as a time-consuming activity which may prove challenging to accommodate within the time-pressured environment of clinical encounters. In addition, its upstream preventive function can be seen as detached, and remote, from the more typical disease management activities of the clinic. Effects of patient education are not typically observable and definitive evidence on its effectiveness is lacking. As a consequence, patient education may be seen as a “common good” and a patient right but not necessarily a critical and integral component of an intervention. However, high levels of patient satisfaction from patient education activities suggest that it can be considered critical to patient-centred care.

**Role of Leadership**
Glogowska and colleagues (2016) emphasise how having a specialist nurse who could take the lead in coordinating the care of the heart failure patient was considered vital by many respondents\(^\text{127}\). It is, however, unclear, whether this refers to Leadership in the sense intended by the PARIHS framework or rather whether it is referring to a form of case management which is more appropriately considered as Facilitation. More importantly, a specific role for leadership in the context of patient education is not identified although it could be a collateral benefit achieved from greater integration, coordination and continuity of care.
Role of Evaluation/Measurement
Delivery of patient education is heterogeneous, not only in the form and format in which it is delivered but equally in the characteristics of the deliverer and in the potential receptivity of the recipient. It is extremely challenging to ensure the fidelity of delivery of patient education within a busy clinic setting. Minimal standards may be monitored; did the patient receive a patient education booklet?, but critical components of the patient education such as did the patient receive and understand key messages and did they receive the information that they needed at that particular time are challenging to elicit on a routine basis.

Role and characteristics of Facilitation
The HCPs accepted that heart failure patients at the end of their lives were repeatedly hospitalised, even when no further interventions would change the course of the condition, because of the lack of planning and provision that could keep them in the community. In location 2, this was attributed to patients being admitted by out of hours doctors who did not know them.

Respondents described a lack of pro-active contact from the healthcare system, both from hospitals and primary care, regarding scheduling appointments and the next stages in their care pathway. These respondents described a degree of uncertainty what would happen next and whose responsibility it was to monitor and support them. They expressed uncertainty about whose responsibility it was to initiate communication, when hospitals or primary care failed to send information to the respondents as they had said they would. Other respondents, however, described certain healthcare professionals as being exceptionally efficient at facilitating direct access to themselves or other parts of the healthcare system quickly. In these instances, patients expressed appreciation for the effectiveness of that particular doctor or nurse, which led to anticipation of a positive future relationship between the healthcare professional and the patient.

Role/skills of Implementation Facilitators
Specialist heart failure nurses were perceived to have more time to dedicate to patients. The nurses’ role in explaining the illness and providing support was greatly appreciated by
The nurses also provided patient education on symptoms that could indicate an exacerbation of their illness. Specialist nurses are able to liaise with different clinicians coordinating care to participants with complex multiple co-morbidities.

**Supporting Evidence**
Numerous studies have identified a lack of patient understanding of heart failure including a lack of patient knowledge of medications and self-care. The Cochrane review of *Patient education in the management of coronary heart disease* concludes that, overall the evidence is only very low to moderate quality. It finds that patient education, as part of a cardiac rehabilitation programme, “does not contribute to fewer deaths, further heart attacks, heart by-pass or angioplasty, or admission to hospital for heart-related problems”. It does acknowledge that there is evidence of fewer other heart-related events and improvements in health-related quality of life with education-based interventions. It was not possible to determine an effect on individual mortality.

The current evidence base seems largely interpreted within a “first do no harm” frame. In the absence of sufficient information at present “to fully understand the benefits or harms of patient education for people with heart disease” the Cochrane review endorses current guidelines that “people with heart disease should receive comprehensive rehabilitation that includes education”. Further research is needed to evaluate how education for people with heart disease can be delivered in an effective and cost-effective way.

**Potential Enhancements of Intervention/Implementation**
Provision of specialist heart failure nurses, alongside GP and specialist clinician input, was recognised as an essential mechanism for ongoing patient education. Time spent in outpatient clinics is brief and highly-pressurised and health professionals have to select judiciously the two or three items of information that they want the patient to recall when they get back home. Specialist heart failure nurses, either in clinic or in the community were seen as having the optimal opportunity to exploit opportunities for ongoing education.
Glogowska and colleagues (2015) report that education represented a considerable portion of the specialist heart failure nurse’s role. The ongoing relationship between the specialist nurse and the patient, in particular during routine home visits, where patients are more relaxed, in control and have more time to assimilate information, offered an opportunity for delivery of patient education. This was considered particularly important given that the patient can only take in a small percentage of what the health professional shares on any one occasion.

Further exploration is required on the degree of tailoring and personalisation required in order for patient education to be effective. Some commentators have suggested the value of the “information prescription” analogous to a medication prescription which combines a formality of exchange with personalisation to patient perspectives. Also in connection with tailoring, a review by the Joanna Briggs Institute suggests that future studies might consider interventions inclusive of more diverse ethnic populations of varying literacy and socio-economic levels.

4.3: Self-management

Summary
Self-management follows from and complements patient education. Written action plans, including information on when to seek medical help, are a key component of many self-management programmes. The key mechanism for self-management is thought to involve increasing the patient’s self-efficacy and confidence to be actively involved in managing their condition. There is strong evidence from systematic reviews of randomised trials supporting the effectiveness of self-management with appropriate support for reducing hospital admissions in respiratory conditions such as asthma and COPD and cardiovascular conditions like chronic heart failure. UK studies did not find a decrease in admissions with self-management relative to usual care, although one study suggested that self-management for COPD is likely to be cost-effective.
Self-management support is most frequently delivered by nurses but GPs and other physicians are also involved. Some studies stress the importance of the whole team in embedding self-management support at the level of the general practice.

**Definition**

Purdy et al. define self-management as a ‘formalised education programme aimed at teaching skills needed to carry out medical regimens specific to the disease, guide health behaviour change, and provide emotional support for patients to control their disease and live functional lives’\(^1\). Self-management education complements traditional patient education by teaching problem-solving skills alongside information and technical skills. Written action plans are a key component of many self-management programmes, especially for respiratory conditions. The plans support patients in managing both chronic conditions and acute exacerbations of their condition, including when to seek medical help.

An early review paper\(^{135}\) identifies three key self-management tasks (medical management, role management and emotional management) and six self-management skills (problem solving, decision making, resource use, formation of a patient–provider partnership, action planning and self-tailoring). Role management involves adapting behaviour and/or activities as required to manage the health condition and self-tailoring involves applying self-management knowledge and skills appropriately to the patient’s individual context.

**Intervention Components**

The key components of self-management interventions are summarised in Table 10. This reflects UK practice as described in the studies selected from the mapping review (see below).

<table>
<thead>
<tr>
<th>Table 10: Key components of self-management interventions</th>
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<tbody>
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<td><strong>By whom</strong></td>
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other physicians were also involved. Some studies stressed the importance of the whole team in embedding self-management support at the level of the general practice\textsuperscript{136, 137}.

| What | The level of self-management support offered to patients varied widely across studies and often appeared to be enhanced for research purposes rather than reflecting normal clinical practice. Key elements included training in self-management\textsuperscript{138}, remote symptom monitoring\textsuperscript{139}, action plans\textsuperscript{136, 140, 141} and home visits\textsuperscript{138, 139}. Named interventions (GOAL and SPACE) were evaluated in three studies\textsuperscript{142-144}. |
| Where | Self-management support is most frequently co-ordinated through general practices and other primary care settings, but is also offered through specialist outpatient services |
| To what intensity | Interventions varied in intensity, including the amount of initial training offered to participants, additional support such as remote monitoring or home visits and support for developing and reviewing action plans |
| How often | Self-management support was typically offered as a ‘one-off’ intervention involving education, sometimes combined with other support such as monitoring. By contrast, action plans are designed to last indefinitely, with regular (preferably annual) reviews to update the plan where necessary |

**Number and Type of UK Studies identified**

The mapping review identified 25 studies of self-management for cardiovascular or respiratory conditions. The largest group of studies dealt with COPD (12 studies), followed by asthma (6) and hypertension (5). One study covered both asthma and COPD\textsuperscript{141}. The studies selected for inclusion in this analysis focused on asthma or COPD (or both) because these were the conditions with most data on the role of self-management for reducing avoidable admissions in the UK. Two studies on heart failure were excluded: one dealt largely with the development of an intervention\textsuperscript{145} and the other was used earlier in the...
review process to develop initial programme theories\textsuperscript{126}. Details of the studies included in the analysis are presented in Table 36 (see Appendix 4).

**Operating Programme Theories**

By definition, PT\textsuperscript{1} is applicable to self-management education and support. However, the UK included studies provided mixed evidence relating to this theory. Studies generally failed to provide clear evidence of a reduction in hospital admissions associated with self-management interventions for patients with COPD or a mixture of long-term conditions\textsuperscript{138, 143, 146}. There was evidence of patients feeling satisfied with non-secondary care provision of self-management support (PT\textsuperscript{2}) but this referred to a service with enhanced support\textsuperscript{139}. Implementation of asthma action plans was hindered by lack of confidence by GPs and other clinicians in the usefulness of the intervention(PT\textsuperscript{3})\textsuperscript{140}. PT\textsuperscript{4}, referring to the possibility of patients delaying seeking treatment leading to greater overall use of health services, may also operate in some circumstances but we did not find evidence of this in our sample of studies.

Several studies related to PT\textsuperscript{5} which stresses the influence of the wider healthcare system and the availability or otherwise of support and incentives. These included factors operating at the level of GP practices, local NHS commissioners and national policies such as the Quality and Outcomes Framework (QOF) which encourage practices to prioritise mandatory targets at the expense of other work\textsuperscript{136, 143, 146, 147}.

**Description of Putative Mechanisms**

The key mechanism for self-management is thought to involve increasing the patient’s self-efficacy and confidence to be actively involved in managing their condition. Lorig and Holman state that increasing self-efficacy can be achieved through four key mechanisms: performance mastery, (role) modelling, reinterpretation of symptoms and social persuasion\textsuperscript{135}. Some relevant mechanisms highlighted in this analysis of UK studies are summarised below (Table 11).
Table 11: Putative mechanisms for self-management

<table>
<thead>
<tr>
<th>Intervention Components</th>
<th>Contextual Factors (Enabling)</th>
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</thead>
<tbody>
<tr>
<td>Education and training</td>
<td>Patient age and family support</td>
</tr>
<tr>
<td>Remote symptom monitoring</td>
<td>Patient support for intervention</td>
</tr>
<tr>
<td>Home visits</td>
<td>Support/advice available for patients</td>
</tr>
<tr>
<td>Action plans (including review/updating)</td>
<td>Commitment to research/evidence</td>
</tr>
<tr>
<td></td>
<td>Active promotion of self-management</td>
</tr>
<tr>
<td></td>
<td>Financial penalties for readmission</td>
</tr>
<tr>
<td></td>
<td>Whole practice approach to implementation</td>
</tr>
<tr>
<td></td>
<td>Support from wider healthcare system</td>
</tr>
<tr>
<td></td>
<td>(managers or commissioners)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Potential Mechanisms (HCPs)</th>
<th>Potential Mechanisms (Patients and Carers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teams feel empowered to support holistic self-management</td>
<td>Acquire skills/knowledge</td>
</tr>
<tr>
<td>Self-management incorporated in routine practice</td>
<td>Reinterpretation/reframing of symptoms</td>
</tr>
<tr>
<td></td>
<td>Partnership with HCPs</td>
</tr>
<tr>
<td></td>
<td>Social support</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Leading To</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased self-efficacy</td>
<td>Appropriate use of health services</td>
</tr>
<tr>
<td>Ongoing self-management</td>
<td>Reduction in preventable admissions</td>
</tr>
</tbody>
</table>

**Contextual Factors**

**Role of Patient Preference**
Patient preference was generally seen as a barrier to participation in self-management, although much of the qualitative research on this topic was based on the perspective of health professionals rather than patients. Kennedy et al. noted that patients in their study had only a small amount of time in contact with health professionals and this made it difficult for them.
to embed self-management in their daily routine. They also suggested that patients from deprived backgrounds may have difficulty engaging with concepts like participation in self-management and shared decision-making, particularly when they may be feeling unwell.\textsuperscript{146}

Morrow et al.\textsuperscript{136}, Ogunbayo et al.\textsuperscript{147} and Roberts et al.\textsuperscript{141} all presented qualitative data on health professionals’ views of supporting self-management of COPD and/or asthma. Barriers identified included reluctance to attend review appointments; patients being ‘in denial’ about the severity of their condition; unwillingness to change behaviour; personal circumstances that made it difficult for patients to prioritise self-management; and patient resistance to action plans.

In the study by Patel et al.\textsuperscript{139}, patients who had experienced an enhanced self-management support intervention expressed concerns about continuing self-management without additional support after the study period. Some patients expressed a preference for seeing a GP rather than using rescue medication for an exacerbation, again suggesting barriers to engaging in self-management. In a study of personalised action plans, patients stated that they did not use the plans because they did not meet the patients’ needs, focusing too much on medication and management of worsening symptoms.\textsuperscript{140}

Data from quantitative studies also support the existence of patient preference-related barriers to self-management. Hoskins et al. recruited only 48 patients for their study, compared with a target of 80.\textsuperscript{142} Similarly, 164/464 participants approached declined to participate in the study by Johnson-Warrington et al.\textsuperscript{143} and only 14 of those who did participate expressed an interest in going on to pulmonary rehabilitation. In the Glasgow supported self-management trial, only a minority of those who received the intervention (75/180) were classified as ‘successful’ in self-managing their COPD after 12 months.\textsuperscript{138}

Some examples of patient preference facilitating self-management were also reported. Bucknall et al. identified predictors of successful COPD self-management, including younger
age and living with others. In the trial by Hoskins et al., those patients who agreed to take part were highly motivated, resulting in low rates of attrition. Kennedy et al. recruited 43% of eligible patients to their study, which the authors considered a high participation rate for a primary-based community intervention. In studies of health professionals’ views, respondents recognised that most patients wanted information on how to manage their condition and that improved understanding and ownership may make patients more willing to follow self-management action plans. Patel et al. reported that all the patients in their study were willing to use an electronic diary to allow symptom monitoring regardless of their previous experience with the technology. The authors suggested that patients were willing to engage with self-management because they felt uncomfortable with being frequent users of health services. Finally, Ring et al. found that personalised action plans were perceived by both patients and health professionals to be useful for certain groups, particularly those learning about their asthma and how to manage it.

Role of Culture
This section refers primarily to organisational culture within the healthcare system. See also the section on leadership below.

Cultural barriers to self-management support were identified in several studies. Hoskins et al. found that health professionals found difficulties in producing an action plan in the time available for a consultation, perceiving that discussion of patients’ life goals complicated the process. Another study recruited patients in hospital and reported that short inpatient stays made it difficult to complete all the necessary procedures. Kennedy et al. and Morrow et al. identified the importance of competing priorities for GPs, including a tendency to treat work that was not audited or recognised through the quality and outcomes framework (QOF) as a lower priority. GPs were concerned about delegating self-management support to nurses but often felt they had no alternative. Ogunbayo et al. identified differences in culture between teams working in different settings. Health professionals from primary care backgrounds tended to view self-management from a narrow perspective focusing on
medication management and annual reviews, whereas those from specialist respiratory teams felt empowered to deliver a more ‘holistic’ style of support. In Patel et al.’s study of enhanced self-management support, some patients expressed frustration with the attitude of the health service, particularly GPs, in relation to waiting times for appointments and pressure to see a nurse rather than a doctor.

Ring et al. found that despite guideline recommendations many health professionals did not fully support the use of personalised asthma action plans. This meant that they did not routinely issue plans or review them with patients. A specific cultural barrier identified by Roberts et al. was lack of self-efficacy among health professionals, with a third of respondents stating that they lacked confidence in their ability to construct an action plan. Lack of confidence was more common among doctors than nurses.

Cultural facilitators to implementing self-management support included buy-in at the general practice level and support from the local health management organisation (primary care trust). As noted above, professionals working in specialist respiratory teams felt able to deliver more ‘holistic’ support compared with their primary care colleagues. Research nurses were viewed positively by patients as a source of advice, although this reliance cast some doubt on patients’ ability to manage unsupported self-management after the study. In studies of action plans, health professionals shared the view that such plans were appropriate for certain patients and were in line with the culture of evidence-based practice.

Role of Leadership
Leadership and culture are closely linked so this section should be considered in conjunction with the previous one.

In relation to the GOAL intervention for asthma, Hoskins et al. identified introduction of a time consuming intervention into routine practice as a major challenge and identified leadership at the whole practice level as a means of overcoming this. In this study, a large
urban practice with a commitment to research was the only participating practice that met its target for patient recruitment. Morrow et al. also identified engaging the whole practice team as a way of developing and implementing asthma self-management. Kennedy et al. noted that their study received support from the local primary care trust, although the significance of this declined over time as the trusts gave way to clinical commissioning groups. The support was reflected in high levels of practice recruitment and staff attendance at training events.

A different form of leadership was exercised by the wider health system in the form of audit, incentives and penalties. One study’s authors noted that ‘fines’ to providers for readmissions within 30 days of discharge may facilitate implementation of self-management interventions. Practice priorities were reported to be shaped by national policies and priorities including the QOF and there was an expectation that practices would also focus on areas of relative weakness. The system of commissioning was reported to lead to lack of continuity in service provision and variation between geographic areas.

Role of Evaluation/Measurement
The included studies evaluated some combination of the effectiveness of self-management, implementation of the intervention in practice and patient or health professional views and perceptions of self-management. Only one study evaluated cost-effectiveness; Dritsaki et al. found that participants who received the SPACE intervention for COPD gained 0.1 QALYs compared with usual care at an estimated cost of £280.39 per QALY. This translated to a 97% chance of the intervention being cost-effective at a threshold of £20,000 per QALY.

As noted above, Bucknall et al. identified the characteristics of patients who were more likely to be successful in implementing self-management, mainly younger age and living with others. The GOAL intervention to support goal setting for asthma self-management was successful in changing the process of asthma review but the extra time required was a problem given the constraints of routine practice. This suggested that further refinement was
required before proceeding to a definitive trial of the intervention\textsuperscript{142}. In terms of evaluating interventions against usual care, Johnson-Warrington et al. noted that participants in their study received specialist follow-up routinely, suggesting that usual care may already be close to optimum\textsuperscript{143}. Kennedy et al. drew attention to the need to better understand the active components of interventions that contribute to effective self-management support\textsuperscript{146}.

Morrow et al. \textsuperscript{136} and Ogunbayo et al. \textsuperscript{147} both emphasised the role of measurement operating within the health system (specifically the QOF system that was formerly in operation) in influencing how self-management was implemented at the organisational (specifically the general practice) level.

Qualitative evidence about the barriers and facilitators to self-management is discussed above. Evidence from the included studies about the effectiveness of self-management interventions for reducing hospital admissions in UK settings is discussed in the section on supporting evidence below.

**Role and characteristics of Facilitation**

Facilitation of the implementation of self-management operates on two levels: between the healthcare system and health professionals delivering self-management support and between those health professionals and the patients they serve. The included UK studies provided examples of both levels of facilitation. In two studies, training was provided to participants in advance to enable them to participate in the study \textsuperscript{138, 143}. A third study involved time-limited support for participants, including home visits by research nurses, with the aim of self-management continuing unsupported after the end of the study period\textsuperscript{139}.

In terms of facilitation at the level of the health professional, this was provided through the research team in two studies\textsuperscript{142, 146}. Training was relatively brief (one half-day workshop and two practice-based sessions) and Kennedy et al. noted that this was the maximum achievable within the constraints imposed by other demands on staff time\textsuperscript{146}. The role of health
professionals in facilitating self-management through action plans in routine practice was explored qualitatively by Roberts et al.\textsuperscript{141}; participants noted that GPs often delegated this work to nurses or other practice staff but further details were not reported.

**Role/skills of Implementation Facilitators**

Role and skills of implementation facilitators were discussed in most of the included studies. Seven studies reported at least some data as summarised in Table 12. Three of the studies involved facilitation at the level of health professionals and in four cases facilitation was delivered to patients directly in the context of research (two studies) or routine practice (two studies).

**Table 12: Role/skills of implementation facilitators in self-management studies**

<table>
<thead>
<tr>
<th>Study reference</th>
<th>Role/skills of implementation facilitators</th>
<th>Who was facilitated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bucknall 2012\textsuperscript{138}</td>
<td>Nurses were trained to deliver structured self-management in four fortnightly home visits, each lasting about 40 minutes. Nurses' training was based on self-regulation theory. Those without previous respiratory experience completed three half-day training sessions covering COPD and communication strategies designed to empower patients</td>
<td>HP →Patients</td>
</tr>
<tr>
<td>Hoskins 2016\textsuperscript{142}</td>
<td>Training was delivered to nurses by two nurse practitioners and a health psychology researcher</td>
<td>HP →Patients</td>
</tr>
<tr>
<td>Johnson-Warrington 2016 \textsuperscript{143}</td>
<td>Introductory session involved a trained physiotherapist who used motivational interviewing techniques to support behaviour change, goal setting and problem solving. Details of staff facilitating further support were not reported</td>
<td>Patients</td>
</tr>
<tr>
<td>Kennedy 2013 \textsuperscript{146}</td>
<td>Two facilitators employed by the primary care trust delivered training and provided access to self-management support activities and resources</td>
<td>HP →Patients</td>
</tr>
</tbody>
</table>
### Supporting Evidence

This is a brief summary of evidence from systematic reviews, concentrating on hospital (re)admission as the outcome of interest. Key results from UK studies included in this analysis are also presented.

For asthma, a Cochrane review published as long ago as 2003\(^{148}\) found that optimal self-management for adults with asthma almost halved the risk of hospitalisation (risk ratio 0.58, 95% CI 0.43 to 0.77). Optimal self-management was defined as provision of a written action plan for self-management of exacerbations together with self-monitoring and regular medical review. The finding was based on 36 randomised trials involving 6090 participants. Supported self-management is strongly recommended in national and international guidelines, including those of the British Thoracic Society/Scottish Intercollegiate Guideline Network (BTS/SIGN)\(^{149}\). These guidelines cite 261 randomised trials included in 22 systematic reviews in support of the recommendation for self-management to be provided.

In a 2014 Cochrane review\(^6\), self-management for patients with COPD was associated with a lower probability (compared with usual care) of respiratory-related hospitalisations (odds ratio (OR) 0.57, 95% CI 0.43 to 0.75, nine studies, 1749 participants, moderate-quality

<table>
<thead>
<tr>
<th>Author</th>
<th>Description</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ogunbayo 2017(^{147})</td>
<td>Participants were from primary care (8), specialist respiratory (7) and pulmonary rehabilitation (5) teams, with highly varied professional backgrounds</td>
<td></td>
</tr>
<tr>
<td>Patel 2016(^{139})</td>
<td>Research nurses monitored symptoms as reported in electronic diaries and visited patients as required</td>
<td></td>
</tr>
<tr>
<td>Roberts 2012(^{141})</td>
<td>For asthma, 25% of physicians reported undertaking self-management support themselves. Support was more commonly delegated to a practice nurse or nurse specialist (64%). For COPD, 25/44 physicians and 10/14 nurses reported undertaking self-management support</td>
<td></td>
</tr>
</tbody>
</table>
evidence) and all cause hospitalisations (OR 0.60; 95% CI 0.40 to 0.89, 6 studies, 1365 participants, moderate-quality evidence). The authors calculated that over one year of follow-up, eight (95% CI 5 to 14) participants with a high baseline risk of respiratory-related hospital admission needed to be treated to prevent one participant with at least one hospital admission. The corresponding figure for those at low baseline risk was 20 (95% CI 15 to 35).

Although heart failure was not covered in this section of the report, systematic reviews and meta-analyses suggest a benefit of self-management interventions to reduce hospital admission in this condition also. However, interpretation of findings is complicated by heterogeneity arising from issues such as varying trial designs, intervention components, follow-up periods and methods of outcome assessment\(^\text{150}\).

In summary, there is strong evidence from systematic reviews of randomised trials supporting the effectiveness of self-management with appropriate support for reducing hospital admissions in respiratory conditions such as asthma and COPD and cardiovascular conditions like chronic heart failure. This evidence has resulted in strong recommendations in clinical guidelines in favour of implementing self-management as widely as possible. However, guidelines also recognise the challenges of implementing a complex intervention with limited resources and of involving patients as active partners in managing their condition.

The UK research did not entirely support the findings of the systematic reviews. None of the three studies that evaluated the outcome found a decrease in hospital admissions with self-management relative to control groups\(^\text{138}, 143, 146\). The influence of these findings on UK practice is unclear and it should be noted that we did not attempt to identify all relevant UK studies or even a representative sample of them. The only economic evaluation included in our analysis suggested that self-management for COPD is likely to be cost-effective in the UK, with an estimated cost of £280 per QALY gained compared with usual care\(^\text{144}\).
Potential Enhancements of Intervention/Implementation

Suggestions for improving the implementation of self-management came from three qualitative studies. The suggestions originated from health professionals participating in the studies or from study authors rather than from patients or the public.

Suggestions from the study by Morrow et al. included emphasising the evidence for benefit, improving teamwork (including team-based education), and organisational strategies (including remote consulting) which would need to fit within existing practice routines. Technology was thought to offer some potential solutions but these must be integrated with existing practice information technology systems. In Ogunbayo et al.’s study, normalising self-management into routine practice was identified as a theme at the practitioner level. Participants perceived that this involved use of various self-management planning tools as well as changing practitioner or practice culture.

Finally, Ring et al. discussed the potential role of multi-faceted intervention to facilitate implementation of personalised action plans by tackling identified barriers, e.g. using standard templates, electronic prompts to review plans and encouraging patients to bring plans to review appointments.
4.4: Telehealthcare

Summary
Telehealthcare appears to offer inherent advantages in terms of feedback mechanisms, condition monitoring and communication between health provider and patient. However, some systemic issues remain – either the patient has to make the decision as to when emergency admission is appropriate, based on feedback data which needs to be calibrated according to likely severity, or the health care professional remains in control of that decision. In the latter case it is critical whether the health care provider has all the information that is required to facilitate the decision. For example, they may wish to corroborate the telemonitoring data with observation of physical signs. Provision of telemonitoring data does not address the essential issues of patient self efficacy or practitioner efficacy, namely the confidence to make a decision about the appropriateness of admission within a risk averse culture or a safety first psychological state.

Definition
Frequently the term “telemedicine” is used as an umbrella term. However, this term carries unwelcome connotations by placing the doctor at the centre of the interaction. Terms such as telehealthcare, telehealth and telecare are to be preferred. Telehealth involves the remote exchange of data between a patient and healthcare professionals as part of the patient’s diagnosis and healthcare management. Examples include monitoring of blood pressure or of blood glucose for diabetes. Telehealth may facilitate an improved patient understanding of their health conditions, providing them with tools for self monitoring, encouraging better self management of health problems, and alerting additional professional support if devices signal a problem.

A Cochrane review of services for patients with asthma\textsuperscript{151} combines both the -health and -care suffixes to define “telehealthcare” (adapted from Miller, 2007) as “the provision of personalized healthcare at a distance.” Telehealthcare embodies three components:
information obtained from the patient; electronic transfer of data over a distance; and
personalised feedback from a health professional.

“At a distance” requires use of a “tool of distance communication that works without the
simultaneous physical presence of the participants in the interaction”. Such a technology
might be “telephone, e-mail, the internet or any other networked or mobile device”. The
emphasis is on the nature of the interaction; the novelty or sophistication of the technology is
irrelevant to an understanding of how the interaction is successful although unfamiliarity and
complexity of the technology may add further barriers to implementation. Feedback from the
health care professional to the patient could be synchronous or asynchronous (i.e., by store-
and-forward technology, in which a patient’s data are kept in an electronic repository and
forwarded to a health care professional on request). Advice should be tailored to the
consulting patient. Many telehealthcare interventions are designed to help patients manage
their condition and therefore several of the underpinning mechanisms may relate to the
facilitation of self-management.

There are no recommendations for telehealthcare for the management of chronic heart failure
in the respective National Institute for Health and Care Excellence (NICE), European Society
of Cardiology (ESC) or American College of Cardiology Foundation/American Heart
Association guidelines. Despite the lack of UK guidance, the Government has vigorously
advanced the telehealth agenda through the 3 Million Lives initiative. This policy initiative
aspired to enhancing the lives of the population by encouraging and supporting (but not
directly funding) the use of telecare and telehealth applications as a vehicle for providing
more person-centred and integrated care.

**Intervention Components**
The key components of telehealthcare interventions are summarised in Table 13. This reflects
UK practice as described in the studies selected from the mapping review (see below)

| Table 13: TiDIER-Lite characteristics for telehealthcare | 81 |

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the terms of a commissioning contract issued by the Secretary of State for Health. This document
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should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation,
Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park,
Southampton SO16 7NS, UK.
By Whom | Health care professionals
---|---
What | Interaction including telemonitoring, feedback and provision of tailored information (e.g. symptom questions and educational messages).
Where | “Tool of distance communication that works without the simultaneous physical presence of the participants in the interaction”. Can be “telephone, e-mail, the internet or any other networked or mobile device”.
To What Intensity | Can be patient initiated or clinician instigated in response to monitoring.
How Often | At intervals determined by clinician, patient or symptoms.

**Number and Type of UK Studies identified**
The mapping review identified one UK quantitative study of telehealthcare, from the Whole System Demonstrator Project, for COPD, diabetes and heart failure. The quantitative TELESCOT RCTs that accompanied several UK qualitative studies predated our date cut-off being published in 2009.

The mapping review identified a total of seven UK qualitative studies; three examined COPD and one hypertension. The remainder explored multiple conditions. Three UK qualitative studies had been conducted alongside the TELESCOT trials\textsuperscript{153-155}. Further qualitative studies examined COPD patients receiving a community respiratory service\textsuperscript{156} and patients with hypertension\textsuperscript{157, 158} both in the West Midlands. Ure and colleagues\textsuperscript{159} conducted a qualitative study examining a COPD telemonitoring service in NHS Lothian and a critical commentary\textsuperscript{160} examined transferable lessons from this experience. Finally, Williams and colleagues (2014) examined patients’ expectations and experiences of an mHealth application for COPD in Oxfordshire\textsuperscript{161}.

Details of the studies included in the analysis are presented in Table 37 (see Appendix 4).
Operating Programme Theories
Crundall-Goode & Goode identify four types of barriers to successful implementation of telehealthcare applications for chronic health conditions; patient related, health and social care organisation related, technology related and evidence/economic related)\(^{152}\). The first and second of these barriers figure prominently among our candidate programme theories with technology-related being specific to telehealthcare interventions and evidence/economic related being picked up across all interventions within our PARIHS framework.

Specifically telehealthcare, in the form of telemonitoring, operates within Programme Theory 1. This states that if patients are equipped with knowledge and information for self-management, they will only access health services when required, leading to appropriate resource use and a reduction in unplanned admissions. Telemonitoring addresses fear and anxiety that the patient experiences if they are not sure whether or not to call the health services. They have the reassurance that their condition is being monitored, thereby accelerating the feedback loop between patient and clinician. However telemonitoring is limited given its focus only on specific signs whereas the patient’s symptoms may cross a wide range of circumstances, either linked or independent of what they are being monitored for. In this case the telemonitor may be offering an alternative or contradictory picture which increases, rather than reduces the uncertainty.

Alternatively, people with chronic conditions may perceive that presentation to an emergency department holds relative advantage (e.g. quality, ease of access, response etc.) over GP-based or other primary or community care services [PT2]. People with chronic conditions may pressure GPs to admit them to hospital. All of the above explanations assume that people behave in a “rational” manner when seeking information. However, information need has an important affective dimension. As has already been demonstrated much inappropriate utilization by patients is attributable to anxiety and uncertainty. Provision of information does not always allay this – its effectiveness depends upon whether it is trusted or whether it needs further verification or validation. Under such circumstances a patient may consult an...
information source but have an outstanding need for a “second opinion” particularly if the information they have to hand is not situated in their specific circumstances. The perceived authority of the local hospital may be seen to eclipse the less satisfactory response from local primary care provision.

Alternatively, GPs or other health professionals may lack confidence in their own diagnoses or may lack confidence in, or knowledge of, alternative sources of healthcare provision and so may refer people with chronic conditions or admit them direct to hospital. GPs or other health professionals may feel under pressure to admit people with chronic conditions directly to hospital [PT3]. In the context of patient education, and not the educational needs of the health professionals themselves, health providers may find it challenging to identify and locate information for patients that is again situated within the patient’s specific needs. Alternatively, they may encounter contradictions between what the available information recommends and their own clinical judgement.

People with chronic conditions may also use health services inappropriately; delaying their presentation to a GP or hospital [PT4] because of perceptions of the service either anticipated or based on the past experience of either themselves or others. Such mental imprints may exert a stronger and more powerful influence over their behaviour than the provision of patent education is able to influence.

Salisbury and colleagues identify the existence of the Chronic Care model as a dominant way of conceptualising chronic disease management162. However, they highlight that this model was not designed with telehealthcare in mind and that it does not, therefore, readily accommodate considerations relating to this type of intervention.

**Description of Putative Mechanisms**

See table 14 below for a summary of putative mechanisms. We believe that telehealthcare is unique among the interventions examined within this report given that a realist synthesis has already been conducted to identify the core mechanisms underpinning telehealthcare interventions. Vassilev and colleagues (2015) examined three chronic health conditions,
including COPD and heart failure which are eligible for this review, and identified three concepts that suggest how telehealthcare engages with patients, carers and health professionals: (i) relationships: whether or not and how a telehealth intervention enables or limits the possibility for relationships with professionals and/or peers; (ii) fit: how well telehealthcare interventions can be integrated into everyday life and health care routines and the extent to which they are easy to use, compatible with patients’ existing environment, skills, and capacity, and do not significantly disrupt patients’ lives and routines; (iii) visibility: visualisation of symptoms and feedback has the capacity to improve knowledge, motivation, and a sense of empowerment; engage network members; and reinforce positive behaviour change, prompts for action and surveillance.

These three concepts of communication, fit and visibility clearly have a critical role in acceptance of the intervention. Our own programme theories have a different emphasis and particularly confirm aspects of visibility, namely the closure of a feedback loop so that a patient and professional can respond to current symptoms and their severity and make a judgement on whether emergency admission is indeed appropriate or whether appropriate alternatives exist. The fact that this assessment can be conducted in real time adds the additional benefit that neither patient nor professional has to worry less about the deterioration or indeed, improvement of the symptoms in the interval between the “trigger” symptoms (e.g. an exacerbation) and contact with a health professional.

Table 14: Putative mechanisms for telehealthcare

<table>
<thead>
<tr>
<th>Intervention Components</th>
<th>Contextual Factors (Enabling)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information supplied by the patient; whether orally, in written or</td>
<td>Integration of IT systems across sectors</td>
</tr>
<tr>
<td></td>
<td>Reliability of technology</td>
</tr>
</tbody>
</table>
graphical form or though some type of monitoring
- Electronic transfer of information to a care provider
- Feedback from the healthcare provider tailored to the individual patient

<table>
<thead>
<tr>
<th>Potential Mechanisms (HCPs)</th>
<th>Potential Mechanisms (Patients and Carers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Real time monitoring of patient</td>
<td>Reassurance and feedback alleviating stress and anxiety</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Leading To</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resolution within primary care</td>
<td>Reduced utilisation of secondary care</td>
</tr>
<tr>
<td>Increasing dependence on practitioner support for telemonitoring</td>
<td>Increased or inappropriate use of telemonitoring/practitioner support</td>
</tr>
<tr>
<td>Possible over-treatment</td>
<td>Increased health service utilisation</td>
</tr>
<tr>
<td>Challenges in how best to organise services to support the technology</td>
<td>Diversion from existing service delivery</td>
</tr>
</tbody>
</table>

**Contextual Factors**

**Role of Patient Preference**

Overall, patients appear more positive than professionals about using telehealth\textsuperscript{163, 164}.

However, the Whole System Demonstrator project\textsuperscript{165} identified patients who resisted telehealthcare because they believed that dependence upon technology would reaffirm their sick dependency role and lack of independence. Clearly the technology was imbued with a symbolic significance that went beyond a pattern of dependence signalled by frequent visits.
to a GP or other health professional or by frequent home visits. Patients were also concerned that the technology would raise their own awareness about their condition causing increased anxiety. Health professionals have also raised concerns that the creation of a person-mediated intervention role, such as a case manager would increase patient dependence rather than facilitate self-management. This tension between monitoring and dependence, self-management and independence is central to the success of several of the included interventions.

Within the specific context of telemonitoring, Crundall-Goode and Goode\textsuperscript{152} observe how some patients reported finding the daily readings/questionnaires monotonous, questioning their effectiveness due to lack of knowledge and conflicting advice from the team. The team sought to address patient boredom by adapting care plans as much as the technology would allow, providing a more flexible and patient-sensitive approach to self-monitoring.

In other cases, the technology was seen, typically by carers, as a way of seeking to replace care already provided through face to face interaction with an inferior care package delivered by technology. The carer saw the visible dependence of the patient on the personalised health care as appropriate recognition of their illness state.

**Role of Culture**

The TELESCOT studies sought to facilitate convergence between health and social care partners by making this a condition of the bidding process. According to Lluch (2011\textsuperscript{166}) the Scottish government believed that the funding was effective in changing how care was traditionally delivered by inducing the organisational changes needed to coordinate health and social care and the cultural change for stakeholders involved at a local level. The momentum of the telehealthcare projects helped to mainstream the interventions and consolidate this change. Other commentators have warned against “bolting on” telehealthcare provision to existing services emphasising the need to integrate provision within clinical pathways\textsuperscript{152}.

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Concerns about increased workloads frequently feature in clinician concerns. These can be addressed to a certain extent by attention to improving clinician user interfaces.\textsuperscript{160}

The TELESCOT evaluations revealed additional issues that need to be addressed at a cultural or organisational level. Organisations need to devise an acceptable balance between self-care and professional support.\textsuperscript{160} They also need to develop interventions to overcome the prejudices of health professionals towards telemonitoring technologies. In connection with patients they need to develop effective measures to prevent patients from under-reporting their symptoms for fear of bothering their health care providers,\textsuperscript{167} or to let technological readings override their judgment. Other technological nuances frequently overlooked by RCTs include the need to reduce uncertainty around data transmission and to simplify self-assessment of symptoms by debilitated patients.\textsuperscript{160}

\textbf{Role of Leadership}

Technological developments, as required for the development of telehealthcare, are seen as particularly dependent upon leadership. In an analysis of telehealthcare systems for chronic conditions in England and Scotland, Lluch observes how the lack of strategic leadership for structural change hampers the natural uptake and diffusion of these technologies.\textsuperscript{166}

\textbf{Role of Evaluation/Measurement}

Investment in telehealth has often been justified partly on the basis that its cost can be recovered by reductions in the use of secondary healthcare. However, it is difficult to evaluate and realise the results of such an effect. Where patients selected for intervention have a history of emergency care, and in the absence of a control group, such patients tend to exhibit reductions in use of emergency care over time (i.e. regression to the mean).\textsuperscript{168} Therefore, in the absence of a control group, whether observed reductions are attributable to the intervention is unclear. Telehealth service evaluations are characterised as being poorly organised with few focusing on the economic benefits. This has probably
contributed to subsequent withdrawal of funding and to the consequent paucity of peer-reviewed service evaluations in the published literature\textsuperscript{152}. Guidance for commissioners and service providers on how best to evaluate and audit a telehealth service has been published\textsuperscript{169}.

One of the potential criticisms of the Whole System Demonstrator projects in the UK\textsuperscript{170} is that the final trial evaluation assessed the added value of telehealth and telecare over a reorganised service and not the benefits of whole systems redesign compared to conventional care. Therefore, generalisability of the results was limited to reorganised services\textsuperscript{166}. This observation resonates with other interventions where a whole system redesign approach is advocated rather than “bolting on” specialist interventions alongside existing service provision.

**Role and characteristics of Facilitation**

Within the context of telehealthcare facilitation has two specific applications;

(i) the added requirement to facilitate the reporting and repair of faulty equipment to minimise patient and staff dissatisfaction\textsuperscript{152}. This requirement typically lies outwith the skillsets of those delivering the clinical service.

(ii) there is some evidence to suggest that the valuable time and energies of health professionals may be diverted away from clinical duties and redirected to entry-level technical support\textsuperscript{152}. Technical facilitation may therefore come at the opportunity cost of providing facilitation in the form of clinical support, patient education etcetera

**Role/skills of Implementation Facilitators**

See Table 15 for a summary.

**Table 15: Role/skills of implementation facilitators in telehealthcare studies**

<table>
<thead>
<tr>
<th>Study reference</th>
<th>Role/skills of implementation facilitators</th>
<th>Who was facilitated</th>
</tr>
</thead>
</table>

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### Supporting Evidence

This is a brief summary of evidence from systematic reviews, concentrating on hospital (re)admission as the outcome of interest. Key results from UK studies included in this analysis are also presented.

For COPD, Polisena et al (2010) showed lower rates of emergency admissions for patients receiving home monitoring plus telephone support\textsuperscript{171}. Their systematic review tentatively suggested that home telehealth could reduce the rate of hospitalisation for patients with COPD, but was limited by the quality of the studies included\textsuperscript{171}.

An important review outside our inclusion period by Paré and colleagues reviewed 65 empirical studies across four conditions and distinguished the effects of telehealth between different conditions. They suggested that effects on reduced visits to emergency departments, hospital admissions, and average length of hospital stay) were more consistent in pulmonary and cardiac disorders than in diabetes and hypertension\textsuperscript{172}.

A Cochrane review of studies for heart failure reported that telemonitoring and structured telephone support reduced admissions for heart failure\textsuperscript{173}. However, findings were based on generalising a large number of studies with a mean sample size of 330. A study of 1653 patients with heart failure found no significant effect on hospital use or mortality\textsuperscript{174}.

| TELESCT (reported in Lluch, 2011\textsuperscript{166}) | In each TDP pilot, telehealthcare implementation and day-to-day activity were mainly driven by trained, community nurses. For the pilots, community nurses received additional, specific training about the conditions they were dealing with and about the telehealthcare technology. | Community nurses |
| TELESCT (reported in Lluch, 2011\textsuperscript{166}) | Trained, community nurses responsible for delivering training to patients. | Patients |

\textsuperscript{166} Telehealthcare 

\textsuperscript{171} Polisena et al. (2010) 

\textsuperscript{172} Paré et al. (2010) 

\textsuperscript{173} Cochrane review 

\textsuperscript{174} Study of 1653 patients with heart failure
Data supporting the efficacy of telemonitoring on reducing hospital admissions is mixed. Clinical trials of telemonitoring reported within the inclusion period have not demonstrated the positive impact on hospital admissions found from a systematic review based on smaller studies175-177.

**Potential Enhancements of Intervention/Implementation**

Peirce and colleagues draw on stakeholder interviews to conclude that telemonitoring systems have not overcome the drawbacks of conventional care because “they existed as an off-the shelf ‘bolt-on’ and could not be connected with many of the different care services that these patients engage with”178. They assert that a future early detection telemonitoring system should be designed with high levels of user input and therefore be characterised by high usability and integration with multiple services. To this they add such technical requirements as more versatility of monitoring capabilities and proven automated methods of pattern detection. Crundall-Goode and Goode152 highlight how there is little guidance outside a trial context on the optimal duration of telemonitoring arrangements citing evidence that mortality benefits may be lost past a certain duration of intervention. They therefore suggest the enhancement of a care plan that proposes when to step down telehealth and have devised their own example of this.

**4.5: Cardiac rehabilitation**

**Summary**

Cardiac rehabilitation is offered to people with cardiovascular disease, typically those who have survived a heart attack but also patients with angina or heart failure. CR programmes typically involve tailored exercise together with education and advice to help patients reduce risk factors and recover their confidence. Cochrane reviews of CR concentrate on explaining the benefits of the intervention through the physiological effects of exercise on the cardiovascular system. However, given that most CR programmes involve interventions other than structured exercise, other mechanisms are likely to be involved in most cases.
CR should be delivered by a multi-disciplinary team (MDT) led by a clinical co-ordinator (a senior clinician responsible for co-ordinating, managing and evaluating the service. There is a strong international evidence base for CR but interpretation of the evidence for the UK is complicated by multiple factors, including a trial casting doubt on its effectiveness as delivered in UK practice. At a national level, the National Audit of Cardiac Rehabilitation (NACR) has provided leadership for CR programmes in most countries of the UK. The publication of regular reports and data has been accompanied by a campaign of support for CR backed by the British Heart Foundation (BHF).

**Definition**
Cardiac rehabilitation is an intervention offered to people with cardiovascular disease, typically those who have survived a heart attack but also patients with angina or heart failure. CR programmes typically involve tailored exercise together with education and advice to help patients reduce risk factors and recover their confidence. More detailed definitions are available from the UK National Audit of Cardiac Rehabilitation (NACR) ([http://www.cardiacrehabilitation.org.uk/patient-information.htm](http://www.cardiacrehabilitation.org.uk/patient-information.htm); accessed 9th March 2018) and the British Association for Cardiovascular Prevention and Rehabilitation (BACPR) 179.

**Intervention Components**
The six core components of CR as defined by the BACPR are health behaviour change and education; lifestyle risk factor management; psychosocial health; medical risk management; long-term strategies; and audit and evaluation. Table 16 summarises the key features of the intervention.

**Table 16: TIDieR-Lite components for cardiac rehabilitation**

<table>
<thead>
<tr>
<th>By Whom</th>
<th>Multi-disciplinary team</th>
</tr>
</thead>
</table>

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The BACPR standards for CR specify that the intervention should be delivered by a multi-disciplinary team (MDT) led by a clinical co-ordinator (a senior clinician responsible for co-ordinating, managing and evaluating the service)\textsuperscript{179}. The standards acknowledge that the composition of the MDT may vary but state that overall the team must ‘have the necessary knowledge, skills and competencies to meet the standards and deliver all the core components’ \textsuperscript{179}. The disciplines considered key to the delivery of CR include dietitian; exercise specialist; nurse specialist; occupational therapist; pharmacist; physician with special interest in prevention and rehabilitation; physiotherapist; and practitioner psychologist. The BACPR standards also stress the importance of active engagement with the patient’s wider care time, for example the GP, other general practice staff and social worker\textsuperscript{179}.

The content of CR programmes is designed to deliver the six core components mentioned above while meeting individual goals and taking account of patient preference and choice. The BACPR recommend that patients should be offered a choice in terms of venue (e.g. home, community setting or hospital) and timing of sessions. CR may be delivered in a variety of different ways (centre-based, home-based, manual-based, web-based etc.). However the programme is delivered, patients are encouraged to engage in structured exercise at least two to three times a week, with documentation of regular review, goal setting and exercise progression. The BACPR standards specify that the patient and MDT should

<table>
<thead>
<tr>
<th>What</th>
<th>Six core components: health behaviour change and education; lifestyle risk factor management; psychosocial health; medical risk management; long-term strategies; and audit and evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where</td>
<td>Ideally setting of patient’s choice (e.g. home, community setting or hospital)</td>
</tr>
<tr>
<td>To What Intensity</td>
<td>Patients are encouraged to engage in structured exercise at least two to three times a week</td>
</tr>
<tr>
<td>How Often</td>
<td>Patient and MDT should work together for at least 8 weeks</td>
</tr>
</tbody>
</table>
work together for at least 8 weeks\textsuperscript{179}. Detailed standards for the non-exercise components of programmes are also provided.

**Number and Type of UK Studies identified**

The mapping review included just two UK studies coded for CR: a qualitative study of web-based CR in primary care\textsuperscript{180} and a pilot study of early rehabilitation for patients hospitalised for heart failure\textsuperscript{181}. Two systematic reviews of CR provided evidence for the effectiveness of CR and identified further UK studies\textsuperscript{182, 183} (Table 38, see Appendix 4), although many of these were outside the date range of interest for this review. A key UK study identified from the reviews was the RAMIT (Rehabilitation after myocardial infarction trial) trial, which concluded that ‘the value of cardiac rehabilitation as practised in the UK is open to question’\textsuperscript{184}. The publication of RAMIT was accompanied by editorials and commentaries which, while not empirical research, provided important insights into the implementation of CR programmes in the UK\textsuperscript{185-187}. Another randomised trial questioned the effectiveness and cost-effectiveness of exercise-based rehabilitation for elderly patients with heart failure\textsuperscript{188}. Finally, we included the latest report from the UK NACR, which provides detailed statistical information about the delivery of CR in different regions of the UK (excluding Scotland)\textsuperscript{189}. A recent publication using NACR data identified factors influencing patient engagement with CR programmes, including service-level factors\textsuperscript{190}.

**Operating Programme Theories**

CR is primarily concerned with preventing further events and readmissions for people hospitalised for coronary heart disease or heart failure. As the intervention includes behaviour change and education, overarching theory PT\textsuperscript{1} appears relevant. This states that IF patients are equipped with knowledge and information for self-management, they will only access health services when required, LEADING TO appropriate resource use and a reduction in unplanned admissions. The main evidence for this comes from the RAMIT trial, where the majority of CR patients rated seven out of eleven elements (information on heart disease, risk factors, medication, advice on diet, exercise training, relaxation training and stress management training) as being very or fairly helpful on a four-point scale\textsuperscript{184}. However, this
finding is difficult to interpret as the study did not find evidence of a reduction in admissions in the CR group.

If patients are undergoing CR as part of a co-ordinated programme of care at home or in the community, overarching theory PT2 may operate. Briefly, IF patients are satisfied with provision outside secondary care, THEN they will not feel it necessary to access secondary care services, LEADING TO appropriate use of services and reduction in unplanned admissions. Evidence on provision outside secondary care was lacking in the included studies, making the role of PT2 difficult to evaluate.

PT3, relating to clinicians’ confidence in diagnosis and referral, is of limited relevance because CR is mainly used to reduce readmission in patients who have already been diagnosed and hospitalised. A similar statement may be made about PT4 (adverse effects of patient delays in accessing treatment) but there is evidence from the included studies of patients failing to take up CR or dropping out before completing the programme, which would prevent them from obtaining the benefits claimed for CR189, 190.

**Description of Putative Mechanisms**

Cochrane reviews of CR concentrate on explaining the benefits of the intervention through the physiological effects of exercise on the cardiovascular system. For example, Anderson et al. list six direct benefits of exercise training on the heart and coronary vasculature. They also note possible indirect effects of exercise on risk factors for atherosclerotic disease such as blood lipids, smoking and blood pressure182. These indirect effects include changes in behaviour as well as physiological changes.

The Cochrane review of exercise-based rehabilitation for heart failure also stresses the physiological benefits of exercise training while acknowledging that the precise mechanism(s) leading to benefits in health outcomes is unclear183.
Given that most CR programmes involve interventions other than structured exercise, other mechanisms are likely to be involved in most cases (Table 17). Core components of CR aim to support people to change their behaviour and hence reduce their modifiable risk factors for hospital admission or readmission and other adverse outcomes. This includes increasing participants’ knowledge but also increasing their confidence so that they continue to exercise, abstain from smoking etc. after the end of the formal CR programme. Since most CR programmes are delivered in groups, support from other group members as well as programme staff is likely to be important191.

Table 17: Putative mechanisms for cardiac rehabilitation

<table>
<thead>
<tr>
<th>Intervention Components</th>
<th>Contextual Factors (Enabling)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behaviour change and education</td>
<td>Patient interest in participating</td>
</tr>
<tr>
<td>Lifestyle risk factor management</td>
<td>Programmes offering choice reflecting</td>
</tr>
<tr>
<td>Psychosocial health</td>
<td>patient needs and preferences</td>
</tr>
<tr>
<td>Medical risk management</td>
<td>Positive feedback from previous</td>
</tr>
<tr>
<td>Long-term strategies</td>
<td>participants</td>
</tr>
<tr>
<td>Audit and evaluation</td>
<td>Multi-disciplinary team delivering</td>
</tr>
<tr>
<td>(Note: exercise is also a key component, although not defined as such by the BACPR)179</td>
<td>programme</td>
</tr>
<tr>
<td></td>
<td>Evidence to support effectiveness and cost-effectiveness</td>
</tr>
<tr>
<td></td>
<td>Clinician endorsement</td>
</tr>
<tr>
<td></td>
<td>Policy initiatives to promote CR</td>
</tr>
<tr>
<td>Potential Mechanisms (HCPs)</td>
<td>Potential Mechanisms (Patients and Carers)</td>
</tr>
<tr>
<td>Personal commitment to CR</td>
<td>Physiological benefits of exercise</td>
</tr>
<tr>
<td>Diverse multidisciplinary team</td>
<td>Professional support to reduce risk factors</td>
</tr>
<tr>
<td>Guidelines and standards</td>
<td></td>
</tr>
</tbody>
</table>

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Social support in group settings

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Leading To</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-efficacy</td>
<td>Reduced hospital (re)admissions</td>
</tr>
<tr>
<td>Continued adherence to programme</td>
<td>Potential reduced mortality</td>
</tr>
</tbody>
</table>

**Contextual Factors**

**Role of Patient Preference**
Patient preference and other patient factors substantially influence the success of implementation of CR programmes. Most UK studies reported on patient preference as a barrier to implementation. Some patients were unwilling to engage in CR programmes or dropped out before completing the programme. In the latest NACR report, the percentage of patients who were not interested or declined to attend increased from 14% for early rehabilitation to 54% for long-term maintenance\(^{189}\). Factors associated with lower engagement with CR in a separate study using NACR data included increasing age, being female, socioeconomic deprivation and belonging to a minority ethnic group\(^{190}\). In a trial of a web-based CR programme, 78.6% of potential participants declined or did not respond\(^{192}\). Participants perceived lack of time, bad weather and the need for self-motivation as barriers. Older participants perceived a web-based programme as more suitable for younger people\(^{180}\). In the context of the RAMIT trial, West et al. reported that most control patients did not feel the need for further support or advice, despite being aware of the existence of CR programmes\(^{184}\). In their study of patients with heart failure, Witham et al. suggested that...
increases in activity due to the programme may be counterbalanced by decreases elsewhere, resulting in no overall increase in physical activity\textsuperscript{188}.

Factors associated with positive patient preference were also reported by most of the included studies. Al Quait et al. reported that CR programmes were attractive to younger male patients\textsuperscript{190}. Houchen et al. began rehabilitation early and reported that potential participants expressed interest in CR while they were still in hospital\textsuperscript{181}. Patients following a web-based programme gained confidence as they engaged with the programme and valued the fact that they were no longer coping with their condition without support\textsuperscript{180}. The RAMIT trial found that patients referred to CR programmes rated much of the content as helpful or very helpful\textsuperscript{184}. Positive feedback from previous participants could potentially assist recruitment to CR programmes, although we are not aware of whether any programmes have used or evaluated this strategy. The latest NACR report emphasises the importance of CR programmes being menu-based and reflecting patient preferences, which it notes are influenced by factors including age, gender and diagnosis\textsuperscript{189}.

**Role of Culture**

See also the section on leadership below.

Implementation of CR programmes is influenced by the internal culture of the NHS organisations involved as reported in several included UK studies. Studies of both patients with angina\textsuperscript{180, 192} and those with heart failure\textsuperscript{181} reported that these patients were under-represented in terms of referral to and participation in CR programmes. If CR programmes are seen as being primarily for patients recovering from a heart attack, this would be a major cultural barrier to participation by people with other cardiac conditions. One study also noted an effect of the source of referral, patients referred by a cardiac nurse being less likely to engage with CR than those referred from other sources, while patients referred from general practice were more likely to engage\textsuperscript{190}. Providing patients with a definite date for starting a programme promoted engagement.
The disciplinary make-up of teams delivering CR is likely to reflect the organisation’s culture and its perception of CR as an intervention. The NACR found considerable variation across countries in the UK in the range of professionals supporting CR, although 93% of programmes were delivered by staff from three or more disciplines\textsuperscript{189}. A commentary on the publication of the RAMIT trial, however, noted that fewer than 5% of CR programmes in the UK have a doctor as part of the team. The authors argue that this ‘lack of medical patronage’ may partly explain why CR remains a ‘Cinderella service’\textsuperscript{186}. Witham et al. failed to show a benefit of CR for elderly patients with heart failure in their study using a level of intervention considered to reflect what is realistically achievable in routine practice\textsuperscript{188}.

Evidence-based (or evidence-informed) decision-making is seen as central to the culture of modern healthcare systems. CR in the UK expanded in the 1990s and was recommended in guidelines from that time\textsuperscript{184}. However, the publication of the RAMIT study (2012), which appeared to question the effectiveness of UK CR programmes\textsuperscript{184}, has proved a barrier to implementation of CR. The trial results led to the evidence for CR being challenged by clinicians, managers and commissioners\textsuperscript{186}. In particular, questions were raised about the effectiveness of CR in the context of modern medical management of MI and the boundary between rehabilitation and ongoing secondary prevention\textsuperscript{184, 185}. Houchen et al. noted the importance of evidence establishing clearly that CR can reduce readmissions for heart failure in the context of financial penalties for 30-day readmissions in the NHS\textsuperscript{181}. Broader cultural influences on the implementation of CR mainly reflect topics discussed above under patient preference, for example different attitudes to exercise or to use of online resources may influence how CR is implemented for different patient groups.

Role of Leadership
Leadership and culture are closely linked so this section should be considered in conjunction with the previous one. One study (citing other research) noted a link between individual health professionals’ endorsement of CR and its uptake by patients\textsuperscript{190}.
At a national level, the NACR has provided leadership for CR programmes in most countries of the UK. The publication of regular reports and data has been accompanied by a campaign of support for CR backed by the British Heart Foundation (BHF). The BACR (now the BACPR) published its standards for CR in 2007\(^1\). This work has prompted policy initiatives from the Department of Health and new guidelines are expected to reduce variation and specify minimum standards of service\(^1\). The NACR already provides data on services’ compliance with standards on a regional basis\(^1\).

The included studies also identified some barriers associated with national and local leadership in the UK. West et al. noted that the emerging National Service Framework for CHD was a factor in halting recruitment for the RAMIT trial (leading to questions about the trial’s statistical power)\(^1\). Inadequate staffing and resourcing of many CR programmes\(^1\) may be a reflection of lack of commitment to CR by clinical leaders (hospital specialists and commissioners) at a local level.

**Role of Evaluation/Measurement**

Several included studies were pilot or uncontrolled studies and their authors noted the need for more robust evaluation of CR programmes, with randomisation and an adequate sample size\(^1,\)\(^2\). The RAMIT trial, by contrast, was designed to evaluate typical CR programmes as delivered in the NHS in England\(^3\). However, the inconclusive results of the study and its shortfall in recruitment have led to controversy about how the trial should be interpreted and its implications for implementation of current CR programmes\(^3-\)\(^5\).

As noted above, the NACR plays a key role in measuring uptake and evaluating the quality of CR programmes. The published reports demonstrate improvements over time but as noted by one author they also reveal ‘daunting challenges’ and ‘substantial scope for improvement’\(^3\).
Role and characteristics of Facilitation
The included UK studies report limited information about the facilitation of implementation of CR programmes. In some studies, support was provided to participants by researchers involved in development and evaluation of the intervention under test\textsuperscript{192} and in others research was carried out in existing CR programmes\textsuperscript{181, 184}. A key role in facilitation is played by the NACR through its identification of variations in practice and measurement of programmes against common standards\textsuperscript{187, 189}. However, few details of the facilitation process are contained in the available reports.

Role/skills of Implementation Facilitators
None of the included studies reported on the role and skills of implementation facilitators as distinct from researchers conducting a study and health professionals delivering a CR service. In particular, the NACR annual reports and web site do not appear to report on active facilitation other than making information available to service providers (audit and feedback).

Supporting Evidence
This is a brief summary of the evidence for the effectiveness of CR in terms of reduction of hospital (re)admissions, based on systematic reviews and guidelines.
CR is recommended in the NICE guidelines on secondary prevention after MI\textsuperscript{193} and management of chronic heart failure\textsuperscript{119}, and in other national and international guidelines\textsuperscript{194}. The Department of Health published guidance on commissioning CR in 2010\textsuperscript{195}.

There are Cochrane systematic reviews of CR (described as ‘exercise-based rehabilitation) for coronary heart disease\textsuperscript{182} and heart failure\textsuperscript{183} as well as numerous other systematic reviews and meta-analyses. In the review of CR for CHD, CR reduced overall risk of hospital admissions by 18\% compared with no-exercise controls (15 trials; RR 0.82, 95\% CI 0.70 to 0.96)\textsuperscript{182}. A larger effect was seen in the Cochrane review of CR for patients with heart failure\textsuperscript{183}. Compared with control, exercise training reduced the rate of overall (15 trials, 1328 participants: RR 0.75; 95\% CI 0.62 to 0.92, fixed-effect analysis) and HF specific
hospitalisation (12 trials, 1036 participants: RR 0.61; 95% CI 0.46 to 0.80, fixed-effect analysis).

Numerous factors complicate the interpretation of this evidence for the UK NHS setting. As noted above, the RAMIT trial questioned the effectiveness of CR programmes as delivered to patients with CHD in NHS hospitals. This prompted a considerable amount of discussion. Some authors questioned the relevance of the Cochrane reviews on the grounds that they include older studies that do not reflect the improved treatment offered to patients receiving ‘usual care’ in modern practice. However, advocates of CR point out that there is no strong evidence of a decline in the effect of CR on mortality over time. The issue remains unresolved and appears to be a potential barrier to full implementation of CR in the NHS.

**Potential Enhancements of Intervention/Implementation**

Factors favouring successful implementation were identified as follows:
- Giving patients a firm date for initial assessment
- Web-based programmes may promote wider engagement with CR
- Early (within 4 weeks of hospital discharge) rehabilitation for patients with heart failure
4.6: Pulmonary rehabilitation

Summary
The British Lung Foundation definition of pulmonary rehabilitation (PR) is “a programme of exercise and education for people with a long-term lung condition.” UK programmes are diverse in setting, length, type and intensity of exercise, and provision of education. A key mechanism for the effect of PR appears to be increased self-efficacy for both exercise and self-management. There is strong evidence for the effectiveness of PR (including reducing readmissions) from systematic reviews of randomised controlled trials of PR for COPD196, 197193, 194187, 188. However, further research is needed to investigate the components of COPD that are most important, how long the programme should be and the frequency of the training.

Definition
The British Lung Foundation definition of pulmonary rehabilitation (PR) is “a programme of exercise and education for people with a long-term lung condition.” PR consists of a tailored physical exercise programme combined with general health advice and education on managing the condition and associated symptoms. 198

The British Thoracic Society Guideline on Pulmonary rehabilitation for Adults (2013) has recommendation for the physical exercise training and education components of PR 199.

Intervention Components
The updated Cochrane review highlights how PR programmes offer diverse components 68. They can be based in inpatient, outpatient or home-based settings. The length of the programmes can also differ ranging from 6 weeks to 6 months and training intensity can range from daily to twice weekly. The exercise training component can include endurance or strength training or both with specific exercise training selected to best meet the needs of the
individual patient. Additionally, the patient education component of the programme can extend from basic advice through to more extensive self-management programmes. All of these differences in the components can influence their effectiveness and contribute to the complexity of implementation. Key components of pulmonary rehabilitation are detailed in Table 18. This reflects UK practice as described in the studies selected from the mapping review.

Table 18: Key components of pulmonary rehabilitation

<table>
<thead>
<tr>
<th>By whom</th>
<th>A range of healthcare professionals, including physiotherapists, nurses, nurse specialists, occupational therapists and dietitians. Practice nurse and physiotherapist(^{200-202}), Occupational therapists (^{203}), Pulmonary rehabilitation team on acute ward consisting of physiotherapists and nurses (^{204,205}), Physiotherapist team (^{206}).</th>
</tr>
</thead>
<tbody>
<tr>
<td>What</td>
<td>Programmes consist of group sessions that include physical exercise training, patient education, dietary advice and psychological and emotional support.</td>
</tr>
<tr>
<td>Where</td>
<td>Out-patient departments or community settings including community halls, leisure centres and health centres. Primary care setting (cluster) (^{200-202}), Community gym facilities (^{203}), Lung Centre (^{207}), Web-based (^{208}), Hospital as acute admission (^{205}), Community settings (^{206}).</td>
</tr>
<tr>
<td>To what intensity</td>
<td>The British Thoracic Society 2013 guideline found that “In the UK, for practical and economic reasons, programmes lasting longer than 6–8 weeks are not standard; however, there is some ongoing debate as to the efficacy of programmes lasting less than 6 weeks.” (^{209}: ii11). The guideline states that “Pulmonary rehabilitation programmes of 6–12 weeks are recommended. (Grade A)” (^{209}). 8 week programme with follow-up (cluster) (^{200-202}), 7 weeks (^{208}), 8 weeks (^{210}), 6 weeks (^{203,205,206}).</td>
</tr>
</tbody>
</table>
How often

| How often | The British Thoracic Society 2013 guideline recommends “Pulmonary rehabilitation programmes including the attendance at a minimum of 12 supervised sessions are recommended, although individual patients can gain some benefit from fewer sessions. (Grade A).” 209. Twice weekly 203, 206, weekly 2 hour session (cluster) 200-202, |

Number and type of UK studies

The mapping review identified 17 papers of 15 UK studies for PR for COPD, one of the studies was for exacerbations of chronic respiratory disease but the majority of the patients had a primary diagnosis of COPD 205. Additionally, three systematic reviews of PR were identified 67, 197, 211. These reviews demonstrated the effectiveness of PR and helped with the identification of further UK studies, many though were outside the date range of interest for this review. There are 5 qualitative studies and 11 quantitative studies included in the realist synthesis (Tables 39 and 40, see Appendix 4). One of the quantitative studies is reported in 3 papers 200-202.

Operating Programme Theories

PR programmes aim to improve the length of time that patients with COPD can exercise for without feeling out of breath and improve their symptoms, self-confidence and emotional wellbeing. According to the Cochrane Review by McCarthy (2015197), pulmonary rehabilitation is likely to achieve its effect through several mechanisms. Collectively, pulmonary rehabilitation seeks “to reduce COPD symptoms, re-establish and improve functional ability, enhance participation in everyday life, promote autonomy and improve [quality of life]”. PR focuses on systemic aspects of the disease common among patients with COPD. The three principal components are (i) an exercise component, (ii) an educational component and (iii) a behaviour change element.

The exercise component of PR targets physical improvement by increasing inspiratory volume and reducing dynamic hyperinflation. Exercise increases muscle function, delaying fatigue and resulting in increased exercise tolerance197. Simultaneously, the educational
component of PR focuses on collaborative self-management and behaviour change. Patients are provided with information and knowledge regarding COPD; building skills such as goal setting, problem solving and decision making; and developing action plans that allow them to better recognise and manage their disease. The behaviour change element focuses on modifying nutritional intake and smoking patterns; adhering to medication and regular exercise; and utilising effective breathing techniques and energy-saving strategies. These latter two elements emphasise the similarities of PR with other interventions such as patient education and self management.

As PR programmes include patient education PT1 resonates as one possible theory of change. When patients are equipped with knowledge/information for self-management of COPD, including when and where to seek help as appropriate, they will hopefully access the Hospital/Health Services as required. This in turn could lead to appropriate utilisation of health resources and a reduction in unplanned admissions. Participants in one programme described how their relationship with health care professionals changed to a more collaborative relationship and that they felt that they now knew what to ask health professionals for and how to self-manage their condition which was empowering for them. One study worked with GPs and practice nurses to develop strategies that would influence and consequently increase their referrals to PR. This relates to PT5 when GPs and other health professionals are influenced by the wider context of the healthcare system and the availability or otherwise of support and incentives may influence their adoption of PR which could help avoid unnecessary referrals and admissions to hospital.

PT4, refers to the possibility of patients delaying seeking treatment which then leads to greater overall use of health services, this could happen with certainly happen with patients with COPD and one of the UK studies investigating whether how professionals introduce the possibility of a PR affected uptake discussed this. The study found that COPD patients are often self-conscious about their condition; this can be related to shame or stigmatisation and they can believe that the COPD is their own fault. This can be associated with a reluctant to ask for help from health professionals which could lead them to not taking up PR or not
complete it which could them mean that their health deteriorates and they then need to access other services. Their reluctance to ask for help therefore could lead to them making greater use of the health service or unavoidable admissions.

**Description of Putative Mechanisms**

Pulmonary rehabilitation consists of two components exercise and patient education (Table 19). The patient education component can be basic information or advice about COPD or medication or a more extensive self-management programme. One mechanism in self-management involves enabling participants to successfully understand the need for change, appreciate the benefits of change and to live the change long term. This mechanism occurred in the UK study where Occupational Therapists delivered a participant empowered approach to pulmonary rehabilitation that built upon traditional models of self-management. The programme was highly beneficial and patients improve their physical fitness and wellbeing and confidence to manage their condition.

Self-management programmes also work on increasing the patients’ self-efficacy and confidence in managing their own condition. Through completing a self-management programme and the exercise component patients could also increase their confidence in ability to exercise meaning that they will then exercise more. Enhanced understanding of the benefits of regular activity as part of disease management prompted increased participation.

Pulmonary rehabilitation programmes are provided to patients in group and exercising in a group can have important benefits for the patients. “The key premise of social identity theory is that group membership (e.g. exercise group) to which a person belongs can provide an individual with a sense of who they are in terms of a defined group identity (i.e. ‘we’ and ‘us’ rather than ‘I’ and ‘me’), that is, the way person feels and thinks about self is derived from their social groupings.”

The operation of social identity theory can be demonstrated in UK studies on pulmonary rehabilitation. A qualitative study considering the barriers and facilitators for patients...
continuing to exercise following the programme found that continued peer and professional support was important to participants. Participants on another programme also described how working in the group helped them by making them motivated to continue with the programme and helped them to focus on what they wanted to achieve. One qualitative study found that professional and peer support were important aspects of the programme. Participants want to exercise within a peer group and saw this as an opportunity for social interaction.

Table 19: Putative mechanisms for pulmonary rehabilitation

<table>
<thead>
<tr>
<th>Intervention Components</th>
<th>Contextual Factors (Enabling)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient exercise programme</td>
<td>Accessible location</td>
</tr>
<tr>
<td>Patient education</td>
<td>Location where participants feel comfortable</td>
</tr>
<tr>
<td>Emotional and psychological support</td>
<td>Access to follow-up</td>
</tr>
<tr>
<td></td>
<td>Available physical and human resources</td>
</tr>
<tr>
<td></td>
<td>Organisational structure of the programme</td>
</tr>
<tr>
<td></td>
<td>Patient age and family support</td>
</tr>
<tr>
<td></td>
<td>Patient support for intervention</td>
</tr>
<tr>
<td></td>
<td>Support/advice available for patients</td>
</tr>
<tr>
<td></td>
<td>Patients support for intervention</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Potential Mechanisms (HCPs)</th>
<th>Potential Mechanisms (Patients and Carers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belief in capacity for exercise</td>
<td>Acceptance of care and services offered</td>
</tr>
<tr>
<td>Belief in ability to self-manage</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Leading To</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved quality of life</td>
<td></td>
</tr>
</tbody>
</table>
| Improved skills and self-efficacy of facilitators | Improved functional status  
 Improved self-efficacy  
 Improved confidence in ability to exercise  
 Improved ability to self-manage  
 Appropriate utilisation of health resources  
 Reduction in preventable admissions |
Contextual Factors
Role of Patient Preference
The location of the pulmonary rehabilitation programme and how easily accessible it is for patients can help the programme to succeed or act as a barrier to patients. To make the programmes more accessible to patient’s health services have started to try run programmes in community settings. One programme provided by general practices in Ireland used inexpensive equipment and trained practice nurses and physiotherapists with no prior COPD expertise to facilitate a PRP in primary care. Another programme that was offered in the local community gym facilities received very positive patient feedback.

A qualitative study considering the barriers and facilitators for patients continuing to exercise following the programme found that continued peer and professional support was important. Participants that attended maintenance sessions stayed more physically active than participants that were just offered a list of facilities where they could exercise. Participants wanted facilities where they could exercise with people with a similar condition. Participants also wanted to exercise within a peer group and saw this as an opportunity for social interaction.

Participants on another programme discussed how working in the group made them more motivated to continue attending the programme and helped them to focus on what they wanted to achieve. Another study found that the facilitators of exercise included encouragement, company, professional support, goal setting, personal attributes and availability of a range of exercise options.

The venue for pulmonary rehabilitation used can also be a barrier, one qualitative study suggested facilities where programme participants could exercise following completion of the programme but found that they felt unsure about using them due to the environment and perceived healthier fitter members. The exercise facility presented a possible barrier to attendance due to its potential to provoke feelings of embarrassment or intimidation. Familiarity with staff helped to ease anxiety associated with moving to a new venue. Supervision, albeit in a less intensive form than during pulmonary rehabilitation,
important for guiding components of the exercise programme for which participants lacked confidence – such as the cooldown – or for altering or progressing regimens. Participants in one programme described how their relationship with health care professionals developed into a more collaborative relationship that they know what to ask health professionals for and how to self-manage their condition. Patients’ reasons for not exercising was often related to symptoms of their COPD or stigma about their disease. Breathlessness was a common reason for not participating in exercise. Additionally, how symptoms varied or started unexpectedly could influence activity. The education aspects of the programme improved their knowledge and understanding of symptom management leading to greater control over breathlessness. Education about the benefits of regular activity as part of self-management of COPD lead to increased participation in exercise.

Role of Culture
To encourage programme accessibility, one study offered a web programme which was a popular choice. This could be a barrier though for some other groups of patients though as to participate patients had to have internet access and be web literate. How professionals introduce the possibility of a PR was found to affect uptake. The study found that COPD patients are often self-conscious about their condition; this can be related to shame or stigmatisation and they can believe that the COPD is their own fault. This can be associated with a reluctant to ask for help from health professionals or socially. All of these feeling of low self-worth can make their interactions with health professionals difficult potentially seeing them critical or judgmental this may mean that they will not seek help or might refuse PR. When introducing PR, professionals should be aware of such sensitivities and facilitate open discussion which offers, time, compassion and understanding as a means of facilitating uptake.

The role of the group was important to participants. Professional and peer support were identified as key elements; participants expressed a desire to exercise within a peer group combined with an opportunity for social interaction.
Role of Leadership
The role of leadership was not investigated in the included studies.

Role of Evaluation/Measurement
Future trials could investigate choice based PR enabling patients to choose location or web programme\(^{208}\).

One study\(^{205}\) investigated whether introducing rehabilitation while in hospital for an acute exacerbation of COPD could reduce risk of readmission. The study found that early rehabilitation did not reduce the risk of subsequent readmission and conclude that the results from their study suggest that beyond current standard physiotherapy practice, progressive exercise rehabilitation should not be started during the early stages of the acute illness.

Patients that decline referral to pulmonary rehabilitation described feeling of shame, guilt and fear of others opinions of them which related to their lowered self-worth and lead them to decline interventions or reduce their help-seeking from health care professionals\(^{204}\). Another study found that people with COPD experienced difficulties in maintaining an active lifestyle and the findings suggest that confidence is an important determining factor in physical activity participation in patients with COPD\(^{215}\). When introducing pulmonary rehabilitation health care professionals need to be mindful of patients' feelings about their COPD and could try to enable an open discussion with patients which offers, time, compassion and understanding of their feelings as a means of facilitating pulmonary rehabilitation uptake.\(^{204}\).

Role and characteristics of Facilitation
Findings from a qualitative study suggest that people with COPD perceive peer and professional exercise-focused support to be important for maintaining an active lifestyle after pulmonary rehabilitation\(^{215}\). The study data highlight the difficulties experienced by people with COPD in maintaining an active lifestyle and suggests that confidence is an important determining factor in physical activity participation in people with COPD. Health services should look to work in collaboration with local authorities and voluntary organisations to increase opportunities for people with COPD to be physically active, recognising the
importance of continued peer and professional support. People with COPD can suffer from breathlessness which can worsen in certain circumstances and access to advice and reassurance from skilled staff was very valuable to improve PR participations confidence in their ability to exercise.

**Role/skills of Implementation Facilitators**

Hospital based PR programmes generally use expensive equipment and are delivered by respiratory specialists. The SEPRP used inexpensive equipment and trained practice nurses and physiotherapists with no prior COPD expertise to facilitate the PR programme in primary care. Training the practice nurses and physiotherapists increased their skills and ensured that the knowledge gained remained within primary care so it could potentially have a more lasting impact 200-202.

In initial discussion about starting a pulmonary rehabilitation programmes professionals need to give time, compassion and understanding to their patients which could potentially facilitate pulmonary rehabilitation uptake 204.

**Supporting Evidence**

Three systematic reviews of PR were identified 67, 196, 197. Two are updated Cochrane systematic review, 2015 197 and 2016 196.

The 2015 updated review reviewed RCT studies found that PR improves the health-related quality of life of people suffering from COPD and that it should be part of the management and treatment of patients with COPD 197. Further research within in this area could beneficially consider which components of PR are the most important, the ideal length of the programme and intensity of training required and how long the programme benefits actually last.

The second updated Cochrane review 196 and the other review 67 considered the effect of pulmonary rehabilitation following acute exacerbations of COPD. Puhan 196 196 found that pulmonary rehabilitation improves quality of life and exercise capacity and is a safe intervention for patients with COPD following an exacerbation. The reasons for diverse effects on hospital readmissions and mortality shown in the studies, however, are not fully
clear and future studies should research whether the extent of the rehabilitation programme and the organisation of such programmes within specific healthcare systems (e.g. within the rehabilitation setting vs embedded in the continuum of care from hospital to home to outpatient care) influences the effects of rehabilitation after COPD exacerbations. The third review 67 reviewed the results from 10 RCTs which suggested that PR reduces subsequent admissions but pooled results from the 3 cohort studies did not. This could possibly be explained by the heterogeneous nature of individuals included in observational research and the varying standard of PR programs.

**Potential Enhancements of Intervention/Implementation**

A study investigating the impact of deprivation on PR completion found that patients living in more deprived areas are less likely to complete a PR programme 218. However, people in deprived areas that completed a PR programme had similar clinical outcomes to patients in more affluent areas. Therefore, interventions targeted at enhancing referral, uptake and completion of PR among patients living in deprived areas could reduce morbidity and healthcare costs in this hard-to-reach populations. Another study found that introducing strategies that are relatively easy to implement lead to the potential of more patients accessing the health and quality of life benefits that PR offers. 212.

A large well-conducted RCT compared the efficacy of pulmonary rehabilitation delivered in a community setting to pulmonary rehabilitation delivered in a more traditional hospital-based setting 206. Both settings producing significant improvements in terms of exercise capacity and quality of life acutely and after long-term follow-up. The costs of the two programmes were similar. The choice of model therefore will depend on local factors of convenience, existing availability of resources and incremental costs. Another RCT found that a primary care based structured education pulmonary rehabilitation programme is feasible and may increase local accessibility to people with moderate and severe COPD. 200-202.

Occupational Therapists can deliver a participant empowered approach to pulmonary rehabilitation which builds upon traditional models of self-management. Critically this
approach enables participants to successfully understand the need for change, appreciate the benefits of change and to live the change long term. 203
Introducing the GOIS improved the graduation rates at The North Bristol Lung Centre PR Course and reduced wasted assessments 207.
Professionals should facilitate an open discussion with patients which offers, time, compassion and understanding as a means of facilitating pulmonary rehabilitation uptake 204.
For patients who refused referral to PR, had not completed a course, or had yet to be referred, the way the service was introduced was an important determinant of willingness to participate 219. Recognition of the role that uncertainty plays in patients with COPD is the first step towards developing interventions focused on reducing this uncertainty, thereby reducing the burden of the disease for the individual patient and facilitating PR attendance 220.

Smoking status, availability of social support and markers of disease severity were predictors of attendance and adherence to PR 221.

4.7: Specialist clinics

Summary
Specialist clinics provide advanced diagnostic or treatment services for specific conditions, often in primary care or community settings, with care delivered by specialist nurses or multidisciplinary teams. Possible mechanisms for effectiveness of specialist clinics include improved self-efficacy and open communication with health professionals, especially
specialist nurses. Limited UK research on specialist clinics was identified. Systematic review evidence supported their effectiveness for heart failure but evidence for hypertension was less clear. Potential enhancements to improve effectiveness include clinics being run by nurses already known to the patient and a high intensity of contact immediately after discharge, decreasing over time.

**Definition**
“A specialised clinic provides advanced diagnostic or treatment services for diseases/conditions. Specialist clinics have been set up in both primary and secondary care settings, which may utilise nurses to provide specialist nurse led clinics or multidisciplinary care teams to help manage long term conditions.”

**Intervention Components**
Specialist clinics are provided by a range of healthcare professionals trained in the specialist care of the specific condition or patient type. The clinics are provided in the community and can include staff from primary and secondary care. The clinics are of varying intensity and comprise different components of care. More detail of the key components of specialist clinics are provided in Table 20 below. This reflects UK practice as described in the studies selected from the mapping review.

**Table 20: Key components of specialist clinics**

<table>
<thead>
<tr>
<th>By whom</th>
<th>Nurses led specialist nurse led clinics with consultant back-up or multidisciplinary care teams that can include staff from primary and secondary care</th>
</tr>
</thead>
<tbody>
<tr>
<td>What</td>
<td>Treatment and management of condition including education for patient and family or carer about the condition and any medication.</td>
</tr>
<tr>
<td>Where</td>
<td>Primary care settings, Purdy also includes studies in secondary care settings.</td>
</tr>
<tr>
<td>To what intensity</td>
<td>Specialist clinics research included in Purdy varied in intensity from weekly to fortnightly to monthly. Both of the included UK.</td>
</tr>
</tbody>
</table>

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studies had one clinic appointment with follow-up as required by individual patient 222, 223.

| How often | A hypertension clinic offered follow-up by the specialist nurse on a monthly basis for a maximum of 6 months or until blood pressure was below the optimal target. Monthly appointments include motivational interviews and encouraged behavioural changes to reduce cardiovascular risk factors. Following reduction in patient’s blood pressure to below target, nurse had a short telephone call with the patient on a monthly basis briefly every month to remind and promote continuation of agreed lifestyle and medication changes. Following the 6-month trial the specialist nurse had no further contact with the patients who were then asked to see their usual health care professions when required. 222. |

---

**Number and Type of UK Studies identified**

Two UK research studies were identified on specialist clinics published from 2010 onwards from the mapping review. One of the clinics was for patients with hypertension 222 and one was for high-risk respiratory patients with COPD or asthma 223. The research studies were both quantitative, one was an RCT 222 and the other an uncontrolled observational study 223. A summary table of the included studies is provided below (Table 41, see Appendix 4).

**Operating Programme Theories**

Specialist clinics included education about the chronic condition and any medication which relates to PT1. If the specialist clinics can educate patients about their condition this can lead to self-management which could then lead to a reduction in unplanned admissions. The RCT for hypertension 222 found a reduction in systolic blood pressure, this reduction potentially means that the condition is being appropriately managed and thus should mean these patients will not have unplanned admissions. The observational study found a reduction in acute
respiratory exacerbations, unscheduled visits to GPs and hospital admissions for acute respiratory exacerbations.

Linking to the GP programme theory, PT5. Potentially several aspects of the UK RCT had a beneficial effect on patient blood pressure, firstly a letter about the clinic and explaining that they had been invited as their last recorder blood pressure was higher recommended levels. While they might not attend the clinic they might see more regularly take their tablets and see their own GP for regular blood pressure checks. Patients, that did attend might start taking their medication more regularly as they learnt more about the risks of cardiovascular disease and because their blood pressure was being monitored on a regular basis.

Motivational interviews conducted by the nurse could also have helped to reinforce regular taking of medication and lifestyle changes. Additionally, in this study the patients with blood pressure over target were being regular followed up which might not be the norm in primary care. This links to the idea of clinical inertia and if nurse led specialist clinics can overcome clinical inertia then they could be effective.

Additionally, for PT5 if clinicians and other health service staff believe that specialist clinics provide appropriate support, then they will refer patients to them if they are established or will implement the setting up of specialist clinics where appropriate which through the changes to practice and their professional role will lead to appropriate utilisation of health resources and potentially a reduction in unplanned admissions.

The 2 included studies offered specialist clinics in the primary care setting which links to PT2. The provision of a specialist clinic in the primary care setting will hopefully mean that the patients feel confident and satisfied with the care offered to them and will continue to use these services and not request secondary care services. Positive written feedback from patients indicated that the patients found the joint clinics provided by primary and secondary care professionals for high-risk respiratory patients acceptable and were satisfied with health services provided, this observational study found a reduction in hospital admissions indicating the clinic was potentially effective. Satisfaction with the clinic was also demonstrated by the high attendance levels and some of the patients attending had previously missed their routine annual COPD check-up.
Potentially PT3 could be relevant in terms of GPs and primary care staff. If GPs and primary care staff have confidence in and knowledge of specialist clinics available within primary care then they will be more likely to refer patients to the specialist clinics instead of secondary health care provision. Diffusion of innovation is relevant here, if now roles i.e specialist nurse clinics are not supported and embedded into the existing system then patients will not be referred to them. A case study of consultant nurse posts discussed how they developed in an ad hoc manner and that new posts need to be supported by health professionals and embed into the system to succeed 225. This diffusion of innovation is based on an earlier systematic review by Greenhalgh 226.

**Description of Putative Mechanisms**

Possible mechanisms of action are summarised in Table 21.

**Table 21: Putative mechanisms for specialist clinics**

<table>
<thead>
<tr>
<th>Intervention Components</th>
<th>Contextual Factors (Enabling)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Identification of appropriate patients</td>
<td>• Knowledge and motivation of specialist or practice nurse</td>
</tr>
<tr>
<td>• Specialist nurse as main contact</td>
<td>• Clarity of nurse role</td>
</tr>
<tr>
<td>• GP or consultant back-up</td>
<td>• Clarity of GP and consultant back-up role</td>
</tr>
<tr>
<td>• Regular monitoring</td>
<td>• Access to training for nurse</td>
</tr>
<tr>
<td>• Regular support</td>
<td></td>
</tr>
<tr>
<td>• Knowledge of referral options</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Potential Mechanisms (HCPs)</th>
<th>Potential Mechanisms (Patients and Carers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Accountability of nurse to patient</td>
<td>• Belief in capacity for self-care</td>
</tr>
<tr>
<td>• Reduced fragmentation among services</td>
<td></td>
</tr>
</tbody>
</table>
### Outcomes
- Improved skills of nurses
- Improved self-efficacy of nurses
- Changes to medication in conjunction with GP or consultant
- Ongoing self-management

### Leading To
- Improved quality of life
- Improved functional status
- Improved self-management
- Self-efficacy of patient and informal caregiver
- Appropriate use of health services

**Contextual Factors**
Both of the included studies discussed how patient preference could work either as a barrier or a facilitator. Feedback from patients, who attended the joint clinics for high-risk respiratory patients\(^2\) was positive. All patients described attending the clinic as a positive experience in terms of patient experience of the clinic and the interventions made. The reduction in hospital admissions indicating in this study suggest that the clinic was potentially effective. Satisfaction with the clinic was also demonstrated by the high attendance levels and some of the patients attending had previously missed their routine annual COPD check-up.

The RCT study researched patients from two inner city practices that were invited to a specialist nurse-led hypertension clinic or usual care\(^2\). Eighty-two patients were randomised to the specialist nurse-led hypertension clinic; of these 27 or 33% chose not to attend. The study authors thought that potentially the attendance would have been higher if the clinic was run by a practice nurse with whom patients were familiar.

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Role of Culture
The specialist nurse-led hypertension clinic was conducted in two London Inner city practices with over 40% of participants of Black African, Black Caribbean or Asian ethnicity. The study found that the intervention was associated with reduced systolic blood pressure. However the results could be different with practices with different ethnic groups.

Role of Leadership
The role of leadership as a barrier or facilitator in specialist clinics was not reported in the included studies.

Role of Evaluation/Measurement
The role of evaluation/measurement in specialist clinics was not reported in the included studies.

Role and characteristics of Facilitation
The integrated model of care provided in a joint clinic by primary and secondary care professionals for patients with high-risk respiratory problems allowed for shared learning between primary and secondary care, and intra-organisationally, within the multidisciplinary team. “Initiative placed strong emphasis on importance of patient and carer education. The emphasis on education for patients was intended to leave a legacy of patients who are able to self-manage more effectively and healthcare professionals who are upskilled in the management of patients with respiratory disease and more technically assured in performing specialist respiratory assessment.”

Role/skills of Implementation Facilitators
The joint clinic intervention increased the skills of healthcare professionals in the management of patients with respiratory diseases enabling them to become more competent in performing specialist respiratory assessments.

The specialist clinic for hypertension trial was conducted by an experienced cardiovascular research nurse with backup from a consultant physician who had a specialist interest in hypertension. It was conducted in just two inner London general practices meaning that the findings may not be applicable to other clinical staff or populations.
Supporting Evidence
Evidence for specialist clinics was found in the Purdy series of systematic reviews \(^1\) and one conference abstract of a review on specialist clinics for hypertension \(^227\).

Purdy 2012 found that “specialist clinics for patients with heart failure can reduce the risk of unplanned admission; these were most effective when there was a high intensity of clinic appointments close to the time of discharge which then reduce over the follow up period.” \(^1\)

The other review \(^227\) considered the involvement of nurses in the management of hypertension, particularly in the UK. The systematic review found evidence of improved outcomes with nurse prescribers from non UK healthcare settings. However, the review was only able to identify one trial of adequate size recruiting patients with hypertension in UK primary care and found that currently while it is practice for hypertension management to move from GPs to nurses in the UK there is actually no good quality trial evidence from UK primary health care that supports the widespread employment of nurses in hypertension management.

Potential Enhancements of Intervention/Implementation
The RCT authors \(^223\) suggested that a specialist clinic run by a practice nurse known to patients might increase uptake.

Purdy \(^1\) found that Specialist clinics were most effective when there was a high intensity of appointments immediately after discharge from hospital which then steadily reduced.

4.8: Community interventions
**Summary**

Community interventions are those that take place in community settings but do not primarily involve case management, attending a specialist clinic, education or exercise/rehabilitation. Examples were identified from the UK for heart failure and COPD, including a ‘natural experiment’ comparing different COPD service models commissioned in demographically similar areas of Wales. Key components involve providing support to people living in the community, often through home visits. Possible mechanisms of action depend on formation of a trusting relationship between the patient and the health professional (usually a nurse) delivering the service.

Overall, the systematic review evidence identified by our mapping review is not strongly supportive of the effectiveness of community interventions for reducing hospital admissions. However, this may reflect the inherent clinical heterogeneity of the interventions in this group. Study authors have suggested a diverse range of possible enhancements to interventions without any clear themes emerging.

**Definition**

Community interventions are defined by exclusion as those that take place in community settings but do not primarily involve case management, attendance at a specialist clinic, education or exercise/rehabilitation.

**Intervention Components**

Key components are summarised in Table 22 based on the TiDIER-Lite checklist. This is based on our sample of included UK studies.

<table>
<thead>
<tr>
<th>Table 22: Key components of community interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>By whom</td>
</tr>
</tbody>
</table>

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failure. One included study compared interventions delivered by specialist and
generically trained nurses with and without links to secondary care228

<table>
<thead>
<tr>
<th>What</th>
<th>Most community interventions involve providing support for patients living in the community. In the case of heart failure specialist nurses, this involves providing education to help patients manage their condition but also liaising with other health professionals to ensure co-ordination and continuity of care. ‘Hospital at home’ as an alternative to admission or to support patients after discharge may also be considered to belong to this group of interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where</td>
<td>Community interventions are often delivered in patients’ own homes</td>
</tr>
<tr>
<td>To what intensity</td>
<td>Varies between interventions/populations. For heart failure, community-based specialist nurse services may operate alongside other services such as cardiac rehabilitation in community settings. Intensity of interventions that can be offered to patients is limited by caseload and availability of administrative support</td>
</tr>
<tr>
<td>How often</td>
<td>Varies between interventions/populations. Specialist nurse services generally aim to offer patients at least one home visit, with any subsequent appointments either at home or in a clinic setting. Care is planned on an individual basis, with provision for discharge of stable patients to standard primary care and liaison with palliative care for those approaching the end of life</td>
</tr>
</tbody>
</table>

**Number and Type of UK Studies identified**
The mapping review identified eight UK studies covering community interventions. Two were qualitative studies of specialist heart failure nurse services in the community125, 229. Both studies presented health professionals’ perspectives only.

Three other studies dealt with COPD. A qualitative study of barriers and facilitators to physical activity for patients in primary care230 appeared relevant to designing community interventions that might be less demanding for patients than full pulmonary rehabilitation. An evaluation of a telephone alert service provided by the Met Office231 differs from other
community intervention studies in that the intervention was not provided by the NHS (although it was commissioned by multiple PCTs) and did not involve home visits. The service reduced hospital admissions when admissions with a co-morbid diagnosis of COPD were included it was discontinued in 2013 and evaluated retrospectively. Flood-Page et al. used a ‘natural experiment’ to compare different models of community care implemented in neighbouring areas with similar demographic characteristics. The authors suggested that service models with close links between primary and secondary care may be more effective in reducing hospital admissions than those involving primary care alone.

Table 42 (Appendix 4) summarises the included studies. A news article, a narrative literature review and a conference abstract were excluded on the grounds of being too short to provide relevant data for this analysis.

Purdy et al.’s review of community interventions included only one UK study. This was a randomised trial of home-based support for older patients with heart disease following hospital discharge. The study fell outside the time period for inclusion in our review. A citation search of this study did not identify any more recent relevant community intervention studies.

Operating Programme Theories
The relevant programme theories are:

PT1: IF patients are equipped with knowledge/information for self-management, THEN they will access hospital/health services as required, LEADING TO appropriate utilisation of health resources and a reduction in unplanned admissions. Increased patient knowledge could result from working with specialist nurses or other community-based health professionals but this was not reported in our included studies, which concentrated on the perspectives of health professionals.

PT2: IF patients feel satisfied with non-secondary care provision, THEN they will not consider it necessary to access secondary care services, LEADING TO appropriate
utilisation of health resources and a reduction in unplanned admissions. The included studies from the UK do not directly support this theory because they do not include data on patient satisfaction and related outcomes.

PT3: IF GPs/primary care staff feel confident in their own ability to diagnose and/or refer patients appropriately and have confidence in and knowledge of services available within primary and community care, THEN they will not refer patients to hospital, LEADING TO an increase in use of self-management and non-secondary care services and a reduction in unplanned admissions. This theory appears relevant to some of the studies included below. Flood-Page et al. found that services with close links between primary and secondary care appeared most effective for reducing COPD admissions. Similarly, MacKenzie et al. highlighted the improving relationships between GPs and specialist nurses with time following implementation of a specialist nurse service and the role of the nurses in providing co-ordination and continuity of care for patients with heart failure.

PT5: IF clinicians and other health service staff perceive that the wider health system provides appropriate support and incentives THEN they will feel confident in implementing (and evaluating) interventions that involve changes to practice and professional roles LEADING TO appropriate utilisation of health resources and a reduction in unplanned admissions.

Again, support for this programme theory comes from studies of health professionals’ perspectives on the implementation of new services, generally based on specialist nurses working in the community as part of a multidisciplinary team covering COPD or heart failure.

Description of Putative Mechanisms
Table 23 summarises key mechanisms to explain how the intervention is believed to work.
### Table 23: Putative mechanisms for community interventions

<table>
<thead>
<tr>
<th>Intervention Components</th>
<th>Contextual Factors (Enabling)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient education and support</td>
<td>Ongoing relationship with patient</td>
</tr>
<tr>
<td>Co-ordination of services</td>
<td>Home visits</td>
</tr>
<tr>
<td>Ongoing relationship with patient</td>
<td>National policies/guidelines</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Potential Mechanisms (HCPs)</th>
<th>Potential Mechanisms (Patients and Carers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance of nurse role</td>
<td>Developing relationship with nurse</td>
</tr>
<tr>
<td>Effective communication within MDTs</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Leading To</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved patient knowledge and self-efficacy</td>
<td>Improved care co-ordination and continuity</td>
</tr>
<tr>
<td>Secondary care and GP satisfaction with care quality</td>
<td>Reduction in inappropriate admissions</td>
</tr>
</tbody>
</table>

**Contextual Factors**

**Role of Patient Preference**

Just two studies reported on patient preference as a barrier to implementing community interventions. Glogowska et al. reported that the challenging nature of the information supplied about their condition may be a barrier to some patients working with community specialist nurses. This suggests that for some patients, knowledge and information for self-management may not translate into behavioural change leading to more appropriate use of care.
services as suggested by programme theory PT1. For patients with COPD, Kosteli et al.
identified both personal and social factors that could influence patients against engaging in
physical activity programmes\(^{230}\). In terms of programme theories this again potentially relates
to PT1, because knowledge and information for self-management may not be sufficient to
overcome barriers such as patients’ perceived physical limitations and lack of motivation, as
well as social barriers such as overprotective family members and perceived lack of time.

Kosteli et al. identified facilitators of physical activity arising from patients’ personal choice
and feelings of obligation to others\(^{230}\). Support from family members and/or other people in a
similar situation were identified as social facilitators. This again relates to PT1 and suggests
that whether patients are willing to engage in physical activity to reduce their risk of hospital
admission may depend on the balance between barriers and facilitators in their personal
circumstances.

**Role of Culture**

Some of the patient-related and socially-mediated barriers and facilitators identified by
Glogowska et al.\(^ {125}\) and Kosteli et al.\(^ {230}\) might also be considered as influenced by culture in
its broadest sense. Glogowska et al. also identified ‘heart failure’ as a ‘loaded term’ that
could negatively influence patients’ perception of the condition and their ability to manage
it\(^ {125}\).

Organisational culture as a barrier was only addressed by MacKenzie et al.\(^ {229}\). They reported
that nurses running a community-based service found it difficult to gain trust from GPs, while
some GPs considered that the nurses’ role was unclear and the service disjointed. However,
other GPs found the service valuable and nurses reported that relations with GPs improved
over time, suggesting that the cultural barriers were mainly short-term. Participants in the
study by Glogowska et al. saw home visits as an important facilitator of their service,
perceiving patients to feel more relaxed in their own home than a hospital or other clinical
setting\(^ {125}\).
Role of Leadership
The study by Flood-Page et al. was possible because different local health boards in Wales developed different models for community-based services for people with COPD. This is an example of the importance of local decision-making for implementing effective interventions in a devolved healthcare system like the UK NHS: national guidelines and policy initiatives will have little impact unless they are taken up at local level. At the local level, both Glogowska et al. and MacKenzie et al. noted tensions between professional groups and/or teams about who has ‘control’ of a patient’s treatment. This type of leadership (or cultural) problem could hinder effective implementation of interventions, which is facilitated when health professionals work together effectively in multi-disciplinary teams. GPs appeared ready to provide leadership on heart failure in the study by MacKenzie et al., with 70/84 reporting that they had read the latest national guidance.

Role of Evaluation/Measurement
The included studies took a variety of approaches to evaluation and measurement. Flood-Page et al. analysed routine NHS data and emphasised that their study was a service evaluation rather than research. Sarran et al.’s study of a telephone alert service for COPD patients was one of several that evaluated this intervention so its findings should not be considered definitive. The authors noted that it was important to take account of patients with a co-morbid diagnosis of COPD as well as those with a primary diagnosis in evaluating the intervention. The remaining three studies used qualitative methods, two investigating the perspective of health professionals and one that of patients.

Role and characteristics of Facilitation
The studies reported limited data about facilitation. Flood-Page et al. explicitly stated that they were investigating services as implemented in routine NHS practice. This meant that services were delivered by different groups in each area as described in the following section. The heart failure specialist nurses in the service examined by Glogowska et al. worked with patients from initial diagnosis and were generally regarded as the lead clinician for their patients. MacKenzie et al. examined a similar specialist nurse service and reported that
nurses perceived that better pre-launch planning would have facilitated implementation of the service.229

**Role/skills of Implementation Facilitators**

Flood-Page et al. identified several different models of service delivery.228 In Caerphilly LHB, COPD was managed by COPD nurse specialists working effectively in isolation. In Newport and Monmouthshire, generically trained nurses managed COPD and other long-term conditions, working alongside GPs without direct secondary care input. In Torfaen and Blaenau Gwent, COPD was managed by nurse specialists, GPs and consultant chest physicians around a weekly outpatient clinic. Consultants provided telephone advice at other times. In two studies of heart failure specialist nurses, one identified the nurses’ role as a link between secondary and primary care125, while the other, set in Scotland, emphasised cooperation between nurses and GPs to facilitate evidence-based management of patients with heart failure.229 This small sample of studies thus suggests that a wide range of different models of facilitation of community interventions exist in the UK NHS, reflected in the different roles and skills of the staff involved (primarily nurses).

**Supporting Evidence**

Evidence on the effectiveness of community interventions (including hospital at home) comes from Cochrane and other systematic reviews. Cochrane reviews have assessed hospital at home interventions for admission avoidance, early discharge and specifically for acute exacerbations of COPD. Although the interventions were delivered in the patient’s home, staff delivering the service could be community-based, hospital-based or a mixture of the two. Of the three reviews, only the one covering acute exacerbations of COPD found a significant effect on reducing hospital readmissions compared with hospital inpatient treatment.238 It should be noted that Purdy et al. treat hospital at home separately from community interventions1.
Health Quality Ontario systematically reviewed studies of early follow-up (within 7 or 30 days) after hospital discharge for heart failure or COPD in reducing readmissions\(^31\). Follow-up could be conducted by telephone or by home visits, so the review scope was relatively broad. Early follow-up was associated with reduced all-cause readmissions after adjusting for confounders but the strength of evidence was classed as low to very low on the GRADE system. A Cochrane review by Wong et al. examined home care by outreach nurses for people with COPD\(^239\). This review also failed to find a significant effect of the intervention on hospital admission or mortality. Significant heterogeneity was present for hospital admissions, possibly related to the presence of one outlying study with a large decrease in admissions while other studies showed an increase.

Other reviews identified by the mapping review focused on community-based programmes for hypertension but with a focus on Canada\(^240\) and on transitional care interventions which are dealt with in the next section.

Overall, the systematic review evidence identified by our mapping review is not strongly supportive of the effectiveness of community interventions for reducing hospital admissions. Most of the evidence relates to heart failure or COPD. The definition of community interventions covers a mixed group of interventions and the limitations of the evidence base may reflect the inherent clinical heterogeneity of this group.

**Potential Enhancements of Intervention/Implementation**

Study authors suggested a diverse range of possible enhancements without any clear themes emerging. Flood-Page et al. emphasised the importance of links between primary and secondary care\(^228\), while MacKenzie et al. pointed to the need to consider urban vs. rural settings\(^229\) as GPs see their roles differently in the two settings. Participants also mentioned the need for effective planning and preparation before implementing a new community service. Glogowska et al. stressed the importance of both the nurse’s ongoing relationship with the patient and their role in co-ordinating and ensuring continuity of care\(^125\)
4.9: Multiple/other interventions

**Summary**
It is difficult to provide a formal definition of this group of miscellaneous interventions. Most examples of multiple interventions involve co-operation between different elements of the healthcare system/workforce. Other interventions are generally simpler interventions not covered by any of the other groups of interventions in the review. Five UK studies were included, of which three involved multiple interventions (two for COPD and one for heart failure) and two were classified as ‘other interventions’. Two studies included explicit statements about how the intervention is believed to work, both relating to programme theories PT1 and PT2. The disparate nature of the interventions in this group makes it difficult to identify relevant systematic reviews and other sources of synthesised evidence. Contextual factors around implementation were relatively well reported for this group of studies, with differences in facilitation between interventions implemented across a whole area and those implemented at a smaller scale (e.g. a single hospital or practice).

**Definition**
It is difficult to provide a formal definition of this group of miscellaneous interventions. Most examples of multiple interventions involve co-operation between different elements of the healthcare system/workforce, in some cases affecting all stages of the patient pathway from diagnosis to end of life. ‘Other’ interventions are generally simpler interventions not covered by any of the other groups of interventions in the review.

**Intervention Components**
Key components for each included UK study are summarised in Table 24 based on the TiDIER-Lite checklist.
**Number and Type of UK Studies identified**

Five studies were included, of which three involved multiple interventions\(^{241-243}\) and two were classified as ‘other interventions’\(^{244,245}\). Two of the multiple intervention studies were for COPD and one for heart failure. All three studies used an observational design and only one had a control group (Table 43, see Appendix 4).

The intervention reported by Roberts et al. was an integrated COPD service covering the inner-city area of Salford\(^{241}\). Ghosh et al. evaluated a complex intervention involving telehealth, health coaching and a specialist nurse service, also in an urban setting (Leicester)\(^{242}\). The heart failure transitional care service evaluated by Williams et al. involved discharge planning; patient education; and follow-up. Patients received regular visits during their hospital stay and follow-up in nurse-led clinics or home visits\(^{243}\). This study had a historical control group.

The two other interventions involved a consultant-led community-based service for COPD patients with frequent admissions and education, spirometry training and case finding for primary care\(^{245}\) and a hospital in-reach service to optimise management and support early discharge to community services\(^{244}\).

**Operating Programme Theories**

The overarching programme theories appear to operate to different extents in different interventions. PT1 (patient knowledge for self-management) was part of the interventions reported by Williams et al.\(^ {243}\), Cope et al. \(^ {244}\) and Ghosh et al. \(^ {242}\). The latter two studies reported increases in patient confidence to self-manage their condition, although based on a small sample, while Williams et al. only assessed patient satisfaction. As this was a short-term study of a transitional care service, it appears to have limited relevance to PT2 (patient satisfaction with non-secondary care provision). Other studies did not report data relevant to PT2.
PT3 (GP/primary staff confidence) appears relevant to those studies where enhanced education and training for health professionals was part of the intervention\textsuperscript{241, 245}. However, outcomes related to increased health professional confidence were not reported in these studies. PT4 (patient delay in seeking treatment) appears relevant to the work of Wilkinson et al., who identified a group of patients with frequent admissions who had become disengaged from primary care and were more likely to visit the ED\textsuperscript{245}. PT5 (wider health system support and incentives) appears to operate in those studies where new services were implemented across a broad area with input from a range of relevant stakeholders. This is exemplified by the studies of Ghosh et al.\textsuperscript{242}, Roberts et al.\textsuperscript{241} and Wilkinson et al.\textsuperscript{245}.
Table 24: TIDIER-Lite checklist for miscellaneous interventions

<table>
<thead>
<tr>
<th>Study</th>
<th>By whom</th>
<th>What</th>
<th>Where</th>
<th>To what intensity</th>
<th>How often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Roberts et al. 2010</td>
<td>Whole system</td>
<td>Five stages focusing on prevention/accurate diagnosis; treatment and management of stable disease; enhanced services for severe/complex disease; specialist and generalist unscheduled care; community and hospital end of life care</td>
<td>General practice Community Secondary care</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Williams et al. 2010</td>
<td>Clinical nurse specialist</td>
<td>Transitional care comprising discharge planning; patient education; follow-up</td>
<td>Hospital and home/community</td>
<td>Regular visits during hospital stay; follow-up in nurse-led clinics or home visits</td>
<td>Not reported</td>
</tr>
<tr>
<td>Ghosh et al. 2016</td>
<td>CCG and community NHS Trust plus commercial partners</td>
<td>Telemonitoring; case management by respiratory specialist nurses; health coaching to increase knowledge and</td>
<td>Home</td>
<td>Variable intensity (except telehealth) but</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>confidence, leading to more effective self-management</td>
<td>averaged 7 patient contacts per month</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>-----------------------------------------------------</td>
<td>-------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>—</td>
<td>—</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wilkinson et al.(^{245})</td>
<td>Project team (consultant, respiratory nurse specialist and registrar) working with existing community teams and general practice staff</td>
<td>Two workstreams: consultant-led community-based service for patients with frequent admissions and education, spirometry training and case finding for primary care</td>
<td>Community in city with well-resourced respiratory services</td>
<td>1.5 h consultant-led appointment followed by open access to services (respiratory centre and community nursing team)</td>
<td>Not reported</td>
</tr>
<tr>
<td>Cope at al.(^{244})</td>
<td>Respiratory clinical nurse specialist and community early assisted discharge service</td>
<td>Hospital in-reach service to optimise management and support early discharge</td>
<td>Large acute county hospital</td>
<td>Nurse visited admissions unit twice daily to identify newly admitted patients. All patients had respiratory medications reviewed; inhaler technique assessed; pulmonary</td>
<td>Monday to Friday only</td>
</tr>
</tbody>
</table>

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| | | | rehabilitation offered; smoking status assessed and a smoking cessation programme offered if appropriate; and a written self-management plan. |

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**Description of Putative Mechanisms**

Two studies included explicit statements about how the intervention is believed to work. Williams et al. invokes the Health Belief Model, arguing that support in the transition from hospital to community would increase patients’ self-efficacy and develop their confidence to make decisions about their health\(^ {243} \). Cope et al.\(^ {244} \) states that early assessment followed by supported discharge is thought to work through patients being more aware of the community services available to them and therefore having the confidence to access such services again in the future. Patients have a better understanding and ability to self-manage their respiratory condition. These mechanisms relate to programme theories PT\(^ {1} \) and PT\(^ {2} \). Other relevant factors identified from the included studies are summarised below (Table 25).

### Table 25: Putative mechanisms for miscellaneous interventions

<table>
<thead>
<tr>
<th>Intervention Components</th>
<th>Contextual Factors (Enabling)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telehealth; clinical coaching; specialist nurses (Ghosh)</td>
<td>Partnership between NHS organisations (Ghosh, Roberts)</td>
</tr>
<tr>
<td>Discharge planning; nurse-led follow-up (Williams)</td>
<td>Patient involvement in intervention design (Ghosh, Roberts)</td>
</tr>
<tr>
<td>Integrated service model (Roberts)</td>
<td>Intensive support (Ghosh)</td>
</tr>
<tr>
<td>Hospital in-reach; early assisted discharge (Cope)</td>
<td>Partnership with industry (Roberts)</td>
</tr>
<tr>
<td>Community service for people with repeat admissions; primary care education and case finding (Wilkinson)</td>
<td>Awareness of problem, support from national policy initiatives (Williams, Cope)</td>
</tr>
<tr>
<td>Project team working with both patients and HCPs (Wilkinson)</td>
<td></td>
</tr>
<tr>
<td>Urban setting with ‘critical mass’ of patients (Ghosh, Roberts, Wilkinson)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Potential Mechanisms (HCPs)</th>
<th>Potential Mechanisms (Patients and Carers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early contact with patients (Williams, Cope)</td>
<td>Increased knowledge of condition and treatment</td>
</tr>
<tr>
<td>Engagement in education/training (Roberts, Wilkinson)</td>
<td>Awareness of community services</td>
</tr>
</tbody>
</table>

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| Identification of patients with greatest needs (Wilkinson, Ghosh) |
| Integration with other services (Ghosh, Wilkinson, Roberts) |
| **Outcomes** |
| Increased self-efficacy (patients) |
| Satisfaction with information and services provided |
| Services appropriate for patient needs |
| **Leading To** |
| Fewer unplanned admissions |
| Improved health outcomes |
| Potential cost savings |

**Contextual Factors**

**Role of Patient Preference**

Ghosh et al.\(^ {242} \) and Roberts et al.\(^ {241} \) reported that patient representatives were involved in the development of the intervention, helping to ensure that services were in line with patient needs and preferences. Wilkinson et al. identified a barrier around patient preference in that patients with frequent admissions had become disengaged from primary care and were often admitted after attending an ED\(^ {245} \). Studies generally found high levels of satisfaction with interventions designed to avoid readmission compared with alternatives\(^ {244} \).

**Role of Culture**

Organisational culture was identified as a barrier in the studies of transitional care\(^ {243} \) and in-reach services\(^ {244} \) with community-supported discharge. The transitional care service required nurses to take a more prominent role in the multi-disciplinary team, while the in-reach service was limited to weekdays because the MDT did not operate a 7-day service. Wilkinson et al. noted that their intervention may not be transferable to less well-resourced or rural settings and also that 2/36 GP practices declined to take part.\(^ {245} \) However, the fact that a pilot 7-day
service was subsequently started\textsuperscript{244} and that the great majority of practices took part\textsuperscript{245} suggested that organisational culture was able to respond to the demands of new services.

**Role of Leadership**

Ghosh et al.\textsuperscript{242} and Roberts et al.\textsuperscript{241} emphasised the role of different NHS organisations and other stakeholders in working together to implement new services across a whole area. For change on a smaller scale, two studies saw the support provided by national guidelines and policy documents as important\textsuperscript{243, 244}.

**Role of Evaluation/Measurement**

All of the studies in this group showed the value of using routinely collected data and audits to identify problems and to support the effectiveness/cost-effectiveness of interventions (while recognising problems with the data for demonstrating causal links).

**Role and characteristics of Facilitation**

Facilitation in the three studies of large-scale interventions\textsuperscript{241, 242, 245} involved education and support to help healthcare professionals to deliver the intervention. Wilkinson et al. also provided education to patients who had experienced repeated hospital admissions for COPD\textsuperscript{245}. The transitional care and in-reach studies involved facilitation by specialist nurses working in MDTs\textsuperscript{243, 244}.

**Role/skills of Implementation Facilitators**

As above, there was a difference between the larger- and smaller-scale interventions. Facilitators in the former group possessed a wide range of skills and included people from outside the NHS, e.g. employees of technology or pharmaceutical companies\textsuperscript{241, 242, 245}. The other studies saw individual nurses acting as implementation facilitators\textsuperscript{243, 244}.

**Supporting Evidence**

The disparate nature of the interventions in this group makes it difficult to identify relevant systematic reviews and other sources of synthesised evidence. For example, one of the studies included evaluates a transitional care intervention for heart failure patients\textsuperscript{243}. While there are several published systematic reviews of transitional care interventions\textsuperscript{246-248}, their
scope is generally wider than that of Williams et al., making their relevance to implementation of this specific intervention uncertain.

**Potential Enhancements of Intervention/Implementation**

In relation to community services for COPD, suggested enhancements were improved access to smoking cessation services, especially in deprived areas\(^241\); and support for practice nurses in primary care\(^245\).

For transitional care and early supported discharge, authors suggested support for 7-day working\(^{243, 244}\) and agreed diagnostic criteria and treatment guidelines for heart failure between primary and secondary care\(^243\).

**Chapter 5: Synthesis of findings: common mechanisms and links to mid-range theory**

This chapter seeks to advance findings from the review of individual interventions by attempting cross-intervention synthesis. In doing so it aims to move from the specifics of individual interventions to the identification of Contexts, Intervention components and Mechanisms that are likely to contribute to intended or unintended Outcomes\(^249\).

Three approaches were used to facilitate the synthesis of findings:

(i) Implementation factors were mapped from individual studies into the PARIHS framework;

(ii) Intervention components were mapped from intervention types into a common five-item TIDieR-Lite framework;

(iii) Programme theory components (PTs 1-5) were interpreted for each intervention type and connections to mid-range theory were actively sought.
In each case the available data were constrained both by the level of reporting present in individual included studies and the degree to which those studies focused on implementation aspects.

**Insights from the PARIHS Framework**

**Evidence**
The clinical conditions selected as the focus for this report, namely cardiac and respiratory conditions were purposively prioritised to represent areas with strong evidence of effectiveness in terms of the reduction of avoidable admissions. However, studies that demonstrated a positive effect had not necessarily demonstrated an effect in a UK context. Indeed, only a very small proportion of the studies identified by Purdy et al and adopted by us as a supposed robust evidence base had been conducted in a UK setting. Furthermore, the types of evidence available to explore implementation constitute a far less robust source of evidence than that for interventions.

**Context**
A typical limitation of the Health Services and Delivery evidence base is its dependence on studies from the United States. While this complicates interpretation of intervention studies, where the U.S. managed care system is so markedly different from the U.K. National Health Service, this challenge is accentuated when examining implementation evidence. We have had to restrict implementation evidence used, at least to a large part, to insights from the U.K. However, such a pragmatic decision should not be allowed to mask the fact that, even within the NHS, contexts may be markedly different in terms of culture, organisation and resources, so pilots or initiatives evaluated in one area may not readily transfer even to adjacent NHS constituencies.

**Facilitation**
The PARIHS framework emphasizes the need for appropriate facilitation to increase the likelihood of a successful outcome\(^1\). The type of facilitation and the role and skill of the facilitator are determined by the specific needs of the organization. Facilitators work with
individuals and teams to enhance the implementation process. In the included studies the most common mode of facilitation was training of staff. This can be challenging to achieve within an NHS environment alongside ongoing delivery of health services. Training was largely procedural with little evidence of attempts to change the organisational culture within which preventable admissions take place. This deficiency may be addressed within the New Models of Care initiative which targets widespread organisational change with preventable admissions as a shared priority.

Much of the evidence on facilitation related to the initiation of the intervention within the context of an experimental evaluation, with the expectation that additional resources for facilitation might be available within the trial setting, rather than in subsequent sustainability and spread. Despite extensive attempts to follow up citations from trials and other experimental studies we found few examples of the implementation of interventions as trial results were rolled out more widely. Those accounts that do exist tend to focus on packages of care that have progressed a relatively long way down the diffusions of innovations curve such as case management and cardiac rehabilitation. This probably reflects the focus on publishing generalisable results from empirical studies in the research literature rather than examining implementation issues related to sustainability and spread.

**Insights from the TIDieR-Lite Framework**

The five-item TIDieR-Lite framework enabled us to capture key features of the interventions and their delivery in a format that allowed comparison across the range. Many of the included interventions were highly variable in terms of setting, delivery, content and duration. This was particularly true of case management and patient education programmes. By contrast, cardiac rehabilitation had a set of national standards and a national audit programme to assess adherence to those standards. However, the actual delivery of programmes showed variation in the professionals delivering the intervention, generally through a multi-disciplinary team. The standards state that patients should have a choice of settings for cardiac rehabilitation, although the extent to which this is available in practice was unclear. The field of pulmonary
rehabilitation also had guidelines for intensity and duration of the intervention, perhaps reflecting the need for patients to participate in these interventions by exercising outside formal supervised sessions. Self-management interventions often included time-limited support for patient education and behaviour change combined with an action plan designed to last indefinitely and be reviewed on a regular basis.

A second key insight was the considerable degree of overlap that often existed between interventions from different groups. In particular, patient education to support self-management was present in programmes labelled as case management, patient education, self-management and telehealth. Education was also key to transitional care interventions designed to reduce readmissions by supporting patients’ discharge from hospital and providing appropriate support in the community. Telehealth interventions were distinctive mainly in their mode of delivery, minimising face-to-face interaction between patients and health professionals. This contrasted with some community-based interventions, which took place in patients’ own homes and involved a co-operative relationship between patients and individual health professionals.

The role of specialist nurses in co-ordinating care for patients as well as delivering care to patients was a key feature of many interventions, particularly case management, self-management support and specialist clinics. Specialist nurses with expertise in heart failure or COPD and other respiratory conditions have become increasingly common in the UK NHS over recent years. These nurses may work in primary, secondary or community care settings. An interesting ‘natural experiment’ in Wales\textsuperscript{228} suggested that services with close links between primary and secondary care may be most effective for reducing hospital admissions for COPD.

In summary, TIDieR-Lite provided a valuable descriptive framework for understanding key features of the interventions and their implementation. Examination of the summary tables for the different interventions highlighted some patterns and contrasts as discussed above.
The roles of national standards and disease-focused specialist nurses in some interventions were of particular interest.

**Insights from the Programme Theories**

Evidence supporting the programme theories is summarised in Table 26.

**Table 26: Evidence supporting programme theories PT1 to PT5**

<table>
<thead>
<tr>
<th>Programme Theory 1</th>
<th>Supporting Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PT1 – IF</strong> Patients are equipped with knowledge/information for self-management, including seeking help as appropriate, <strong>THEN</strong> they will access Hospital/Health Services as required <strong>LEADING TO</strong> appropriate utilisation of health resources and a reduction in unplanned admissions</td>
<td>Where patients lack knowledge of their diagnosis or have little awareness of their condition they do not know when to seek help(^{126}) [Role for Patient Education in increasing awareness of condition and exacerbations; Role of Specialist Nurse in Patient Education]. Successful interventions for managing heart failure trigger mechanisms that promote psychological well-being. In particular they contribute to a greater perception of self-efficacy (Clark et al, 2015)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Programme Theory 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PT2 - IF</strong> Patients feel confident and satisfied with non-secondary care health provision <strong>THEN</strong> they will not consider it necessary to access/request secondary care services</td>
<td></td>
</tr>
</tbody>
</table>
### Programme Theory 3

**PT3** – If GPs/primary care staff feel confident in their own ability to diagnose and/or refer patients appropriately and have confidence in and knowledge of services available within primary and community care **THEN** they will not refer patients to hospital **LEADING TO** an increase in use of self-management and non-secondary care health service provision and a reduction in unplanned admissions.

The impact of increasing the confidence, knowledge and skills of general practitioners in managing patients with heart failure should be considered\(^ {126}\). Where GPs have poor knowledge of available services relational continuity is no longer an advantage\(^ {126}\). May particularly be the case if GP does not know the patient\(^ {126}\).

[Role for Specialist Nurses in knowing about appropriate sources]

### Programme Theory 4

**PT4** - If Patients Delay/Are Delayed in accessing health services **THEN** Patients may experience exacerbation of symptoms **LEADING TO** a higher level of clinical input or resource use when they finally access health care and an increase in unplanned admissions.

A lack of timely and accurate diagnosis of exacerbations resulted in unplanned admissions\(^ {126}\).

### Programme Theory 5

**PT5** - If clinicians and other health service staff perceive that the wider health system provides appropriate support and incentives **THEN** they will feel confident in implementing (and evaluating) interventions that involve changes to practice and professional roles **LEADING TO** appropriate healthcare delivered across multiple services, confusion about eligibility for specialist heart failure services and relational/managerial discontinuity of care added additional complexity and...
utilisation of health resources and a reduction in unplanned admissions

Programme Theory 1 - People with chronic conditions are frequently admitted to hospital when hospital is not the optimal destination for them. People with chronic conditions may have symptoms that could be self-managed or anxieties that could be addressed by patient education or information.

We found evidence to support Programme Theory 1. Challenges to people with chronic conditions related less to being ill-equipped for self-management and more to difficulties in situating their symptoms within the information with which they have been provided. People with chronic conditions are typically only able to interpret their symptoms relative to their own past experience or the observed experience of others, not against some absolute “trigger point”.

There was some evidence to suggest that being equipped with action plans or personalised self-management plans can help people with chronic conditions to assess whether external intervention is required. A similar challenge with patient education related to the need to locate available information within the context of what the patient already knows and what they perceive that they need to know. There was some evidence to suggest that patients are not typically well-equipped to process information on a just-in-case basis, particularly as this may result in a form of information overload. Again, the facility to access contextually-sensitive information at the time it is required, whether this be available as a personalised action plan or telephone advice, rather than being expected to absorb it within a short period of time and then recall it when needed, was positively indicated. The likelihood that patient’s personal experience serves as a benchmark for their decisions about the need for future intervention indicates the potential value of using a trajectory based approach to identification of trigger points e.g. “if you either experience again these symptoms you have previously experienced or start to experience these specific new symptoms then you should…”
People with chronic conditions lack knowledge about alternative health provision and therefore draw disproportionately upon well-signposted channels such as their GP or the emergency department [PT2].

Alternatively, patients perceive that presentation to an emergency department holds relative advantage (e.g. quality, ease of access, response etc.) over GP-based or other primary or community care services [PT2]. People with chronic conditions pressure health professionals to admit them to hospital.

We did not find substantive evidence to suggest that patients exert direct pressure on the decision for emergency admission primarily on the basis of relative advantage. On the contrary we found that people with chronic conditions often resisted admission to an emergency department. Structural constraints such as distance from home, distance from family, the alien (i.e. non-homely) hospital environment and the complexity and duration of the transport and admission process may combine to make emergency admission an unattractive option. It seems therefore that concerns associated with anxiety and risk may constitute a more important driver. Hospitals are seen as a safe place that can offer security and reassurance. However, the presence of perceived, implicit or indirect pressure cannot be underplayed. Health professionals may be influenced by personal factors in their relationship with a specific patient (“soft” factors) or by fear of litigation and ultimately this could impact on the appropriateness of hospital referrals.

Health professionals lack confidence in their own diagnoses or may lack confidence in, or knowledge of, alternative sources of healthcare provision and so may refer people.
with chronic conditions or admit them direct to hospital. Health professionals feel under pressure to admit people with chronic conditions directly to hospital [PT3].

Simmonds et al (2015) use the expression “decision flashpoints” and highlights how clinical misdiagnosis of symptoms (typically breathlessness in the case of comorbid heart failure) can send the patient along a different disease pathway until they require emergency admission126. Simmonds et al (2015) emphasise that inappropriate resolution of “decision flashpoints” is perhaps more likely to occur when there is a lack of relational continuity with a GP126.

Simmonds and colleagues (2015) further report how as “some GPs lacked knowledge of heart failure and specialist services, resulting in ‘mismanaged patients.’”126 Conversely, however, they report that GPs could also be “possessive of their patients”126, reducing the likelihood of referral to specialist heart failure nurses.

People with chronic conditions use health services inappropriately; delaying their presentation to health professionals or hospital [PT4] because of perceptions of the service either anticipated or based on the past experience of either themselves or others.

A weakness of the above programme theories is the extent to which they imply the availability of choice and rational decision-making in determining the decision to admit. This is addressed, at least to a certain extent by the inclusion of Programme Theory 5 namely that GPs and other health professionals are influenced by the wider context of the healthcare system and the availability or otherwise of support and incentives may influence their adoption of interventions and pathways designed to avoid preventable referrals and admissions to hospital [PT5]. An exploration of organisational aspects of the management of heart failure concludes that:

“Different service providers and professional groups had unintentionally co-created structures, systems and professional hierarchies that militated against the provision of seamless care.”126

Such fragmentation and compartmentalisation not only presents barriers within particular episodes of care e.g. interaction between GP and specialist heart failure nurse or between GP
and specialist but also undermines more whole system based interventions such as patient education which requires coherence and consistency across organisational boundaries and telemedicine which logistically requires IT systems and procedures to be joined up.

Simmonds and colleagues (2015) offer evidence that carers adopt an unofficial “ambassadorial” role to help the patient navigate organisational fragmentation and unravel problems caused by poor communication and co-ordination. Carers grew in confidence and proficiency, subsequently being able to became more proactive in challenging the organisation and provision of care on behalf of the person they cared for. However, this added undesirable extra stress and responsibility for carers who often had their own health problems with which to contend.

Within a publicly-funded health service such as the NHS structural constraints and limited availability of alternatives may influence the ultimate decision. Few resources can be accessed urgently (i.e., within a day), and those that exist have limited capacity. Clinicians and patients may factor in anticipated system delays into their decision-making processes and develop compensatory strategies; for example, if a “tipping point” is likely to occur within a particular period. For some patients admission to an acute hospital becomes the only option available if other services cannot be accessed sufficiently rapidly.

Resource-related constraints such as the limited capacity of health and social services and suboptimal communication between primary and secondary clinicians may equally impact on the clinical pathway. Initiatives that offer better coverage of clinical care, yet at the associated expense of a loss of continuity of care, may increase the likelihood of preventable admissions. For example, changes to provision of out of hours services have led to concerns that deputising locums (with less familiarity with the patient's medical or social history) might refer patients to another service or hospital more often than established counterparts. Conversely, specialist nursing provision, seen by many as a potential way of reducing
inappropriate admissions, may constitute an early and easy target for budgetary cuts when resources are limited\textsuperscript{250}.

**Insights from Mid-range Theory**

We searched for papers describing conceptual models or frameworks relevant to each of the interventions included in the synthesis. For pragmatic reasons, we aimed to identify five or six theories per intervention, but in some cases fewer were found. The findings are briefly summarised below.

**Case Management**

The search located 4 theoretical/conceptual papers, published between 2001 and 2018 (Table 27). The majority of the frameworks and models focused on the health provider although the earliest theories were targeted at an individual patient level and the most recent focused on a complex health system model. A total of seven models were identified in the four included papers.

**Table 27: Mid-range theory papers related to Case Management**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Theory/conceptual model</th>
<th>Focus of theory or model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enguidanos et al 2001\textsuperscript{252}</td>
<td>Theory of Planned Behavior</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td>Transtheoretical Model</td>
<td>Patient</td>
</tr>
<tr>
<td>O’Brien et al 2018\textsuperscript{253}</td>
<td>Engagement Through CARInG Framework: Communication and actions to improve health; Relationships built on trust in Intensive outpatient care program staff; and Insight and goal-setting ability.</td>
<td>Health System</td>
</tr>
<tr>
<td>Swanson &amp; Weissert 2017\textsuperscript{114}</td>
<td>Principal-Agent Framework</td>
<td>Health Provider</td>
</tr>
<tr>
<td></td>
<td>Street-Level Bureaucratic Theory</td>
<td>Health Provider</td>
</tr>
<tr>
<td>Van Durme et al 2016\textsuperscript{80}</td>
<td>Conceptual Framework of Integrated Care\textsuperscript{254}</td>
<td>Health Provider</td>
</tr>
</tbody>
</table>
A recent realist synthesis, focusing on the case management of a different population, namely the frail elderly, nevertheless reveals two potentially useful frameworks/models. According to the Conceptual Framework of Integrated Care\textsuperscript{254}, the patient’s perception of their own capability, informed by the perception of informal caregivers, can lead them to accept the primary care services offered as an alternative to hospital admission and to believe that they are able to manage their condition while still at home\textsuperscript{80}. This framework links closely to the self-efficacy beliefs of Bandura which figure prominently in connection with other intervention types such as self management and patient education. Indeed, these efficacy expectations are central to programme theory one (PT1) when a patient does not feel equipped with sufficient situational knowledge to manage their own decision on hospital admission. The converse of this is that self-efficacy, when coping with one’s chronic conditions, will impact upon the extent to which a patient, and their caregiver, feels sufficiently equipped to continue to manage from home.

For the second theory, from the realist synthesis of case management of the frail elderly\textsuperscript{80}, the review team draws on Wagner’s Chronic Care Model\textsuperscript{255}, to identify perceived social support as a mediator for helping patients to stay at home. Several of our own programme theory components draw upon perceived levels of support, available in primary and community care, as an important factor in the decision whether to admit to hospital or not. These perceptions can be held by the patient, the informal caregiver or the health provider. Key for this intervention are the skills of the case manager, who should be facilitated by access to adequate training and sufficient time to fulfil the case management function. A related consideration is the extent to which patients associate their routine care with a local primary/community care community or the extent to which the acute hospital is viewed as the hub for their care. This latter consideration can be managed by engaging with the expectations of peers within the community and may be modified by the ongoing interactions with the case manager.
Patient Education

Patient education is extremely well-theorised and our review team felt that there would be little benefit to be gained by engaging with the totality of this theorisation. Instead the search for theories, conceptual frameworks and models in connection with patient education focused on reviews or compendia covering multiple frameworks. We located 3 reviews, published between 2008 and 2017 (Table 28). All of the frameworks and models focused on the patient, e.g. by seeking to understand and/or explain patient behaviour in relation to the operation of patient education. We were surprised not to identify more transactional based models regarding the mutual reciprocity of information exchange between the patient and the health provider.

Table 28: Mid-range theory papers related to Patient Education

<table>
<thead>
<tr>
<th>Reference</th>
<th>Theory/conceptual model</th>
<th>Focus of theory or model</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Social Cognition Theory</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td>Theory of Planned Behaviour</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td>The Stages of Change Model (or Transtheoretical Model)</td>
<td>Patient</td>
</tr>
<tr>
<td>Syx (2008)</td>
<td>Health Belief Model</td>
<td>Patient</td>
</tr>
<tr>
<td>EuroMedInfo (2017)</td>
<td>Health belief model</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td>Cognitive dissonance theory</td>
<td>Patient</td>
</tr>
</tbody>
</table>
### Self-Management

The search located six papers, published between 1998 and 2016 (Table 29). The majority of the frameworks and models focused on the patient, e.g. by seeking to understand and/or explain patient behaviour in relation to the intervention.

**Table 29: Mid-range theory papers related to self-management**

<table>
<thead>
<tr>
<th>Theory/conceptual model</th>
<th>Focus of theory or model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ryan et al. 2009&lt;sup&gt;258&lt;/sup&gt;</td>
<td>Individual and family self-management theory</td>
</tr>
<tr>
<td>Williams et al. 2004&lt;sup&gt;259&lt;/sup&gt;</td>
<td>Self-determination theory</td>
</tr>
<tr>
<td>Lorig et al. 1999&lt;sup&gt;260&lt;/sup&gt;</td>
<td>Bandura self-efficacy</td>
</tr>
<tr>
<td>Bandura 1998&lt;sup&gt;261&lt;/sup&gt;</td>
<td>Social cognitive theory</td>
</tr>
<tr>
<td>Heisler et al. 2002&lt;sup&gt;262&lt;/sup&gt;</td>
<td>Un-named conceptual model</td>
</tr>
</tbody>
</table>

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The earliest paper to be published\textsuperscript{261} covered a wide range of topics under the broad heading of social cognitive theory, suggesting that theoretical treatment of self-management has a long history. The frameworks used in five further studies were diverse (Table 29). These studies involved patients with chronic health conditions, diabetes or asthma. Heisler et al.\textsuperscript{262} described a conceptual model that focused on how provider behaviour can influence self-management via its influence on self-efficacy. Williams et al.\textsuperscript{259} used a self-determination theory based on the concepts of autonomous or controlled motivation and perceived competence or incompetence in a study of people with type 2 diabetes. The theory was useful for relating changes in self-management behaviour to changes in glycaemic control. The individual and family self-management theory described by Ryan et al.\textsuperscript{258} emphasises the role of dyads within a family and the family as a whole as well as individuals in supporting self-management.

Finally, in a recent empirical study, Hoskins et al.\textsuperscript{142} evaluated a self-management intervention for asthma based on multiple theoretical models. The study suggested that the theory-based intervention was promising but the need for additional time in appointments was a potential barrier to implementation.

### Telehealthcare

Telehealthcare, particularly telemonitoring is a well theorised area requiring some selectivity when mapping interventions to underpinning mid-range theories. The following list is therefore an indicative summary that seeks to extend across different foci and disciplines. A recent review of numerous theoretical frameworks extends this coverage further\textsuperscript{264}.  

| Hoskins et al. 2016\textsuperscript{263} | Goal setting theory; Leventhal self-regulation model; health action process approach | Health system/patient |
The search located 5 papers, published between 2010 and 2016 (Table 30). The majority of the frameworks and models focused either on the patient, e.g. by seeking to understand and/or explain patient behaviour in relation to the intervention or on health providers whose attitudes to adoption and acceptance of technology are critical to the intervention success.

Table 30: Mid-range theory papers related to Telehealthcare

<table>
<thead>
<tr>
<th>Reference</th>
<th>Theory/conceptual model</th>
<th>Focus of theory or model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shankel &amp; Wofford (2016)</td>
<td>Symptom Management Theory</td>
<td>Patients</td>
</tr>
<tr>
<td>Gagnon et al (2012)</td>
<td>Technology Acceptance Model</td>
<td>Health providers; Patients</td>
</tr>
</tbody>
</table>

The earliest paper to be published was published in 2010 meaning that more longstanding theories of telehealthcare (particularly telemonitoring) have not been picked up by this report. Most of these frameworks are used in providing a theoretical basis for intervention development with a recent review demonstrating a higher prevalence of theory-informed interventions than in many comparable areas of healthcare.
Cardiac Rehabilitation

The search located eight papers, published between 1994 and 2010 (Table 31). The majority of the frameworks and models focused on the patient, e.g. by seeking to understand and/or explain patient behaviour in relation to the intervention.

Table 31: Mid-range theory papers related to Cardiac Rehabilitation

<table>
<thead>
<tr>
<th>Reference</th>
<th>Theory/conceptual model</th>
<th>Focus of theory or model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goud et al. 2010</td>
<td>Cabana et al.</td>
<td>Health Provider</td>
</tr>
<tr>
<td>Blanchard et al.</td>
<td>Theory of planned behaviour</td>
<td>Patient</td>
</tr>
<tr>
<td>2003</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grace et al. 2004</td>
<td>Behavioural model of health services utilisation</td>
<td>Patient</td>
</tr>
<tr>
<td>Jeng et al. 1994</td>
<td>Bandura self-efficacy</td>
<td>Patient</td>
</tr>
<tr>
<td>Lau-Walker et al.</td>
<td>Interactive care model</td>
<td>Patient</td>
</tr>
<tr>
<td>2006</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allen et al. 2004</td>
<td>PRECEDE-PROCEED model</td>
<td>Patient and system</td>
</tr>
<tr>
<td>Johnson et al. 1998</td>
<td>Andersen and Newman</td>
<td>Patient and system</td>
</tr>
<tr>
<td>Kitson et al. 1998</td>
<td>Early version of PARIHS?</td>
<td>Whole system</td>
</tr>
</tbody>
</table>

The earliest paper to be published\(^{274}\) used the Bandura self-efficacy theory as a basis for predicting patient behaviour and planning interventions, including methods of increasing self-efficacy and hence optimising outcomes. The frameworks used in three further studies, although named differently, were similar in structure, consisting of predisposing, enabling and reinforcing/need factors\(^{273, 276, 277}\). These studies involved diverse populations, including white and African-American women and rural US populations.

Blanchard et al. (2003\(^{272}\)) found that the theory of planned behaviour was a useful framework for understanding adherence to CR, perceived behavioural control making the largest
contribution to adherence. Lau-Walker (2006\textsuperscript{275}) combined illness representation and self-efficacy theories to produce an Interactive Care Model as a framework for research into intervention design for rehabilitation.

Other conceptual models focused on the wider health system. Kitson et al. (1998\textsuperscript{278}) used CR as an exemplar to test an early version of the PARIHS framework for research implementation. Finally, Goud et al. (2010\textsuperscript{271}) used a framework developed by Cabana et al. to study health professionals’ adherence to guidelines related to CR. The framework includes both internal and external barriers to guideline implementation.

**Pulmonary Rehabilitation**

We identified two mid-range theory papers for pulmonary rehabilitation\textsuperscript{215,216}, both of which used social identity theory (Table 32).

**Table 32: Mid-range theory papers related to Pulmonary Rehabilitation**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Theory/conceptual model</th>
<th>Focus of theory or model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Levy et al. (2018\textsuperscript{216}); Hogg (2012\textsuperscript{215})</td>
<td>Social Identity Theory</td>
<td>Patient</td>
</tr>
</tbody>
</table>

**Specialist Clinics**

We found no relevant mid-range theory papers for specialist clinics.

**Community Interventions**

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Only two relevant papers were located for this group of interventions (Table 33). This may reflect a paucity of literature, the challenges of searching in this area in a limited time frame or both.

**Table 33: Mid-range theory papers related to community and miscellaneous interventions**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Intervention</th>
<th>Theory/conceptual model</th>
<th>Focus of theory or model</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Community</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Falk Rafael 2000(^279)</td>
<td>Community nursing</td>
<td>Watson’s theory of human caring</td>
<td>Patient and nurse</td>
</tr>
<tr>
<td>May 2006(^280)</td>
<td>Any complex intervention</td>
<td>Normalisation process model</td>
<td>Health system</td>
</tr>
<tr>
<td><strong>Miscellaneous</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wee and Vrijhoef 2015(^281)</td>
<td>Transitional care</td>
<td>Unnamed: ‘conceptualisation, implementation and evaluation’</td>
<td>Health system</td>
</tr>
<tr>
<td>Williams 243(^)</td>
<td>Transitional care</td>
<td>Health Belief Model</td>
<td>Patient</td>
</tr>
</tbody>
</table>

Folk Rafael (2000\(^279\)) used Watson’s theory of human caring to investigate community nursing and the importance of the nurse–patient relationship. The normalization process model described by May (2006\(^280\)) can be applied to any complex intervention in healthcare settings. The paper includes the example of nurse-led home telecare for COPD, which is described in terms of the theory’s constructs as moderate for interaction; high for relational integration and skill-set workability; and moderate for contextual integration between primary and secondary care.
**Multiple/Other Interventions**
Transitional care is an example of a multiple-component intervention not covered by any of the other categories. Wee and Vrijhoef (2015\(^{281}\)) described a conceptual framework for evaluating the development, implementation and performance of transitional care interventions (see Table 43 above). The model seeks to explain why and how the interventions should work to minimise readmission for patients admitted to hospital who need to be transferred between different settings or levels of care during their admission.

**Overarching theories**
Several areas of supporting theory may help to explain the phenomenon of inappropriate admissions. In particular we have focused on four particular lines of exploration:

1. Clinical inertia and admission as “the default position”
2. Candidacy and “deservedness”
3. Continuity of and personalisation of care
4. Sick Dependency Roles and Reliance on Health Professionals

**Clinical inertia and admission as “the default position”**
Engaging with the included studies at the level of mechanisms, rather than simply at an intervention-level, revealed the importance of the concept of “clinical inertia” in relation to the phenomenon of emergency admissions, especially readmissions. Clinical inertia is defined as the failure to establish appropriate targets and escalate treatment to achieve treatment goals. This concept appears to have gained initial traction within the context of diabetes\(^{282}\), which along with the conditions covered by this review, figures among the most prominent of ambulatory sensitive conditions. It has subsequently been promoted within evidence based healthcare as an explanation for lack of clinical uptake of clinical decision tools rooted in a lack of confidence in their content and concerns about potential disruption to workflows\(^{283}\). Could a similar lack of confidence, this time in primary care provision, and concerns about disruptive change offer one possible explanation for clinicians’ apparent “reluctance” to explore alternatives to emergency admission? Elwyn and colleagues,
subsequently linked clinician inertia to the related phenomenon of “organisational inertia” which seems to be at play within this particular arena\textsuperscript{283}.

It is interesting to observe that other comparable forms of inertia, attributable to other key protagonists in the decision to admit, are evoked within other included studies. In their Cochrane Review\textsuperscript{284} Glynn and colleagues seek to explain why frequent contact with health care professionals does not guarantee better blood pressure control by drawing on the observations of some commentators to suggest that this may be attributable to ineffective management and inadequate practice organisation (i.e. "clinical inertia"). When monitoring is shifted from health professionals to patients themselves Jones and colleagues remark upon a patient phenomenon comparable to clinicians’ clinical inertia with patients being reluctant to increase medication further in the face of borderline readings, a form of participant inertia\textsuperscript{157}.

Generically, the phenomenon of “clinical inertia” is addressed by encouraging patients and physicians to communicate more effectively and respond appropriately to changes in patient circumstances. It may appear paradoxical to be considering clinical inertia within the context of inappropriate escalation of treatments, namely in admitting a patient from primary to secondary care. However, failure to establish appropriate targets and to respond appropriately to changes in patient circumstances are equally at the heart of what we observe for inappropriate emergency admissions. We have identified a further variant of clinical inertia of particular relevance within the context of emergency admissions, namely as inertia by remaining within admission as the “default position”. As a health improvement document (https://improvement.nhs.uk/documents/720/ae-improvement-programme-good-practice-in-the-north.pdf) states, the culture of an organisation can often be to admit patients as a default position, which can result in admission rates being higher than they need to be.

Consequently, County Durham and Darlington NHS Foundation Trust has implemented measures to minimise admission rates to A&E, with particular focus on the interaction between the A&E department and the AMU. These measures include:
• ensuring all admissions are discussed with a senior decision maker prior to admission, including out-of-hours admissions.
• developing processes to allow direct referrals to the AMU rather than requiring admittance to A&E as a preliminary, unnecessary step.
• ensuring a regular, ongoing two-way dialogue between A&E and AMU staff to ensure referral/admittance decisions are reviewed and challenged
• AMU consultants regularly coming into the A&E department to aid assessment and “pull” patients from A&E where appropriate

Early access to senior decision-makers and appropriate selection processes feature prominently in many of the intervention types identified in this report.

Supplementary ways of addressing clinical inertia are identified in the literature (Box 2) and may serve as a basis for developing new or improved interventions to address this “default” variant:

**Box 2 - Interventions for addressing clinical inertia**

<table>
<thead>
<tr>
<th>Increase provider awareness and knowledge base</th>
</tr>
</thead>
<tbody>
<tr>
<td>– Assessment of performance</td>
</tr>
<tr>
<td>– Evidence-based education</td>
</tr>
<tr>
<td>Implement guidelines</td>
</tr>
<tr>
<td>– Flowsheets, automated reminders</td>
</tr>
<tr>
<td>– Periodic feedback: content, timing, and format</td>
</tr>
<tr>
<td>Provide practical management tools and support</td>
</tr>
<tr>
<td>– Treatment algorithms</td>
</tr>
<tr>
<td>– Patient education</td>
</tr>
<tr>
<td>Individualize patient care</td>
</tr>
<tr>
<td>– Treatment targets</td>
</tr>
<tr>
<td>– Side effects, costs, complexity</td>
</tr>
</tbody>
</table>
According to Phillips et al (2001) clinical inertia is due to at least three problems: overestimation of care provided; use of "soft" reasons to avoid intensification of therapy; and lack of education, training, and practice organization aimed at achieving therapeutic goals. For that variant of clinical inertia where health professionals adopt emergency admission as a default position there is a related pathology but one that may relate to the converse of the original “clinical inertia”. For example, the primary healthcare professional may underestimate the care that is currently being provided (or that might be available) in primary care, or overestimate the additional care that may be provided in secondary care. Additionally, the health care professional may use “soft” reasons to justify and initiate intensified intervention within an emergency department. Finally, they may require recalibration, through education and training, with regard to realistic expectations from intervention. Phillips et al (2001) locate the overcoming of clinical inertia within the context of the benefits of treating to therapeutic targets and the need to structure routine practice to facilitate effective management of disorders for which resolution of patient symptoms is not a sufficient indicator of optimal care. Such systems require sophisticated and reliable mechanisms of feedback and performance evaluation.

While the emphasis on education of GPs, supported by evidence based guidelines, clearly offers a potential to overcome a lack of knowledge of the condition and the available services to which GPs might refer it is worthy of note that a qualitative synthesis of GPs barriers to managing heart failure in primary care reports ongoing difficulties with information overload. It appears that, just as patients do not experience an absence of information, so much as it not being tailored and personalised to their own specific requirements, GPs do not require yet more educational strategies around greater numbers of evidence based guidelines so much as the facility to have guidelines tailored to their own local context.
In the context of emergency department-based interventions the concept of “appropriate deliberate clinical inertia” has been framed in recognition of the need to resist inappropriate or unnecessary interventions. It appears that this concept may be appropriated within primary care to recognise situations in people with chronic conditions that do not result, for example, in any change in the dose or nature of medications. Clear agreement between patient and health professional that emergency admission will not resolve or in any way modify their symptoms or treatment can act as a sound basis for “shared decision-making to improve patient care with the use of clinical judgement”.

Candidacy and "deservedness"
Another important concept relates to “candidacy” which has been previously explored in relation to access to, and utilization of, healthcare in general. The concept suggests that an individual's identification of his or her ‘candidacy’ for health services is structurally, culturally, organizationally and professionally constructed. An unintended consequence of several interventions identified in this report is the “legitimisation” of use of services, leading to a possible increase, rather than decrease in the volume of inappropriate admissions. Exactly how this works may vary; initial use of emergency services, either appropriately or inappropriately, may be seen as opening up a pathway of “deservedness” for future entitlement. The initial episode may be seen as legitimised as a “one-off” or it may open the way for “similar” utilisation in the future. More constructively, appropriate use, as confirmed or ratified by health professionals during admission or subsequently during follow up, may help a patient to “benchmark” their personalised symptoms and set thresholds for external involvement. The complication here is that patients with chronic conditions typically have multiple symptoms and so the “benchmark” only directly relates to those specific symptoms that precipitated admission. This may result in an empirical “trial and error” around emergency admissions for distinct yet potentially related symptoms.

Continuity of, and personalisation, of care
Continuity of care is revealed as an important influence on admissions for long-term conditions. The distinction between continuity of relationship (a continuous caring
relationship with clinicians) and continuity of management (all aspects of integration, coordination and sharing of information) was helpful when completing this analysis; recognizing that both mechanisms are revealed as important within the context of preventable admissions. Systematic reviews have found that relational continuity was associated with lower rates of emergency department attendance, and hospital admissions\textsuperscript{1, 107}Other likely benefits include improved outcomes for patients, including in medication adherence\textsuperscript{126, 290}.

However Simmonds and colleagues also illustrate how relational continuity may be unhelpful, for example where a GP is reluctant to refer a patient to a specialist nurse either because they wanted to hold on to management of the patients themselves or they had little knowledge of the available services\textsuperscript{126} This results in an unhelpful “default” position and can lead to yet another form of “clinical inertia”.

**Sick dependency role and reliance on primary healthcare professionals**

Interventions introduced to prevent emergency admissions can have a disruptive effect on the sickness role of the affected patients. For example, the Whole System Demonstrator project\textsuperscript{165} reported that patients believed that dependence upon technology would reaffirm their sickness role and lack of independence. It would also be a visible reminder of their own condition with the potential to cause increased anxiety.

Health professional-mediated intervention roles, such as case manager, also hold a disruptive potential. Health professionals were concerned that such roles would increase patient dependence rather than facilitate self-management. In particular it is challenging to manage the balance between offering improved access to support and reassurance when needed and creating a dependence upon the health professional that subverts self-management. This links back to the earlier consideration of candidacy – provision of a specialist service and a “passport” to entitlement of follow up services where necessary and appropriate may be seen as legitimising contact with secondary care and lead to increased, rather than reduced, utilisation.
In other cases, the technology was seen, typically by carers, as a way of seeking to replace care already provided through face to face interaction with an inferior care package delivered by technology. The carer saw the visible dependence of the patient on the personalised health care as appropriate recognition of their illness state.

Finally, the addition of specialist intervention alongside existing provision can lead to perceptions that levels of healthcare are excessive or superfluous\textsuperscript{165}. For example, where a patient is already in regular contact with health professionals, perhaps for comorbid conditions, there may appear little need for additional telemonitoring. Such views may reflect actual redundancy and overlap, due to poor integration of specialist services along usual care, or may simply reflect the patient’s perception (i.e. where similar looking interventions have clearly distinct clinical functions) resulting in poor compliance. Experimental interventions, from pilot studies through to full trials, are more likely to result in such perceived duplication than established services but nevertheless the integration of specialist and general care, or between different forms of specialist care for comorbid conditions, is an issue of which those implementing specialist interventions should be aware.

**The role of integrated care mid-range theories**

The fundamental move towards transformation of current models of primary care by means of implementing proactive integrated care hints at the future potential of integrated care approaches to analysing and resolving the systemic issues revealed by the phenomenon of preventable admissions. Attempts to understand the effects of integrated primary care approaches and underlying mechanisms in relation to other populations, such as frail community living older adults, may translate to the condition-specific contexts of COPD and heart failure that are the focus of this report. For example, a theory-based evaluation called "Finding and Follow-up of Frail older persons" (FFF)\textsuperscript{291} offers a theoretical model that incorporates interrelated elements of integrated primary care approaches: (1) proactive case finding, (2) case management, (3) medication review, (4) self-management support, and (5) working in multidisciplinary care teams. Furthermore, this model recognises the importance
of cognitive and behavioural components of both healthcare professionals and patients, targeted by so many of the individual mid-range theories identified for each intervention type. Seemingly intractable problems may well be amenable to analytical lenses developed in alternative arenas.
Chapter 6: Discussion and conclusions

Main findings

Mapping review
The mapping review of studies of interventions to reduce preventable admissions published since 2010 identified 569 publications, predominantly related to heart failure or COPD. The interventions identified by Purdy et al. 1 as having the best evidence of effectiveness (or no effect) were well represented in the map. The largest group of studies originated from the USA. The included studies from the UK showed a similar distribution of studies by intervention and population to that of the map as a whole but there was evidence of some country-specific features such as the prominence of studies of telehealth. The findings of the mapping review were helpful in informing the sampling frame for the subsequent realist synthesis.

The mapping review and subsequent analysis of UK studies for each intervention (Chapter 5) revealed that in many cases a strong international evidence base for effectiveness of an intervention existed alongside limited evidence specific to the UK context. Cardiac rehabilitation (section 5.5) perhaps illustrated this phenomenon most clearly. We often found limited information to help understand how particular interventions have been implemented in the UK NHS and which approaches to implementation work best in NHS contexts. Information on the role of leadership and approaches to facilitating the implementation of interventions was often lacking.

Implementation framework
Within the PARIHS framework, successful implementation is represented as a function of the nature and type of evidence (to be examined from the mapping review), the qualities of the context in which the evidence is being introduced, and the way the process is facilitated16 (to be extracted from included UK studies, both quantitative and qualitative). We found that
interventions with strong evidence of effectiveness overall had not necessarily demonstrated effectiveness in UK settings; that the largest proportion of the evidence came from the USA, where the context for delivery of healthcare is very different from that of the UK; and that facilitation of the implementation of interventions was often not reported or inadequately reported in UK studies, which generally focused mainly on effectiveness or qualitative evidence of patient and health professional experience of service delivery.

**Descriptive framework**
The TIDieR-Lite framework provided a useful descriptive framework for recording key elements of the interventions and their delivery. Many of the included interventions were highly diverse in the way they were delivered, the main exceptions being cardiac and pulmonary rehabilitation. There was also considerable overlap between interventions in terms of their key components. The role of specialist nurses in providing continuity of care and links between primary and secondary care was highlighted in multiple studies.

**Programme theories**
We identified and tested five programme theories (using the sequence context–mechanisms–outcomes) to explain how the interventions might work (see Box 1). The programme theories, expressed as scenarios, were refined and endorsed by our public involvement group. We found evidence to support programme theory PT1, which suggests that hospital admissions could be reduced by optimal self-management. Considering PT2, we did not find substantive evidence to suggest that patients may seek hospital admission primarily on the basis of relative advantage. It seems that concerns associated with anxiety and risk may constitute a more important driver, hospitals being seen as safe places that can offer security and reassurance. However, the presence of perceived, implicit or indirect pressure cannot be ruled out. Programme theory PT3 relates to clinicians’ confidence in their own diagnoses and ability to refer appropriately to services that might avoid admission. In the context of cardiovascular and respiratory disease, this is relevant to patients with symptoms such as breathlessness that could result from various underlying causes.
Direct evidence for PT4 (admissions resulting from patient delay in seeking treatment) was limited in our sample of studies. One study noted that a lack of timely and accurate diagnosis contributed to exacerbations of heart failure. Finally, PT5 (influence of the broader health system context) addressed the limitations on rational decision-making around hospital admissions. This was reflected in our studies. For example, heart failure care delivered across multiple services, confusion about eligibility for specialist care and relational/managerial discontinuity of care increased the likelihood of suboptimal management and unplanned admissions.

Overall, we believe the programme theories considered in this realist synthesis are valuable for understanding why unplanned and avoidable admissions occur and the facilitators and barriers to reducing them.

**Mid-range theories**

We found numerous examples (both descriptive and empirical studies) of mid-range theories relevant to the interventions under review. The largest group focused on the patient, for example factors influencing adherence to recommended interventions, but theories related to health professionals’ behaviour and the overall health system were also located. Some theories were cited in relation to several interventions (for example, Bandura’s self-efficacy theory). However, it is unclear whether the prevalence of efficacy/coping theories reflects their greater utility in this context or simply their higher profile. Nevertheless, self-efficacy was revealed as a key component to programme theory component 1 (PT1), not only determining the level of comfort that a patient had with coping with their own condition but also, more importantly, how well-equipped the patient feels they are to be able to manage their own exacerbations without resorting inappropriately to primary care health provision or to admission to an acute hospital.
Overarching theories
The overarching theories discussed in Chapter 6 may be considered as more exploratory than the programme and mid-range theories. In general, these theories may help to understand the underlying mechanisms at the level of the patient and health professional in the presence and absence of interventions designed to avoid admissions.

Strengths and limitations
The double evidence mismatch

In theory, seeking UK-focused implementation evidence to accompany interventions that had previously been demonstrated as effective in preventing inappropriate hospital admissions for cardiorespiratory conditions appears both a coherent and easily manageable literature review task. In practice, however, we encountered a logic problem that we have labelled the “double evidence mismatch”. First, the review by Purdy et al (2010) demonstrated the average effectiveness of the candidate interventions based on a comprehensive sample of international studies, within which UK studies constituted a small and largely insignificant part. The quest for implementation evidence might therefore largely focus on UK studies which had a small effect, negative effect, or a statistically insignificant effect. Second, a combination of the fact that our review team focused on studies published since 2010 means that interventions being implemented during this period may not resemble the interventions being trialled during evaluation of the original intervention. Indeed, this situation was compounded by the profound shortage of implementation evidence for UK initiatives between 2010-2018. Qualitative evidence constituted a large part of our recent evidence base and may not necessarily be intervention focused, nor linked to relevant trials. This type of evidence “mismatch” is considered rare; we have only previously encountered such a mismatch when trying to map international randomized controlled trials from a Cochrane review against a qualitative research evidence base restricted to the UK and similar health systems. We therefore make the methodological recommendation that the scope of intervention and implementation evidence, or indeed quantitative and qualitative evidence, seeks to be as co-
terminous as possible so as to not artificially constrain the evidence base. However, we also acknowledge that by its nature implementation evidence may need to be more current than the original effectiveness studies.

**Value of PARIHS framework**

We were unable to exploit the full value of the PARIHS framework, not through any limitations of the framework itself but because of constraints in the reporting of the individual interventions. Limitations encountered tended to fall into three categories:

1. Published reports did not articulate implementation issues in terms of Evidence, Context and Facilitation or did not cover the range of aspects of these dimensions included within PARIHS (for example, ‘evidence’ is not limited to research evidence);
2. Published reports covered one or more of these issues but did not structure their reports in a way in which such data was straightforward to extract;
3. Published reports focused on implementation at a level that excluded some of the important PARIHS concepts – for example, only a study specifically on organisational aspects included data on organisational culture whereas leadership issues were almost entirely absent.

This confirms observations previously made in relation to frameworks i.e. that frameworks derived for use in primary research studies may not represent a good match for the level of granularity sustained by their use in synthesis activities with syntheses typically covering issues at a broader level of detail. The version of PARIHS that we chose was not the most recent but we believe that limitations in the reporting of implementation in the included studies mean that little would have been gained by using a more refined version of the framework.

We had reviewed a range of candidate frameworks before selecting the PARIHS framework as our eventual choice. Analysis of included literature during the subsequent realist process
revealed use of alternative frameworks\(^9\), specifically when exploring implementation issues, notably May and colleagues’ Normalisation Process Model\(^{292,293}\) and a framework of barriers and facilitators for quality improvement projects from a systematic review led by Kaplan. It is presently unclear whether these frameworks would share similar limitations with regard to the granularity of synthesised data or, indeed, if selection of these alternative evaluation “lenses” would have yielded more insightful observations.

**Value of TIDieR-Lite template**

In contrast, the TIDieR-LITE framework proved particularly useful both as a means of exploring variation within intervention groups and when seeking to delineate between interventions. It became apparent that several interventions labelled in their own right were also included within other interventions; so, for example, patient education is a key component in self-management. Similarly, self-management is a key function of much telehealthcare. Specialist clinics may hold a primary function in providing patient education and supporting self-management. Use of the framework therefore revealed the difficulties in attributing an effect to particular interventions and in isolating which components are most essential in delivering an effect. The limitations of the classification of interventions further confirmed the value of moving from an intervention-based approach towards the realist synthesis based on mechanisms. Phenomena such as clinical inertia and the default position, the effects, intended and unintended, of candidacy and the pivotal role of continuity and personalisation of care transcend the seven intervention types and therefore offer more transferable messages.

**Implications for service delivery**

We have identified the following implications for service delivery:

1. Our findings suggest that some evidence-based interventions may have limited evidence for effectiveness in the UK context. All available evidence and data sources should be considered alongside other relevant factors in deciding which interventions and service models to implement.
2. Implementation of supported self-management programmes reflects an approach that is supported by both theory and empirical evidence. Patients may need to be reassured that they will not be totally unsupported at the end of time-limited interventions.

3. Service delivery would benefit from better description and specification of both interventions and associated implementation strategies. This includes documentation of service delivery in routine practice as well as in research or demonstration projects. The development of standards and auditing of service delivery by the NACR for cardiac rehabilitation appears to be a useful exemplar.

4. Specialist nurses with expertise in heart failure or COPD make a major contribution to implementation of interventions to reduce avoidable admissions. Specialist nurses can work in a variety of settings and service models depending on the local context. They can support evidence- and theory-informed implementation of relevant interventions by, for example, supporting self-management and signposting patients to appropriate community-based services.

5. Many contextual factors operating at the level of the patient and the health system tend to promote referral and possible admission to hospital as the default course of action for people with exacerbations of a chronic disease. In particular, difficulties in navigating between complex and fragmented services need to be addressed if avoidable admissions are to be reduced. The increasing incidence of multi-morbidity means that it will be important to ensure that patients are not excluded by inappropriately strict criteria for access to specialist services. Literacy and language issues can also create barriers to patients accessing appropriate services that can reduce their risk of hospital admission.

**Implications for research**

We have identified the following implications for research:
1. There is a clear mismatch between the international and national evidence base for some interventions designed to reduce avoidable admissions. This can be a barrier to implementation in practice. While funding of new trials is unlikely to be a priority, research should focus on understanding and interpreting existing evidence and the transferability of findings between different health systems and contexts (including changes in usual care for chronic conditions).

2. Research on effective implementation of interventions and its barriers and facilitators continues to lag behind research on intervention effectiveness. Theory can help to inform design of promising implementation strategies which can be evaluated using appropriate study designs. Depending on the context, evaluation could range from randomised trials to before/after studies (preferably controlled) and audits of local or national data. Researchers could consider conducting process evaluations alongside trials in line with the Medical Research Council recommendations for evaluating complex interventions.

3. Health services researchers should be encouraged to provide clear description/reporting of implementation strategies used in their research using appropriate reporting guidelines and frameworks.

4. Qualitative research is required to investigate patients’ and health professionals’ decision-making around hospital referrals and admissions, including the impact of specific interventions and the current context of pressure on NHS workforce and resources.

Conclusions
Preventable hospital admissions for chronic cardiovascular and respiratory conditions are common and costly for both the health service and the patient/family involved. Systematic reviews have identified interventions with strong evidence of effectiveness in reducing such admissions. However, the synthesised evidence may not be supported by evidence of effectiveness in a specific setting or how best to implement the intervention in routine practice. Our mapping review and supplementary searching indicated that this was the case.
for some interventions widely recommended and employed in the UK health system. The subsequent realist data extraction and synthesis used diverse frameworks and levels of theory to examine how interventions might work and factors that support or hinder their implementation. The TIDieR-Lite framework proved useful in characterising interventions and indicated that interventions with different names often contain the same or overlapping components. The programme theories we developed from the literature were supported to varying degrees by empirical evidence but all provided valuable insights.

Overall, implementation of interventions to reduce avoidable admissions for cardiovascular and respiratory conditions appears to be favoured by:

Support for self-management by patients and their families/carers, including ability to recognise when they need to seek further help

Support for services that signpost patients to consider using less familiar services when appropriate rather than treating GP appointment/referral as the default option
Recognition of possible drivers leading patients to seek admission, for example the need for security and reassurance at a difficult time

Support for GPs and other health professionals to diagnose and refer patients appropriately and with confidence. This includes creation of a supportive background context and set of incentives in the health system

Support for workforce roles, commonly filled by specialist nurses, that promote continuity of care and co-ordination between different services across primary, secondary and community care
Acknowledgements
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Contribution of authors
Anna Cantrell led the literature search processes for both the mapping review and the realist synthesis. Duncan Chambers managed the mapping review and led on analysis of mapping data. Andrew Booth developed the realist synthesis protocol and designed the working methods for the realist synthesis, including the TIDIER-Lite and intervention templates. Andrew Booth generated the embryonic programme theory which was refined and finalised by all the review team. All team members contributed equally to the analysis and writing of the final report.

Data sharing
No new data have been created in the preparation of this report and therefore there is nothing available for access and further sharing. All queries should be submitted to the corresponding author.
References

reduce unplanned hospital admission: a series of systematic reviews. Bristol: University of Bristol;
2012.
2. Purdy S. Avoiding hospital admissions: what does the research evidence say? London: The
King's Fund; 2010.
2018.
https://doi.org/http://dx.doi.org/10.4997/JRCPE.2013.415
5. NHS England. Emergency admissions for Ambulatory Care Sensitive Conditions -
6. Wallace E, Smith SM, Fahey T, Roland M. Reducing emergency admissions through
community based interventions. BMJ 2016;352:h6817. https://doi.org/10.1136/bmj.h6817
https://doi.org/10.1258/1355819054308530
8. James KL, Randall NP, Haddaway NR. A methodology for systematic mapping in
the international knowledge base for new care models to inform and mobilise knowledge for
016-0346-x
knowledge base for new care models relevant to primary care-led integrated models: a realist
synthesis. Health Services and Delivery Research 2018;6. https://doi.org/10.3310/hsdr06250
11. Booth A, Carroll C. How to build up the actionable knowledge base: the role of 'best fit'
https://doi.org/10.1136/bmjqs-2014-003642
12. Dixon-Woods M. Using framework-based synthesis for conducting reviews of qualitative
13. Carroll C, Booth A, Cooper K. A worked example of "best fit" framework synthesis: a
systematic review of views concerning the taking of some potential chemopreventive agents. BMC
15. Rycroft-Malone J, Bucknall T, editors. Models and frameworks for implementing evidence-


https://doi.org/http://dx.doi.org/10.1016/j.pec.2017.02.026


122. Howard C, Dupont S. ‘The COPD breathlessness manual’: a randomised controlled trial to test a cognitive-behavioural manual versus information booklets on health service use, mood and health status, in patients with chronic obstructive pulmonary disease. *npj Primary Care Respiratory Medicine* 2014;24. [https://doi.org/10.1038/npjpcrm.2014.76](https://doi.org/10.1038/npjpcrm.2014.76)

123. Steventon A, Tunkel S, Blunt I, Bardsley M. Effect of telephone health coaching (Birmingham OwnHealth) on hospital use and associated costs: cohort study with matched controls. *BMJ* 2013;347:f4585-f. [https://doi.org/10.1136/bmj.f4585](https://doi.org/10.1136/bmj.f4585)


127. Glogowska M, Simmonds R, McLachlan S, Cramer H, Sanders T, Johnson R, *et al.* "Sometimes we can't fix things": a qualitative study of health care professionals' perceptions of end of


164. Rowsell AC, Pope C, O’Cathain A. Briefing report on evidence from systematic reviews of telehealth for and computerised web-based interventions for depression and mental health problems Southampton: University of Southampton; 2011.

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186. Doherty P, Lewin R. The RAMIT trial, a pragmatic RCT of cardiac rehabilitation versus usual care: what does it tell us? *Heart* 2012;98:605-6. [https://doi.org/10.1136/heartjnl-2012-301728](https://doi.org/10.1136/heartjnl-2012-301728)


188. Witham MD, Fulton RL, Greig CA, Johnston DW, Lang CC, van der Pol M, *et al.* Efficacy and cost of an exercise program for functionally impaired older patients with heart failure: a randomized controlled trial. *Circ Heart Fail* 2012;5:209-16. [https://doi.org/10.1161/CIRCHEARTFAILURE.111.963132](https://doi.org/10.1161/CIRCHEARTFAILURE.111.963132)


192. Devi R, Powell J, Singh S. A web-based program improves physical activity outcomes in a primary care angina population: randomized controlled trial. *J Med Internet Res* 2014;16:e186. [https://doi.org/10.2196/jmir.3340](https://doi.org/10.2196/jmir.3340)


194. Dalal HM, Doherty P, Taylor RS. Cardiac rehabilitation. *BMJ* 2015;351:h5000. [https://doi.org/10.1136/bmj.h5000](https://doi.org/10.1136/bmj.h5000)


204. Harrison SL, Robertson N, Apps L, M CS, Morgan MD, Singh SJ. "We are not worthy"—understanding why patients decline pulmonary rehabilitation following an acute exacerbation of COPD. *Disability & Rehabilitation* 2015;37:750-6.


207. Graves J, Sandrey V, Graves T, Smith D. Effectiveness of a group opt-in session on uptake and graduation rates for pulmonary rehabilitation. *Chronic Respiratory Disease* 2010;7:159-64. [https://doi.org/10.1177/1479972310379537](https://doi.org/10.1177/1479972310379537)


245. Wilkinson T, North M, Bourne SC. Reducing hospital admissions and improving the diagnosis of COPD in Southampton City: Methods and results of a 12-month service improvement project. *npj Primary Care Respiratory Medicine* 2014;24 (no pagination). https://doi.org/http://dx.doi.org/10.1038/npjpcrm.2014.35


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outpatient cardiac rehabilitation. *Int J Med Inform* 2010;79:430-7. [https://doi.org/10.1016/j.ijmedinf.2010.03.001](https://doi.org/10.1016/j.ijmedinf.2010.03.001)


Appendices

Appendix 1: Search strategy for mapping review

**Medline search strategy**

Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

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1. ambulatory care sensitive condition$.ab,ti. (399)
2. "Ambulatory care sensitive conditions".kw. (37)
3. ACSC.ab,ti. (210)
4. primary care sensitive condition$.ab,ti. (39)
5. PCSC.ab,ti. (63)
6. exp Angina Pectoris/ (44306)
7. angina.ab,ti. (51535)
8. heart failure/ or heart failure, diastolic/ or heart failure, systolic/ (108637)
9. ((heart or cardiac or myocardial) and fail$).ab,ti. (207554)
10. Hypertension/ (227011)
11. hypertension.ab,ti. (347343)
12. Asthma/ (118479)
13. asthma$.ab,ti. (143461)
14 Pulmonary Disease, Chronic Obstructive/ (32875)
15 (copd or "chronic obstructive pulmonary disease$").ab,ti. (52948)
16 Lung Diseases, Obstructive/ (18640)
17 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 (903975)
18 Case Management/ (9789)
19 case management.ab,ti. (9810)
20 "specialist clinic$".ab,ti. (1226)
21 "Drug Utilization Review"/ (3572)
22 ((medication or drug) adj3 review$).ab,ti. (7588)
23 self care/ or self administration/ (41630)
24 self-care.ab,ti. (14579)
25 self-management.ab,ti. (14098)
26 pulmonary rehabilitation.ab,ti. (2824)
27 Influenza Vaccines/ (20563)
28 influenza vaccin$.ab,ti. (15110)
29 flu vaccin$.ab,ti. (1062)
30 Practice Guidelines as Topic/ (104685)
31 care pathway$.ab,ti. (3000)
32 care guideline$.ab,ti. (1663)
33 Community Health Services/ (30426)
34 community intervention$.tw. (1653)
35 House Calls/ (3093)
36 home visit$.ab,ti. (7640)
37 Patient Education as Topic/ (81677)
38 patient education.ab,ti. (15166)
39 cardiac rehabilitation/ or exercise therapy/ (36370)
40 exercise based cardiac rehabilitation.ab,ti. (169)
41 Telemedicine/ (17189)
42 telemedicine.ab,ti. (8638)
43 or/18-42 (381151)
44 17 and 43 (31399)
45 Patient Admission/ (22420)
46 (prevent$ or avoid$ or reduc$ or unplanned or unnecessary or unscheduled).ab,ti. (4125882)
47 45 and 46 (4775)
48 ((prevent$ or avoid$ or reduc$ or unplanned or unnecessary or unscheduled) adj3 admission$).ab,ti. (4908)
49 hospitalization/ or patient readmission/ (104518)
50 46 and 49 (25222)
51 47 or 48 or 50 (32244)
52 (implementation or implementing).ab,ti. (230025)
53 (dissemination or disseminating).ab,ti. (52450)
54 (research adj2 integration).ab,ti. (589)
55 (transfer$ adj2 knowledge).ab,ti. (2249)
56 barrier$.ab,ti. (237473)
57 facilitator$.ab,ti. (19882)
58 sustainability.ab,ti. (15412)
59 ((change or changing) adj (behaviour or practice)).ab,ti. (2509)
60 (research adj2 utilisation).ab,ti. (1214)
61 "research into practice".ab,ti. (783)
62 "knowledge to action".ab,ti. (559)
63 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 (529378)
64 51 or 63 (559087)
65 44 and 64 (3868)
66 limit 65 to (english language and yr="2010 -Current") (1943)
### Appendix 2: Publish or Perish searches

Searches conducted on Publish or Perish 19/09/2017 2026 results copied in to Excel and Endnote

<table>
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<th>Any of the words</th>
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<td>preventable</td>
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<td>24</td>
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<td>admissions</td>
<td>programme logic</td>
<td>6</td>
</tr>
</tbody>
</table>
Imported into Endnote 2026 references, 554 duplicates removed leaving 1471 references.
Appendix 3 - Admissions are Possible – Some Realist(ic) Scenarios

Scenario 1: Self-managing Sarah

After visiting her GP because of breathlessness and a persistent cough, Sarah was diagnosed with chronic obstructive pulmonary disease (COPD). With help from her GP practice and community respiratory nurse service, Sarah started a personal self-management plan. Sarah had to give up smoking, take regular exercise, eat a balanced diet and take regular medication. Sarah was also prescribed standby medication to be taken if her symptoms suddenly got worse (exacerbation). She was worried that the standby medication might be risky but she knew she could always phone the community nurse service for advice or, if necessary, call NHS111. After 3 months on the plan, Sarah’s COPD is getting slowly worse but she increases her dose of regular medication as advised by the plan and her symptoms return to their previous level after a couple of days. So far, Sarah has not had to use her standby medication but she feels confident to do so if necessary rather than go straight to A&E.

1. Is the scenario realistic? Would you change anything about how it is written?
2. From Sarah’s perspective what might make it easier or more difficult for her to follow her self-management plan?

Scenario 2: Case management for Kareem

Kareem has recently been in hospital because of a serious heart problem. Now that he is back at home his care is co-ordinated by Mark, a community-based specialist nurse. Mark acts as a case manager for Kareem. Mark visits Kareem regularly at home to talk about his condition and to check his medication. Mark also keeps in touch with Kareem’s GP practice, so that he does not have to go there so often. Kareem is ultimately under the care of a specialist at the local teaching hospital but he is happy with Mark as a first point of contact. He
knows that Mark can arrange for him to have an outpatient appointment at the hospital if he needs it.

1. **Is the scenario realistic? Would you change anything about how it is written?**

2. **From the perspective of a patient what are the possible advantages and disadvantages of this case management approach?**
Scenario 3: Doctor Donna’s dilemma

Donna, a GP in a medium-sized practice, is already running late with her appointment schedule. She looks at the records of her next patient. Joseph has recently been in hospital because of a serious heart problem. The hospital prescribed a number of drugs for Joseph to take but there are many options for treating his condition, for example changing doses or switching to a different drug if he experiences harmful side-effects. Donna has seen patients with Joseph’s condition before, but not many.

Donna knows about a community specialist nurse who would be able to co-ordinate Joseph’s care, but the nurse is part of a new service and she has never met him. On the other hand, Donna knows that the hospital cardiology department has an excellent reputation and they are already familiar with Joseph. If her patient’s symptoms are getting worse, might it be best to send Joseph directly to the hospital and let them sort him out?

1. Is the scenario realistic? Would you change anything about how it is written?
2. What influence do you think a patient might have over the doctor’s final decision?

Scenario 4 – Delaying Doug

Doug has been coping with a chronic disease for just over ten years. Last night his symptoms were very bad causing him discomfort, pain and considerable anxiety. He was wondering whether he should call 111 or wait until morning to see his GP. When morning came he decided not to visit his GP. He recalled a similar occasion in the past when he had made an urgent visit to his GP. The GP had called an ambulance and, after waiting quite some time for the ambulance to arrive, he was taken to hospital to undergo what felt like an endless series of tests. In the end none of the tests seemed to add very much to what he and the doctor already knew. “None of us was any the wiser”, he says.
1. Is the above scenario realistic? Would you change anything about how it is written?
2. Put yourself in Doug’s position, why might you be reluctant to call 111 or to visit your GP in this situation?
**Appendix 4: Study summary tables**

Table 34: summary of included UK case management studies (34a quantitative; 34b qualitative)

### 34a: Quantitative studies

<table>
<thead>
<tr>
<th>Study Id</th>
<th>Setting</th>
<th>Study Design</th>
<th>Aims</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gruffydd-Jones et al (2010)77</td>
<td>Eleven patients in a single general practice</td>
<td>Pilot Study</td>
<td>To examine effect of case management in primary care of patients with COPD at high risk of hospital admission, identified using a novel multidimensional index of disease severity (DOSE index).</td>
<td>No improvement in health status, but non-significant reduction in total hospital admissions (three versus zero) and total bed days (16 versus 0) compared to same reference period in previous year. Increase in self-management knowledge.</td>
<td>RCT required</td>
</tr>
<tr>
<td>Stokes et al (2016a)71</td>
<td>Single clinical commissioning group (CCG) in UK National Health Service (NHS).</td>
<td>Comparative observational study</td>
<td>To evaluate multi-disciplinary team (MDT) case management intervention, at individual (direct</td>
<td>Slight, clinically trivial increases in inpatient non-elective admissions (+0.01 admissions per patient per month; 95% CI</td>
<td>Intervention does not meet its primary aim. Clinical significance and cost-effectiveness of small practice-level effects is debatable.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Objective</td>
<td>Outcomes</td>
<td>Results</td>
<td>Implications</td>
</tr>
<tr>
<td>-------</td>
<td>--------</td>
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<td>--------------</td>
</tr>
<tr>
<td>2049 intervention patients compared using propensity scoring one-to-one with control patients. At practice level, 30 practices compared using natural experiment through staged implementation. Twenty ambulatory sensitive conditions</td>
<td>effects of intervention and practice levels (potential spillover effects).</td>
<td>0.00 to 0.01. Effect size (ES): 0.02; 30-day re-admissions (+0.00; 0.00 to 0.01. ES: 0.03). No indication that highest risk patients benefitted more from intervention. At practice level, small decrease in inpatient non-elective admissions (−0.63 admissions per 1000 patients per month; −1.17 to −0.09. ES: −0.24). However, result did not withstand robustness check; estimate may have absorbed differences in underlying practice trends.</td>
<td>Ongoing need to develop effective ways to reduce preventable attendances in secondary care for high-risk population.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stokes et al, 2017</td>
<td>Extended previous analysis (see above) with 2049 propensity matched case management intervention patients, adding an additional interaction term to Comparative observational study</td>
<td>To explore whether effects of case management vary in patients with different types of multimorbidity. Where results were significant, the vast majority of effect sizes identified in either direction were very small. Trend for very slight increases of admissions with</td>
<td>Results indicate no appropriate multimorbidity subgroup at which to target case management in terms of secondary care utilisation/cost outcomes. The most</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
determine subgroup effects (difference-in-difference-in-differences) by different definitions of multi-morbidity. Outcome measures included diverse secondary care utilisation and cost measures.

Outcomes measures included diverse secondary care utilisation and cost measures.

Treatment for the most complex patients (highest risk). Patients with a Charlson index >5 may benefit slightly more from case management with decreased ACSC admissions (effect size (ES): −0.06) and inpatient re-admissions (30 days, ES: −0.05). Patients with only cardiovascular/metabolic cluster conditions may benefit slightly more with decreased inpatient non-elective admissions (ES: −0.12).

Complex, highest risk patients may legitimately require hospitalisation, and intensified management may better identify these unmet needs. End of life patients (e.g. Charlson index >5)/those with only conditions particularly amenable to primary care management (e.g. cardiovascular/metabolic cluster conditions) may benefit very slightly more than others.

### 34b: Qualitative studies

<table>
<thead>
<tr>
<th>Study Id</th>
<th>Setting</th>
<th>Study Design</th>
<th>Aims</th>
<th>Intervention</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Close et al (2013)</td>
<td>17 patients, 8 care home staff, 5 GPs &amp; 3 HF nurses in residential care</td>
<td>Interview study</td>
<td>To examine experiences and expectations of clinicians, care home staff and residents in interpreting suspected HF diagnosis</td>
<td>Tailored, consultant-led management plan delivered by HF nurses.</td>
<td>Participants perceived no clear lines of responsibility in providing HF care in care-facilities. Many clinical staff.</td>
<td>HF diagnosis and management is of variable quality in long-term care. Conflicting expectations and a...</td>
</tr>
</tbody>
</table>
symptoms of HF and deciding whether and how to intervene.

had negative views of the acceptability and utility of interventions. Some staff inappropriately limited residents’ access to HF diagnosis and treatment. Care-facility staff and residents welcomed intervention but felt there was no opportunity for dialogue about balance of risks and benefits. Most residents wanted to be involved in healthcare decisions but this was not possible because of physical, social and organisational barriers. An onsite HF service was acceptable to residents and care-facility staff.

lack of co-ordinated responsibility for care, contribute to a culture of benign neglect that excludes the wishes and needs of residents. A greater focus on rights, responsibilities and co-ordination may improve healthcare quality for older people in care.

| Gowing et al (2016)² | Community patients receiving primary care in | To explore views and experiences of patients on care received while enrolled on | Case finding using a multidisciplinary team (MDT)-led community case management | Four themes: awareness and understanding of NHRPP, confidence in | Multidisciplinary team-led case management was generally well |

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| Northumberland, England. | Northumberland High Risk Patient Programme (NHRPP). | programme, and support of patients through care planning and regular reviews by primary, community, secondary and social care professionals. | primary healthcare team, limitations of home care and active role of being a patient. Participants lacked detailed awareness of NHRPP but agreed with its broad aim. They were highly satisfied with their care and access to team members. Limitations of alternatives to hospital were related to patients’ psychological needs, importance of overnight care and needs of those without informal carers. Participants recognised the need for NHRPP patients to be active in contributing to planning and managing their own care. | received by patients and their families. |

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| Hall Aiken (2014)\(^{294}\) and Beacon (2015)\(^{295}\) | No details | To present a case study of development of multi-disciplinary Practice-Integrated Care Teams (PICT) in central Manchester. | There has been an overall reduction in secondary care activity for patients the teams have been working with, with the largest reduction being in emergency admissions. Patient feedback indicates increased overall satisfaction with care and advice received from health/social care professionals. Evaluation demonstrated a strong professional commitment to principles of integrated care, improved team confidence and skills, and cost savings from secondary care. | This GP-centred model has enabled primary care to take a key role in development of an out-of-hospital integrated care system. Community professionals such as nurses and social workers have been able to build stronger relationships with general practice, enabling system linkages essential to delivery of integrated health and social care. |

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### Table 35: Summary of included UK patient education studies (35a quantitative; 35b qualitative)

**35a: Quantitative Studies**

<table>
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<tr>
<th>Study Id</th>
<th>Setting</th>
<th>Aims</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Das et al (2013)</td>
<td>Retrospective audit of case notes for all patients admitted with acute asthma (September-October 2012).</td>
<td>To review asthma admissions to investigate whether they may have been preventable with better management in the community. Management in the acute setting was audited against the British Thoracic Society (BTS) guidelines.</td>
<td>Of 41 patients identified, 56% were on treatment step 1 or 2 of the BTS guidelines, 37% were on step 3 and the remaining 7% on steps 4 and 5. At discharge, only 2 patients had a medication dose increase and 6 had a new medication added. Documentation of treatment and provision of self-management plans was poor.</td>
<td>Asthma exacerbations requiring admission can reflect poor disease control. Poor compliance and inhaler technique, limited use of self-management plans and lack of patient education contributed to these admissions. GPs should ensure that regular asthma reviews are undertaken in the community. The authors propose a checklist to improve adherence to BTS guidance.</td>
</tr>
<tr>
<td>Howard &amp; Dupont (2014)</td>
<td>220 COPD patients in Hillingdon, Uxbridge, UK randomly allocated to receive either the COPD breathlessness manual (CM) or IB. Patients were instructed to work through their programme at home, over 5 weeks. Guidance from a facilitator was provided at an</td>
<td>To compare a cognitive-behavioural manual versus information booklets (IB) on health service use, mood and health status.</td>
<td>After 12 months, total A&amp;E visits had reduced by 42% in the CM group, compared with a 16% rise in the IB group. Reductions in hospital admissions and bed days were greater in the CM group. Estimated savings at 12 months were greatest in the CM group.</td>
<td>The COPD manual is a straightforward cost-effective intervention worth offering to COPD patients within primary or secondary care.</td>
</tr>
</tbody>
</table>
Steventon et al (2013) Community based intervention within a large English city with industry. To test effect of a telephone health coaching service (Birmingham OwnHealth) on hospital use and associated costs. Matched controls and intervention patients were similar before the date of enrolment. After enrolment, emergency admissions, outpatient attendances and secondary care costs increased more quickly among intervention participants than controls. Checks showed that reductions in emergency admissions were unlikely to have been missed because of unobserved differences between intervention and control groups.

The intervention did not lead to the expected reductions in hospital admissions or secondary care costs over 12 months, and could have led to increases.

35b: Qualitative Studies

<table>
<thead>
<tr>
<th>Study Id</th>
<th>Setting</th>
<th>Aims</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fry et al (2016) [HoldFAST Cluster]124</td>
<td>Three geographical locations within UK; Midlands, South Central and South West of England. Qualitative interviews with 11 patients who had participated in HoldFAST, multicentre NIHR-funded ethnographic</td>
<td>To use secondary analysis to interrogate a qualitative data set to explore the experiences of patients living with heart failure.</td>
<td>Respondents described how disruption of routine activity due to their symptoms caused them to seek medical care. Respondents disclosed difficulties of living with other co-morbidities (managing multiple and</td>
<td>Facilitated access to healthcare, through good communication between services and having a strong support network of both family and clinicians can reduce the impact of heart failure on</td>
</tr>
<tr>
<td>Study</td>
<td>Participants</td>
<td>Research Methods</td>
<td>Findings</td>
<td>Implications</td>
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<tr>
<td>Glogowska et al (2015) [HoldFAST Cluster]</td>
<td>Three geographical locations within UK; Midlands, South Central and South West of England. HoldFAST, multi-centre NIHR-funded study including Bristol, Oxford and Keele Universities. Qualitative in-depth interviews with 24 clinicians across primary, secondary, and community care.</td>
<td>To explore perceptions and experiences of health care clinicians working in multidisciplinary teams that include specialist heart failure nurses when caring for management of heart failure patients.</td>
<td>Identified two particular challenges when working with heart failure patients: (i) communication with patients, in particular explaining diagnosis /helping patients to understand condition. (Participants recognized that such communication was most effective within a long-term relationship with patients and families and that specialist nurse was important in achieving this relationship). (ii) communication within the team. Multidisciplinary input especially needed because of complexity of many lives of patient and those around them.</td>
<td>Highlights role of specialist heart failure nurses in delivering education tailored to patients and facilitating better liaison among all clinicians, particularly in managing comorbidities and drug regimens. Specialist nurse role as caseworkers for their patients was perceived as a way of ensuring coordination and continuity of care.</td>
</tr>
<tr>
<td>Source</td>
<td>Type of Study</td>
<td>Purpose</td>
<td>Results</td>
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</tr>
<tr>
<td>Glogowska et al (2016) [HoldFAST Cluster]</td>
<td>Qualitative in-depth interviews with 24 health care professionals (HCPs) across primary, secondary and community care in three locations in England, UK – the Midlands, South Central and South West within HoldFAST, multi-centre study including Bristol, Oxford and Keele Universities, funded by NIHR.</td>
<td>To explore perceptions and experiences of HCPs working with patients with heart failure around End of Life care.</td>
<td>HCPs discussed struggle to find alternatives to hospital admission for patients at the end of their life. Patients may be hospitalised because of a lack of planning which would enable them to die at home, if they so wished. HCPs regarded opportunities for patients with heart failure to have ongoing discussions about their EoL care with clinicians they know as essential. These key professionals can help co-ordinate care and support in terminal phase of condition. Links between heart failure teams /specialist palliative care services appear to benefit patients. Further sharing of expertise between teams is recommended.</td>
<td></td>
</tr>
<tr>
<td>Halpin et al (2015)</td>
<td>District General Hospital, Exeter, Devon, UK</td>
<td>To determine the importance of fear and anxiety at the time of an exacerbation of chronic obstructive pulmonary disease. To assess the influence of carers and health professionals on this fear and anxiety.</td>
<td>Four themes emerged: panic and fear; anxiety management techniques used during an exacerbation; intervention from family members and carers; response to medical services. Panic and fear are important emotions prior to admission. Many patients recognised link between panic-fear and worsening symptoms. Some were able to use self-management techniques to reduce their panic-fear. Some relatives were seen as helping and others exacerbating the symptoms. The emergency services</td>
<td></td>
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</table>
Simmonds et al (2015) [HoldFAST Cluster] 126

| 31 patients with severe or difficult to manage heart failure followed for up to 11 months; 9 carers; 55 healthcare professionals across three geographical locations within UK; Midlands, South Central and South West of England. HoldFAST, multi-centre study including Bristol, Oxford and Keele Universities, funded by National Institute for Health Research. | To identify critical points on patient pathways where risk of admission is increased and identify barriers to implementation of evidence-based interventions. | Fragmentation of healthcare, inequitable provision of services and poor continuity of care presented barriers to interventions for heart failure. Critical points affecting risk of current/future admission occurred throughout the pathway. Some patients did not receive a formal clinical diagnosis. Patients lacked information about heart failure, self-care and when to seek help. Some clinicians lacked knowledge about diagnosis and management. Approaching end of life, patients were admitted when other options (e.g. palliative care) could have been appropriate. | Fragmented healthcare and discontinuity of care add complexity and increase the likelihood of suboptimal management and unplanned admissions. The need for clinician education about heart failure and specialist services was acknowledged. |

Table 36: Summary of included UK self-management studies

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<table>
<thead>
<tr>
<th>Reference and population</th>
<th>Study design</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bucknall (2012)</strong>&lt;sup&gt;138&lt;/sup&gt;</td>
<td>Experimental</td>
<td>Supported self-management had no effect on time to first readmission or death due to COPD. Exploratory subgroup analysis revealed a minority of intervention participants who successfully self-managed their COPD. These patients had a significantly reduced rate of COPD readmission compared with other intervention patients. Successful self-management was associated with being younger and living with others.</td>
<td>Authors concluded that supported self-management cannot be recommended for the general population of patients hospitalised for COPD exacerbations in the UK</td>
</tr>
<tr>
<td>Population/condition COPD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Dritsaki (2016)</strong>&lt;sup&gt;144&lt;/sup&gt;</td>
<td>Other Economic evaluation</td>
<td>Participants in the intervention group gained 0.1 QALYs compared with the usual care group at an estimated cost of £280.39 per QALY.</td>
<td>There was a 97% chance of the intervention being cost-effective at a threshold of £20,000 per QALY and 99% at £30,000 per QALY</td>
</tr>
<tr>
<td>Population/condition COPD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hoskins (2016)</strong>&lt;sup&gt;142&lt;/sup&gt;</td>
<td>Experimental</td>
<td>The GOAL intervention changed the process of asthma review and was well received by patients, but required additional time, which was problematic within the limitations of the traditional nurse appointment.</td>
<td>Changes to recruitment methods and further development of the intervention are needed before proceeding to a definitive cluster randomised controlled trial.</td>
</tr>
<tr>
<td>Population/condition Asthma</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study Reference</td>
<td>Study Design</td>
<td>Population/Condition</td>
<td>Intervention Details</td>
</tr>
<tr>
<td>-----------------</td>
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</tr>
<tr>
<td>Johnson-Warrington (2016)¹⁴³</td>
<td>Experimental</td>
<td>COPD</td>
<td>The SPACE intervention did not reduce readmission at 3 months compared with usual care. The intervention provided some benefits in quality of life and increasing time to first readmission with no increase in mortality.</td>
</tr>
<tr>
<td>Kennedy (2013)¹³⁹</td>
<td>Experimental</td>
<td>Multiple</td>
<td>4533 patients (81%) completed 6-month follow-up and 4076 (72.8%) completed 12-month follow-up. There were no differences between intervention and control practices for any outcome measure.</td>
</tr>
<tr>
<td>Morrow (2017)¹³⁶</td>
<td>Qualitative</td>
<td>Asthma</td>
<td>Supported self-management was largely a nurse-led task within clinic-based annual reviews. Barriers included poor attendance at asthma clinics, lack of time, demarcation of roles, limited access to a range of tailored resources, and competing agendas in consultation, often due to multimorbidity.</td>
</tr>
<tr>
<td>Ogunbayo (2017)¹⁴⁷</td>
<td>Qualitative</td>
<td></td>
<td>Factors affecting self-management support implementation were categorised as patient-, practitioner- or system-level. Patient-level</td>
</tr>
<tr>
<td>Population/condition</td>
<td>COPD</td>
<td>factors, including knowledge and understanding of COPD and personal circumstances, were mainly seen as barriers. Practitioners saw their own speciality, interest and experience as an overarching factor in how they provided support to patients.</td>
<td>different self-management planning tools. The authors concluded that all three levels need to be considered for optimal implementation</td>
</tr>
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</tr>
<tr>
<td>Patel (2016)</td>
<td>Qualitative</td>
<td>Patients responded positively to the use of technology and valued the perceived support from remote monitoring. No patient required hospital admission during the study. Awareness of COPD symptoms and confidence in self-management increased during the study.</td>
<td>Patients valued the support of the research nurses and some felt concern about managing COPD at home without this support</td>
</tr>
<tr>
<td>Ring (2015)</td>
<td>Qualitative</td>
<td>Primary care implementation of PAAPs is characterised by a vicious cycle in which negative views/actions of patients and health professionals reinforce one another. Twenty-five years after PAAPs were recommended, many organisational and practical barriers remain.</td>
<td>Authors recommend a whole-system approach, using multi-faceted interventions to tackle identified barriers</td>
</tr>
<tr>
<td>Roberts (2012)</td>
<td>Uncontrolled observational</td>
<td>Questionnaire response rate was 33% (58/175). Respondents expressed strong support for guideline recommendations, but implementation in routine practice was patchy.</td>
<td>Identified barriers included time constraints, lack of training/resources, concerns about patients' ability to self-manage and lack of confidence among clinicians for completing self-</td>
</tr>
<tr>
<td>Population/condition</td>
<td></td>
<td>management plans</td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
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<td></td>
</tr>
<tr>
<td>Asthma</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>COPD</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
Table 37: Summary of included UK telehealthcare studies (37a quantitative; 37b qualitative)

### 37a: Quantitative studies

<table>
<thead>
<tr>
<th>Study Id</th>
<th>Setting</th>
<th>Aims</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steventon et al (2012)</td>
<td>179 general practices in three areas in England. COPD, Diabetes and Heart Failure.</td>
<td>To assess effect of home based telehealth interventions on the use of secondary healthcare and mortality.</td>
<td>Patient characteristics similar at baseline. Compared to controls, intervention group had a lower admission proportion within 12 month follow-up (odds ratio 0.82, 95% confidence interval 0.70 to 0.97, P=0.017). Mortality at 12 months lower for intervention patients than for controls (4.6% v 8.3%; odds ratio 0.54, 0.39 to 0.75, P&lt;0.001). Differences in admissions and mortality remained significant after adjustment. Mean number of emergency admissions per head differed between groups (crude rates, intervention 0.54 v control</td>
<td>Telehealth is associated with lower mortality and emergency admission rates. Reasons for short term increases in admissions for the control group are not clear, but trial recruitment processes may have had an effect.</td>
</tr>
</tbody>
</table>
0.68); these changes were significant in unadjusted comparisons (incidence rate ratio 0.81, 0.65 to 1.00, P=0.046) and after adjusting for a predictive risk score, but not after adjusting for baseline characteristics. Observed differences in other forms of hospital use, including notional costs, were not significant. Differences in emergency admissions were greatest at beginning of the trial with a particularly large increase for the control group.

<table>
<thead>
<tr>
<th>Study Id</th>
<th>Setting</th>
<th>Study design</th>
<th>Aims</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crundall-Goode &amp; Goode (2014)\textsuperscript{52}</td>
<td>Overview of advantages and</td>
<td>Qualitative Review</td>
<td>To guide nurses and their managers on how</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fairbrother et al (2012)</td>
<td>Telemonitoring service for patients with COPD introduced in Lothian, Scotland, in 2009.</td>
<td>Qualitative study, nested within TELESCOT COPD RCT.</td>
<td>To explore the views of patients and professionals on telemonitoring including perceived impact of telemonitoring on continuity of care.</td>
<td>Patients and healthcare professionals considered relationship-based continuity of care important in delivering telemonitoring services. Managers placed emphasis on improved continuity of clinical management to reduce healthcare costs. However, professionals described operational challenges when 'bolting-on' telemonitoring provision to usual care provision leading to additional managerial discontinuities.</td>
<td>Managers and healthcare professionals face major challenges in meeting demands for both relationship continuity and continuity of clinical management when developing telemonitoring services.</td>
</tr>
<tr>
<td>Fairbrother et al (2013)</td>
<td>Patients with COPD and healthcare professionals participating in RCT of telemonitoring in Lothian, Scotland</td>
<td>Semi-structured interviews</td>
<td>To explore patient and professional views on self-management in the context of telemonitoring in COPD.</td>
<td>Patients considered that telemonitoring empowered self-management by enhancing their understanding of COPD and providing additional justification for their decisions to adjust treatment or seek professional advice. Professionals discussed telemonitoring as promoting compliance with medical advice and encouraged patients to exercise personal responsibility within clinical parameters, but expressed concerns about promoting the sick role and creating dependence on telemonitoring. Patients and professionals shared responsibility for prompt management. Care is needed to minimize risk in some patients, of increasing dependence on practitioner support. Many patients were able to embrace greater responsibility for their health. Model of service provision remained clinician-centered. A medical model of 'compliant self-management' may paradoxically promote dependence on professionals.</td>
<td></td>
</tr>
<tr>
<td>Fairbrother et al (2013)(^{296})</td>
<td>Chronic heart failure telemonitoring service set-up by NHS Lothian, Scotland</td>
<td>Semi-structured interviews with 18 patients and five professionals participating at different time points in this new service.</td>
<td>To understand the views of patients and professionals on the acceptability and perceived usefulness of telemonitoring in the management of chronic heart failure in the context of day-to-day care provision.</td>
<td>Five main themes identified: 'information, support and reassurance'; 'compliance and dependence'; 'changes and challenges'; 'determining the criteria for patient applicability to telemonitoring'; and 'continuity of care'.</td>
<td>Patients and professionals considered telemonitoring useful in managing chronic heart failure but with caveats. Patients felt reassured by what was perceived as continuous practitioner surveillance. Professionals expressed concern regarding perceived patient dependence on practitioner support. Increased workload was also a concern. Both groups acknowledged need for improved technology and changes to service provision to better meet intended objectives of the service.</td>
</tr>
<tr>
<td>Study</td>
<td>Patients</td>
<td>Methodology</td>
<td>Objectives</td>
<td>Findings</td>
<td>Summary</td>
</tr>
<tr>
<td>-------</td>
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</tr>
<tr>
<td>Gale &amp; Sultan (2013)</td>
<td>COPD patients receiving a community respiratory service (CRS), Sandwell, West Midlands.</td>
<td>In-depth, qualitative, situated interviews with COPD patients receiving the service.</td>
<td>To document people with COPD’s experience and interaction with the technology, in order to understand how they negotiated incorporating telehealth technologies into their everyday life and home space, and to understand why they valued it.</td>
<td>Telehealth brought peace of mind through two mechanisms: legitimising contact with health professionals and increased patient confidence in the management of their condition. When the home is the primary health space, the introduction of telehealth can modify emotional and bodily experiences to an extent that is significant for people with COPD.</td>
<td>Professionals emphasised importance of case selection and adequate training and support, both for patients and themselves, to maximise expected benefits of the service.</td>
</tr>
<tr>
<td>Hanley et al (2018)</td>
<td>Large dataset from Telescot series of studies (181 patients)</td>
<td>Qualitative interview and focus group data</td>
<td>To explore what drove changes to how telemonitoring</td>
<td>Four major themes identified, using data, empowering</td>
<td>Telemonitoring was valued by patients who found it</td>
</tr>
</tbody>
</table>

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and 109 professionals). From the Telescot programme, was implemented, compare experience of telemonitoring across diverse long term conditions, and identify what issues, in the experience of the participants, need to be considered in implementing new telemonitoring systems. Patients, adjusting the model of care and system design. Empowering and convenient. Professional concerns centred on whether increased surveillance may create dependency. However, despite initial concerns being addressed as the service evolved, primary care professionals identified persistent barriers to widespread routine adoption requiring improved system design.

| Jones et al (2012)\(^{157}\) | 24 general practices in the West Midlands. | Qualitative study embedded within RCT (Telemonitoring and Self Management in the Control of Hypertension) trial of patient self- | To explore patients’ views of self-monitoring blood pressure and self-titration of antihypertensive medication. | Patients confident about self-monitoring. Many felt their multiple home readings were more valid than single office readings taken by their GP. Although Reluctance to change medication for borderline readings suggests behaviour similar to the clinical inertia seen for physicians. |

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<p>| management of hypertension | many patients self-titrated medication when required, others lacked the confidence to increase medication without reconsulting with their GP. Patients were more comfortable with titrating medication if blood pressure readings were substantially above target. Patients were reluctant to implement a change if readings were borderline. Many planned to continue self-monitoring after the study finished and report home readings to their GP, but few wished to continue with a self-management plan. | Additional support for those lacking in confidence to implement prearranged medication changes may allow more patients to undertake self-management. |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Methodology</th>
<th>Purpose</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jones et al (2013)</td>
<td>24 West Midlands general practices</td>
<td>Qualitative study embedded within RCT of healthcare professionals participating in the TASMINH2 trial of patient self-monitoring with self-titration of antihypertensives</td>
<td>To explore health professionals' views and experiences of patient self-management, particularly with respect to future implementation into routine care.</td>
<td>Professionals were positive about self-monitoring, but procedures for ensuring patients measured blood pressure correctly were haphazard. GPs interpreted home readings variably, with many not adjusting for lower home blood pressure. Interviewees were satisfied with patient training and arrangements for blood pressure monitoring and self-titration of medication during the trial, but less sure.</td>
</tr>
</tbody>
</table>
| May et al (2011)²⁹⁸ | 221 health professionals, managers, patients and carers; social care professionals and managers; and service suppliers and manufacturers for telecare services in community and domestic settings in England and Scotland. | Large scale comparative study using qualitative data collection techniques: semi-structured interviews with key informants, task-groups, and workshops; framework analysis of qualitative data informed by Normalization Process Theory. | To identify factors inhibiting the implementation and integration of telecare systems for chronic disease management in the community. | Key barriers to integration were uncertainties about coherent and sustainable service and business models; lack of coordination across social and primary care boundaries, lack of financial or other incentives to include telecare within primary care services; a lack of a sense of continuity with previous service provision and self-care work undertaken by patients; and general uncertainty about adequacy of telecare systems. These problems led to poor integration of policy and practice. | Telecare services may offer a cost effective and safe form of care for some people living with chronic illness. Slow and uneven implementation and integration do not stem from problems of adoption. They result from incomplete understanding of the role of telecare systems and subsequent adaption and embeddedness to context, and uncertainties about the best way to develop, coordinate, and sustain services to assist with chronic disease management. Interventions are needed (i) to reduce

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| Peirce et al (2011)\(^{178}\) | 26 key informants from across the UK. Eighteen had a clinical background, seven in nursing, with four working as community-based nurses providing care for patients with chronic diseases. Eight informants had experience in health informatics, four policy leads in NHS and nine with recent experience of telehealth programmes. Two academics. | Qualitative study using stakeholder interviews | To define current standards of care and user requirements for improved early detection telemonitoring. | Early detection has not informed technology or service design. Telemonitoring is driven by available technology rather than by users' needs. Describes set of requirements questions to inform design and implementation of telemonitoring systems and suggests research needed to develop successful early detection telemonitoring. | uncertainty about ownership of implementation processes and that lock together health and social care agencies; and (ii) to ensure user-centred rather than biomedical/service-centred models of care. | User-centred design and genuine interdisciplinary approaches needed to create solutions that are fit for purpose, sustainable and address real needs of patients, clinicians and healthcare organisations. |

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| Sanders et al (2012)\textsuperscript{55}  
[Whole System Demonstrator Project Cluster] | Participants were recruited from four trial groups (with diabetes, chronic obstructive pulmonary disease, heart failure, or social care needs) from three trial areas (Cornwall, Kent, east London). | Qualitative semi-structured interviews conducted with people who declined to participate in trial or who withdrew. Observations of home visits were conducted by shadowing 8 members of health and social care staff visiting people at home. Field notes were made of observational visits and explored alongside interview transcripts. | To explore barriers to participation and adoption of Telehealth and Telecare from the perspective of people who declined to participate or withdrew from the trial. | Barriers to adoption of TH and TC were identified: requirements for technical competence and operation of equipment; threats to identity, independence and self-care; expectations and experiences of disruption to services. Respondents held concerns that special skills were needed to operate equipment, often based on misunderstandings. Respondents’ identified threats to identity associated with positive ageing and self-reliance. Interventions could also undermine self-care and coping. Participants were | Findings regarding perceptions of potential disruption of interventions to identity and services go beyond common expectations that concerns about privacy and dislike of technology deter uptake. These insights indicate that more detailed information and time for discussion could be valuable especially on introduction. Potential recipients should have the opportunity to discuss their expectations and such views might usefully feed back into design and implementation. |
<table>
<thead>
<tr>
<th>Sharma et al (2010)\textsuperscript{265}</th>
<th>Prior to launch of telehealth service in Nottingham, UK,</th>
<th>Focus group discussions with clinical users (nurses and technicians)</th>
<th>To elicit initial perceptions about the service and describe findings from preliminary phase of larger longitudinal study.</th>
<th>Trust and sense of security are two very salient aspects that govern adoption of new technological innovation. Unattended, these aspects contribute to arousal of conflict and contradiction within a system.</th>
<th>Successful telehealth implementations in health care setting, require providers of the service to focus on how clinical users' trust can be gained and sense of security promoted while using telehealth services and technology.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ure et al (2012)\textsuperscript{159}[Commentary\textsuperscript{160}]</td>
<td>NHS Lothian COPD tele-monitoring service incorporating touch-screen computer for daily recording of symptoms and weekly oximetry and spirometry measurement.</td>
<td>In-depth interviews with patients and professionals before/after installation of tele-monitoring equipment. Interviews recorded, transcribed and thematically analysed. Data on use of healthcare resources obtained from primary care records</td>
<td>To explore perceptions of patients and professionals about pilot implementation of COPD tele-monitoring service.</td>
<td>Patients generally positive about technology (enabled earlier recognition of exacerbations and access to clinical advice). Clinicians had concerns about false positive symptom scores, difficulties in interpreting physiological data, overtreatment (large increase in antibiotics and steroid)</td>
<td>Tele-monitoring was perceived by patients as improving access to professional care, but raised concerns for clinicians about possible overtreatment and how best to organise services to support the technology.</td>
</tr>
<tr>
<td>Williams et al (2014)(^1)</td>
<td>Oxfordshire Primary Care</td>
<td>Embedded qualitative study using interviews with patients with COPD from various community NHS services</td>
<td>To explore patients’ expectations and experiences of using a mobile telehealth-based (mHealth) application and to determine how such a system may impact on their perceived wellbeing and ability to manage their COPD.</td>
<td>Patients identified no difficulties in using mHealth application. Patients who used the application reported increased awareness of variability of their symptoms (onset of exacerbation and recovery time) and reassurance through monitoring (continuity of care).</td>
<td>Patients could use the mHealth application, interpret clinical data, and use the data for self-management without previous knowledge. Telehealth interventions can complement current clinical pathways for self-management.</td>
</tr>
</tbody>
</table>
### Table 38: Summary of included UK cardiac rehabilitation studies

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study design</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Al Quait (2017)</td>
<td>Uncontrolled observational Logistic regression modelling study</td>
<td>Based on data on 59,807 patients, CR engagement decreases by 1.2% per year of age (odds ratio 0.98) and is approximately 7% lower (odds ratio 0.93) in female patients, while patients are 4.4 times more likely to engage if they receive a confirmed joining date (odds ratio 4.4).</td>
<td>Engagement with CR is not purely a patient decision but is related to service level factors, over which healthcare systems have more control</td>
</tr>
<tr>
<td>Devi (2014)</td>
<td>Experimental</td>
<td>In a randomised trial of a web-based CR programme for people with angina, significant benefits were seen at 6-week follow-up, with effects on angina frequency and social quality of life score persisting at 6 months</td>
<td>The intervention may be appropriate to offer to people with angina. The programme is likely to be cheaper to operate and run than conventional alternatives but a larger trial is required to demonstrate effectiveness and cost-effectiveness</td>
</tr>
<tr>
<td>Devi (2014)</td>
<td>Qualitative</td>
<td>The web-based programme was accepted and valued by participants. Participants suggested the programme should be provided at the time of diagnosis.</td>
<td>Barriers to participation were similar to those identified for traditional programmes</td>
</tr>
<tr>
<td>Doherty (2012)</td>
<td>Other Editorial comment on RAMIT trial (West)</td>
<td>The RAMIT trial was not designed to evaluate the efficacy of CR. The evidence that CR reduces mortality and is highly cost-effective remains little changed.</td>
<td>There is unjustifiable variation in CR services across the UK but the RAMIT results should not be generalised to ‘CR as practised in the UK’. Clinical audit and observational analysis of...</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample Characteristics</td>
<td>Findings</td>
</tr>
<tr>
<td>-------</td>
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</tr>
<tr>
<td><strong>Houchen (2012)</strong>&lt;sup&gt;181&lt;/sup&gt;</td>
<td>Uncontrolled observational</td>
<td>‘Early rehabilitation significantly improved exercise capacity and depression and reduced heart failure-associated health care utilisation in patients who had recently been hospitalised. The intervention was safe.’</td>
<td>However, the sample size was small and results were not compared to a control group. Therefore, the effects of natural recovery are unknown.</td>
</tr>
<tr>
<td><strong>National Audit of Cardiac Rehabilitation (2017)</strong>&lt;sup&gt;189&lt;/sup&gt;</td>
<td>Uncontrolled observational UK national audit</td>
<td>Over 100,000 patients were registered with the audit. The age of patients receiving CR ranged from 18 to 108 years, with a mean age of 70 years for females and 66 years for males. Just under 30% of patients were women. The percentage of patients starting and completing core CR was 77% and group CR was the predominant mode of delivery. The audit reported tangible gains compared with the previous report.</td>
<td>Recommended actions include: positive action to recruit more female patients, changing the type of programme offered if necessary; increased referral of patients with HF; offering a wider range of programme options; ensuring assessment of patients as they complete programmes; increasing the duration and frequency of sessions where programmes are not meeting minimum standards</td>
</tr>
<tr>
<td><strong>West (2012)</strong>&lt;sup&gt;184&lt;/sup&gt;</td>
<td>Experimental</td>
<td>There were no significant differences between groups in mortality at 2 years (RR 0.98, 95% CI 0.74 to 1.30) or after 7-9 years (0.99, 95% CI 0.85 to 1.15), cardiac events, seven of eight domains of the health-related quality of life scale or in psychological general well-being. Rehabilitation patients reported slightly less physical activity.</td>
<td>'Rehabilitation programmes may contribute to ‘seamless patient care’ and they are appreciated by many patients but evidence of objective benefit is weak relative to the proven benefits from other aspects of cardiac management'</td>
</tr>
<tr>
<td>Authors</td>
<td>Study Details</td>
<td>Findings/Discussion</td>
<td></td>
</tr>
<tr>
<td>---------</td>
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<td></td>
</tr>
<tr>
<td><strong>West (2013)</strong>&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Other Authors' response to comments on RAMIT publication</td>
<td>Differences between groups were reported in perceived quality of care</td>
<td></td>
</tr>
<tr>
<td><strong>Witham (2012)</strong>&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Experimental Randomised trial</td>
<td>Results do not support the usefulness of a tailored exercise programme for older patients with heart failure.</td>
<td></td>
</tr>
<tr>
<td><strong>Wood (2012)</strong>&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Other Editorial comment on RAMIT trial (West et al 2012)</td>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

Findings of the RAMIT trial, together with other recent trials, support the efficacy and effectiveness of typical courses of outpatient CR.

More work is needed, possibly involving more intensive exercise, better targeting of patients with breathlessness or combining exercise with education and behavioural interventions.

The results of RAMIT should lead CR programmes to re-evaluate their service and outcomes. Although current programmes are appreciated by patients, they are not 'fit for purpose' and need to change. This will require both reconfiguration of services and cultural change, as well as investment by the NHS.
Table 39: Quantitative UK studies of pulmonary rehabilitation

<table>
<thead>
<tr>
<th>Study Id</th>
<th>Setting</th>
<th>Aims</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Casey et al (2012) 201</td>
<td>General Practices (clusters) in the Western region of Ireland.</td>
<td>To evaluate the effectiveness of a structured education pulmonary rehabilitation programme on the health status of people with chronic obstructive pulmonary disease (COPD).</td>
<td>Participants allocated to the intervention group had statistically significant higher mean CRQ Dyspnoea (Mean 4.42 (SD .36) vs Mean 3.85 (SD .45), baseline and covariate adjusted mean difference (MD) TM49, 95% CI aTM2,.78) and CRQ Physical scores (Mean 4.62 (SD . ) vs Mean 4.2 (SD .29), baseline and covariate adjusted MD aTM37, 95% CI TM4,.6). No other statistically significant difference between groups was seen.</td>
<td>The SEPRP delivered in the primary care setting is effective in improving the health status of people with COPD as measured by the CRQ.</td>
</tr>
<tr>
<td>Casey et al (2013) 202</td>
<td>General Practices (clusters) in the Western region of Ireland.</td>
<td>To evaluate the effectiveness of a structured education pulmonary rehabilitation programme on the health status of people with chronic obstructive pulmonary disease (COPD).</td>
<td>Participants allocated to the intervention group had statistically significant higher mean change total CRQ scores (adjusted mean difference (MD) 1.11, 95% CI 0.35 to 1.87). However, the CI does not exclude a smaller difference than the one that was prespecified as clinically important. Participants allocated to the intervention group also had statistically significant higher mean CRQ Dyspnoea scores after intervention (adjusted MD 0.49, 95% CI 0.20 to 0.78) and CRQ Physical scores (adjusted MD 0.37, 95% CI 0.14 to 0.60). However, CIs for both the CRQ Dyspnoea and CRQ Physical subscales do not exclude smaller differences as prespecified as clinically important. No other statistically significant difference between groups was seen.</td>
<td>A primary care based structured education pulmonary rehabilitation programme is feasible and may increase local accessibility to people with moderate and severe COPD.</td>
</tr>
<tr>
<td><strong>Casey et al (2011)</strong>&lt;sup&gt;200&lt;/sup&gt;</td>
<td>General Practices (clusters) in the Western region of Ireland.</td>
<td>To describe the development of a Structure Education Pulmonary Rehabilitation Programme (SEPRP) for the PRINCE (Pulmonary Rehabilitation In Nurse-Led Community Environments)</td>
<td>All participants had enjoyed the programme; the involvement of different health professionals and the teaching strategies used were appropriate. The findings indicate that nurse-led primary care-based structured education programmes have the potential to empower clients with COPD to better self-manage their chronic health condition. The PRINCE study has demonstrated that nurses working in primary care can have a key role in pulmonary rehabilitation. Their expertise was essential to the development of the PRINCE SEPRP, and they also were able to facilitate the programme effectively. The philosophy of PRINCE was based on empowerment with the programme activities designed to give clients the knowledge, confidence and skills they need to self-manage. Nurses working in the community have the opportunity to work with people in empowering ways, and PRINCE is one example of how this can be put into practice.</td>
<td></td>
</tr>
<tr>
<td><strong>Chaplin et al (2016)</strong>&lt;sup&gt;208&lt;/sup&gt; Conference abstract</td>
<td>Not reported.</td>
<td>To determine if an interactive web-based PR programme is a feasible alternative to conventional PR.</td>
<td>103 patients were recruited. The largest proportion of patients randomised wanted the web programme (n=38%). A statistically significant improvement (p&lt; 0.01) was observed within each group in the ESWT (WEB:mean change 189+/-211.1;PR classes:mean change 184.5+/-247.4secs) and CRQ-D (WEB:mean change 0.7+/-1.2;PR classes:mean change 0.8+/-1.0). There were no significant differences between the groups in any outcome. A web-based PR programme is feasible and acceptable when compared to conventional PR. Future trials maybe around choice based PR enabling stratification of patient care.</td>
<td></td>
</tr>
<tr>
<td><strong>Condon et al (2015)</strong>&lt;sup&gt;209&lt;/sup&gt;</td>
<td>Two academic teaching</td>
<td>To identify referral, uptake and PR</td>
<td>Of 183 people with confirmed COPD, 98 (54%) met the HSE Model of Care criteria for PR. Referral to PR was adequate but timely uptake by patients remains poor. Low</td>
<td></td>
</tr>
<tr>
<td>Location</td>
<td>Facilities</td>
<td>Study Purpose</td>
<td>Study Details</td>
<td>Findings</td>
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<tr>
<td>----------</td>
<td>------------</td>
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</tr>
<tr>
<td>Dublin, Ireland</td>
<td>hospitals in Dublin, Ireland</td>
<td>completion rates over the 3-month period.</td>
<td>Thirty-nine (21%) were not functionally limited by the disease and 23 (12%) were considered not suitable for PR. Approximately half (n = 50) of those eligible were referred for assessment but after six months, only 7 people had completed a PR programme.</td>
<td>uptake has implications for the effectiveness of PR in reducing mortality and hospital readmissions.</td>
</tr>
<tr>
<td>Dublin, Ireland</td>
<td>Community gym facilities in the borough of Gateshead</td>
<td>To determine whether a PR programme provided in community gym facilities can lead to sustainable behaviour change to support effective self-management of patients with mild to moderate symptoms of COPD.</td>
<td>The programme has proved to be highly beneficial and very positive participant feedback has been received. A significant number of patients have sustained long term genuine health behaviours. Participants have benefitted by having greater knowledge and understanding of the management of their condition with improved physical fitness, well-being and have been able to achieve personal goals. In addition participants have the long term sustainable benefits of maintaining progress and confidence to manage their condition, which represents improved outcomes for patients, and potentially demonstrates economic value, with decreased need for social/medical care.</td>
<td>Occupational Therapists can deliver a participant empowered approach to pulmonary rehabilitation which builds upon traditional models of self-management. Critically this approach enables participants to successfully understand the need for change, appreciate the benefits of change and to live the change long term.</td>
</tr>
<tr>
<td>Gateshead</td>
<td>Community gym facilities in the borough of Gateshead</td>
<td>To determine whether a PR programme provided in community gym facilities can lead to sustainable behaviour change to support effective self-management of patients with mild to moderate symptoms of COPD.</td>
<td>The programme has proved to be highly beneficial and very positive participant feedback has been received. A significant number of patients have sustained long term genuine health behaviours. Participants have benefitted by having greater knowledge and understanding of the management of their condition with improved physical fitness, well-being and have been able to achieve personal goals. In addition participants have the long term sustainable benefits of maintaining progress and confidence to manage their condition, which represents improved outcomes for patients, and potentially demonstrates economic value, with decreased need for social/medical care.</td>
<td>Occupational Therapists can deliver a participant empowered approach to pulmonary rehabilitation which builds upon traditional models of self-management. Critically this approach enables participants to successfully understand the need for change, appreciate the benefits of change and to live the change long term.</td>
</tr>
<tr>
<td>Exeter</td>
<td>General practices in Exeter</td>
<td>To determine the feasibility of recruiting patients with early chronic obstructive pulmonary disease (COPD) to the Health Enhancing Activity in Lung THERapy (HEALTH).</td>
<td>Out of 27 practices approached, 16 (59.3%) agreed to participate. Of 215 potentially eligible patients contacted, 60 (27.9%) replied. Twenty (33.3%) were randomised to either HEPA intervention (n=10) or usual care (n=10). Fourteen patients attended a postintervention assessment.</td>
<td>This study provides important evidence that may inform future recruitment strategies for PR for patients with GOLD stage II COPD. Based on these study findings we estimate that to recruit 100 patients it would be necessary to approach approximately 7000 patients on a COPD register and a multicentre trial would be required to achieve a suitable sample. Given the</td>
</tr>
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<table>
<thead>
<tr>
<th>Reference</th>
<th>Setting</th>
<th>Objective</th>
<th>Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foster et al (2016)</td>
<td>Eight general practices in Stoke.</td>
<td>To work with primary care clinicians (GPs and practice nurses) from eight practices, to develop strategies for influencing clinician and patient behaviours to increase referral rates for PR.</td>
<td>The baseline survey of clinicians (n=22) revealed inadequate knowledge about PR, particularly among GPs. Actionable changes recommended included in-house education sessions, changes to practice protocols, and ‘pop-ups’ and memory aids (mugs and coasters) to prompt clinician/patient discussions about PR. Audit findings resulted in changes to improve the quality and availability of coded information about patients eligible for PR. These changes, supported by clinicians (n=9) in the follow-up survey, aimed to facilitate and increase the quality of patient/clinician discussions about PR. Findings from the patient survey (n=126, response rate 25.7%) indicate that such changes will increase the uptake of PR as patients who accepted a referral for PR provided more positive feedback about their discussions with clinicians. The strategies introduced were relatively easy to implement and the anticipated advantage is more patients accessing the health and quality of life benefits that PR offers.</td>
</tr>
<tr>
<td>Graves et al (2010)</td>
<td>PR courses at The North Bristol Lung Centre</td>
<td>To determine the effect on course uptake and completion of a group opt-in session (GOIS) before baseline assessment for a PR course.</td>
<td>The proportion of referred patients taking up the offer of individualised baseline assessment or a GOIS was similar (75% vs. 72.2%, p value not significant [ns]). However, since in the GOIS group the opt-in session preceded the individualised baseline assessment and some patients opted-out, a smaller proportion of The GOIS improved the graduation rates at The North Bristol Lung Centre PR Course and reduced wasted assessments. There was no effect on initial uptake. Analysis of the behaviour of patients invited to a GOIS suggested that age, lung function and travel</td>
</tr>
</tbody>
</table>
referred patients underwent this assessment than in the non-GOIS group (58.7% vs. 75%, p < 0.001). In addition, dropouts following individualised baseline assessments were also reduced (7% vs. 22%, p < 0.001). Both of these factors reduced ‘wasted’ assessments. Similar proportions of patients referred began the PR course in both groups (53% vs. 51.7%, ns), but a higher proportion of patients graduated in the GOIS group (87.9% vs. 76.4%, p < 0.05). Drop-out rates due to illness were similar in both groups (8.5% pre vs. 6.8% post, ns). However, drop-out rates not due to illness were much higher in the non-GOIS group (15.1% vs. 5.3%, p < 0.001). In the GOIS group, patients who did not attend the GOIS were, on average, younger (64.6 years vs. 69.7 years, p < 0.001) and had a higher mean percent predicted Forced Expiratory Volume (50.6% vs. 43.8%, p < 0.05) than those that did attend. A greater proportion of patients who opted in to the GOIS and attended the PR course lived less than 25 minutes from the PR centre than either those who did not attend the GOIS or who attended and then opted out (77.4% vs. 63%, p<0.005).

| Distance were important factors influencing patient choice. Since the introduction of the GOIS, we have been able to treat more patients without increasing our staffing. We commend this approach to others providing PR courses. |

<p>| Greening et al (2014) 205 | An acute cardiorespiratory unit in a teaching hospital and an acute medical unit in an acute medical unit | To investigate whether an early rehabilitation intervention initiated during acute admission for exacerbations of chronic respiratory disease had a primary diagnosis of chronic obstructive pulmonary disease. 233 (60%) were readmitted at least once in the following year (62% in the intervention group and 58% in the control group). No significant difference between groups was found. | Of the 389 participants, 320 (82%) had a primary diagnosis of chronic obstructive pulmonary disease. 233 (60%) were readmitted at least once in the following year (62% in the intervention group and 58% in the control group). No significant difference between groups was found. | distance were important factors influencing patient choice. Since the introduction of the GOIS, we have been able to treat more patients without increasing our staffing. We commend this approach to others providing PR courses. |</p>
<table>
<thead>
<tr>
<th>Affiliated Teaching District General Hospital, United Kingdom.</th>
<th>Disease reduces the risk of readmission over 12 months and ameliorates the negative effects of the episode on physical performance and health status (hazard ratio 1.1, 95% confidence interval 0.86 to 1.43, <em>P</em>=0.4). An increase in mortality was seen in the intervention group at one year (odds ratio 1.74, 95% confidence interval 1.05 to 2.88, <em>P</em>=0.03). Significant recovery in physical performance and health status was seen after discharge in both groups, with no significant difference between groups at one year.</th>
<th>At 12 months was higher in the intervention group. The results suggest that beyond current standard physiotherapy practice, progressive exercise rehabilitation should not be started during the early stages of the acute illness.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hayton et al (2013)</td>
<td>Norwich</td>
<td>To assess predictors of attendance and adherence of PR. Of patients referred for PR, 31.8% did not attend and 29.1% were non-adherent. Multiple logistic regression revealed that LTOT use and living alone were independent predictors of poor attendance. Current smoking, poor shuttle walking distance and hospitalisations were independent predictors of poor adherence.</td>
</tr>
<tr>
<td>Steiner et al (2017)</td>
<td>PR Services across England and Wales</td>
<td>To investigate whether socioeconomic deprivation is associated with rates of completion of PR or the clinical benefits bequeathed by PR. 210 PR programmes enrolled 7413 patients. Compared with the general population, the PR sample lived in relatively deprived neighbourhoods. There was a statistically significant association between rates of completion of PR and quintile of deprivation (70% in the least and 50% in the most deprived quintiles). After baseline adjustments, the risk ratio (95% CI) for patients in the most deprived relative to the least deprived quintile was 0.79 (0.73 to 0.85), <em>p</em>=0.001. After baseline adjustments, IMD was not significantly associated with improvements in exercise performance and health status.</td>
</tr>
</tbody>
</table>

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To determine whether pulmonary rehabilitation carried out in a community setting is more effective than that carried out in a standard hospital setting and which is more cost-effective; also whether telephone follow-up is both cost-effective and useful in prolonging the beneficial effects of a pulmonary rehabilitation programme.

Patients in the hospital rehabilitation group increased the distance they could walk at the post-rehabilitation follow-up by 283 m (SD 360 m), an increase relative to baseline of 109% (SD 137%). Patients in the community rehabilitation group increased the distance they could walk at the post-rehabilitation follow-up by 216 m (SD 340 m), an increase relative to baseline of 91% (SD 133%). There was no statistically significant difference between the groups [17.8% (95% CI - 24.3 to 59.9, p = 0.405)]. For longer term outcomes at 6, 12 and 18 months post rehabilitation there was no evidence of a rehabilitation group effect.

After allowing for the initial post-rehabilitation baseline distance walked, time (follow-up visit) and the factorial design (telephone follow-up group), the average difference in the post-rehabilitation follow-up distance walked on the ESWT between the hospital and community rehabilitation groups was 1.5 m (95% CI -82.1 to 97.2, p = 0.971), and between the telephone and no-telephone groups it was 56.9 m (95% CI - 25.2 to 139, p = 0.174). There was no difference between hospital or community groups in terms of acute effect or persistence of effect. Health economic analysis favoured neither hospital nor community settings, nor did it clearly favour telephone follow-up or routine care.

Pulmonary rehabilitation delivered in a community setting has similar efficacy to that produced in a more traditional hospital-based setting, both settings producing significant improvements in terms of exercise capacity and quality of life acutely and after long-term follow-up. Health economic analysis showed that neither hospital nor community programmes were greatly favoured. The choice of model will depend on local factors of convenience, existing availability of resources and incremental costs. Staff characteristics may be important in gaining optimal outcome, and care should be taken in staff recruitment and training.

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Table 40: Qualitative UK studies of pulmonary rehabilitation

<table>
<thead>
<tr>
<th>Study Id</th>
<th>Aims</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harrison et al (2015)</td>
<td>To explore how patients who refuse referral to pulmonary rehabilitation (PR) appraise acute exacerbations of chronic obstructive pulmonary disease (COPD), in the context of having considered and declined PR.</td>
<td>Three conceptual themes emerged comprising: &quot;Construction of the self&quot;; &quot;Relinquishing control&quot;; and &quot;Engagement with others&quot;. Prominent in the participants' narratives are self-conscious cognitions which appear founded in shame and stigmatization. Perceived personal culpability for COPD appears to sensitize participants' towards their interactions with health care professionals, construed as critical and judgmental which may increase avoidant behaviours, such as refusal of PR.</td>
<td>When introducing pulmonary rehabilitation health care professionals need to be mindful of patients' sensitivities to being shamed which stem from perceived culpability for COPD. Compassion focused interventions which encourage trust and safety may promote active partnership working and facilitate engagement in pulmonary rehabilitation.</td>
</tr>
<tr>
<td>Hogg et al (2012)</td>
<td>What are the views and perceptions of people with chronic obstructive pulmonary disease (COPD) regarding maintaining an active lifestyle following a course of pulmonary rehabilitation.</td>
<td>Five main themes emerged: value of pulmonary rehabilitation, ongoing exercise, professional support, peer social support, and health status. Pulmonary rehabilitation was seen as enabling a more active lifestyle by improving physical ability and confidence to manage breathlessness, and reducing fear of exertion. An exercise routine following rehabilitation was seen as essential for maintaining activity. Participants identified a need for ongoing, structured and supervised sessions to maintain new found abilities. The exercise facility presented a possible barrier to attendance because of</td>
<td>The opportunity for structured exercise with peer and professional support, in a suitable venue, is perceived as important for supporting an active lifestyle following pulmonary rehabilitation. The desire for such opportunities may be related to individuals' self-efficacy towards physical activity.</td>
</tr>
</tbody>
</table>
its potential to provoke feelings of embarrassment or intimidation. Professional and peer support were identified as key elements and participants wanted to exercise in a group that offered an opportunity for social interaction. COPD symptoms had a negative impact on physical activity participation. Confidence or self-efficacy for physical activity emerged as a prominent factor within main themes.

| Lewis et al (2014) | To explore COPD patient experiences during the key period from referral to initiation of PR in the United Kingdom. Twenty-five COPD participants aged 42–90 were interviewed. ‘Uncertainty’ affected participants throughout their lived experience of COPD that negatively impacted illness perceptions, PR perceptions and increased participant’s panic and anger. Participants who perceived COPD less as a chronic condition and more as a cyclical process experienced fewer feelings of panic or anger. The experience of uncertainty was disabling for these COPD participants. Recognition of the role that uncertainty plays in patients with COPD is the first step towards developing interventions focused on reducing this uncertainty, thereby reducing the burden of the disease for the individual patient and facilitating PR attendance. |
| Lewis and Cramp (2010) | To explore the attitudes of people with COPD to exercise and reasons for non-concordance with exercise maintenance post-pulmonary rehabilitation. From the focus group discussion, three main themes were identified: · effects of exercise · facilitators of exercise · barriers to exercise The effects of exercise were perceived to be mainly positive, although tiredness was also mentioned. Facilitators of exercise included encouragement, company, professional support, goal setting, personal attributes, and availability of a range of exercise The above themes may guide service providers in planning maintenance exercise sessions and in assisting people with COPD to strengthen exercise facilitators and overcome barriers to exercise. As individuals have different needs and their health status and circumstances change, communication needs to be ongoing and the exercise maintenance adaptable. A range of exercise options need to be available and combined with

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| Moore et al (2012) | To assess the obstacles to participation in PR among COPD patients in a community-based PR programme and associated general practices. | Twenty-four patients (13 male, 12 not referred) were interviewed. There were major concerns about the acceptability of PR. Some were concerned about the feasibility of attending the sessions. Other barriers included perceptions of PR and of exercise, how a smoker might be seen and the suitability of group activity. The views of professionals were influential, as were recommendations from other patients. The location of the centre was important. Participants’ willingness or reluctance to take on something new was a central element of the decision. Many saw a role for experienced patients in introducing the treatment. For patients who refused referral to PR, had not completed a course, or had yet to be referred, the way the service was introduced significantly influenced their willingness to participate. | options. Barriers to exercise included changing health status, fear, lack of support, and environment. A range of exercise options need to be available and combined with professional support, goal setting, encouragement, company and a suitable environment. |
### Table 41: UK studies of specialist clinics

<table>
<thead>
<tr>
<th>Study Id</th>
<th>Setting</th>
<th>Aims</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dean et al (2014) 222</td>
<td>Two inner city general practices in London, UK</td>
<td>To evaluate the effect of a specialist nurse-led hypertension clinic with consultant backup on change in systolic blood pressure.</td>
<td>Follow-up was 89% (313/353). There was greater reduction in systolic blood pressure in the clinic group (n = 144) than usual care group (n = 169, adjusted difference 4.4 mmHg; 95%CI 0.7 to 8.2).</td>
<td>Invitation to a specialist nurse-led hypertension clinic with consultant backup was associated with reduced systolic blood pressure.</td>
</tr>
<tr>
<td>Gillett et al (2016) 223</td>
<td>To evaluate an integrated service managing high-risk respiratory patients at risk of poor outcomes.</td>
<td>Two GP practices in the UK region of Wessex. One urban and one rural practice.</td>
<td>82 patients were identified, 55 attended. 13 (23.6%) had their primary diagnosis changed. In comparison with the seasonally adjusted baseline period, in the 9-month follow-up there was an increase in inhaled corticosteroid prescriptions of 23.3%, a reduction in short-acting beta-agonist prescription of 33.3%, a reduction in acute respiratory exacerbations of 67.6%, in unscheduled GP surgery visits of 53.3% and acute respiratory hospital admissions reduced from 3 to 0. Only 4 patients (7.3%) required referral to secondary care. Health</td>
<td>This service-development evaluation demonstrates that patients with respiratory disease at risk of suboptimal outcomes can proactively be identified for management by an integrated team in the community without the need for extensive, expensive secondary care technologies and warrants further evaluation at scale to determine its impact in other regions to fully determine health economic outcomes.</td>
</tr>
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</table>
economic evaluation showed respiratory-related costs per patient reduced by 231.86.
Table 42: Summary of UK community intervention studies

<table>
<thead>
<tr>
<th>Short Title</th>
<th>Reference</th>
<th>Study design</th>
<th>Results/Findings</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flood-Page (2016)</td>
<td>Study ID Study ID Flood-page (2016) (^{228})</td>
<td>Study design Controlled observational</td>
<td>Between 2003-2009 there was a 5.5% increase in COPD admissions across Gwent and a 5% increase for Wales as a whole. LAB admissions increased in all bar two areas where they fell by 4.6 and 4.3% respectively.</td>
<td>Authors (while acknowledging limitations of the study) concluded that services with close links between primary and secondary care may be more effective than those based around primary care alone</td>
</tr>
<tr>
<td>Glogowska (2015)</td>
<td>Study ID Study ID Glogowska (2015) (^{125})</td>
<td>Study design Qualitative</td>
<td>Specialist heart failure nurses have key roles in delivering education to patients and facilitating communication among the clinicians involved in their care.</td>
<td></td>
</tr>
<tr>
<td>Population/condition</td>
<td>Study ID</td>
<td>Study design</td>
<td>Study description</td>
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</tr>
<tr>
<td>Heart failure</td>
<td>Kosteli (2017)</td>
<td>Qualitative</td>
<td>Participants perceived nurse role as important for ensuring co-ordination and continuity of care.</td>
<td></td>
</tr>
<tr>
<td>COPD</td>
<td>MacKenzie (2010)</td>
<td>Qualitative</td>
<td>Understanding patient-specific social cognitive influences on PA participation can inform planning of tailored interventions for people with COPD.</td>
<td></td>
</tr>
<tr>
<td>Heart failure</td>
<td>MacKenzie (2010)</td>
<td>Qualitative</td>
<td>GP response rate was 32%. Despite strong supporting evidence, the nurse-led service was not welcomed by all doctors.</td>
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<table>
<thead>
<tr>
<th>Study ID</th>
<th>Study design</th>
<th>settings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarran (2014)</td>
<td>Controlled observational</td>
<td>The difference between intervention and control practices for admissions with a primary diagnosis of COPD was -0.8 % points (95% CI -1.8 to 0.2). For admissions with a primary or co-morbid diagnosis, the corresponding values were -2.3 (-4.2 to -0.4). Authors concluded that Healthy Outlook reduced hospital admissions for COPD when co-morbid diagnoses were included.</td>
</tr>
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<table>
<thead>
<tr>
<th>Population/condition</th>
<th>Study ID</th>
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</thead>
<tbody>
<tr>
<td>COPD</td>
<td>Sarran (2014)</td>
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Table 43: Summary of UK studies for other/multiple interventions

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study design</th>
<th>Results/Findings</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Multiple interventions</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Study ID</strong></td>
<td><strong>Ghosh (2016) 242</strong></td>
<td><strong>Study design</strong></td>
<td><strong>Uncontrolled observational</strong></td>
</tr>
<tr>
<td><strong>Population/condition</strong></td>
<td><strong>COPD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Study ID</strong></td>
<td><strong>Roberts (2010) 241</strong></td>
<td><strong>Study design</strong></td>
<td><strong>Uncontrolled observational</strong></td>
</tr>
<tr>
<td><strong>Population/condition</strong></td>
<td><strong>COPD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study ID</td>
<td>Population/condition</td>
<td>Study design</td>
<td>Study findings</td>
</tr>
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<tr>
<td>Williams (2010)</td>
<td>Heart failure</td>
<td>Controlled observational</td>
<td>The number of readmissions was lower in the intervention group compared with the control group (4/47 vs. 7/50) but the sample size was too small for statistical significance. Questionnaire responses indicated that patients were satisfied with the new service.</td>
</tr>
<tr>
<td>Cope (2015)</td>
<td>COPD</td>
<td>Uncontrolled observational</td>
<td>Compared with pre-service data, the in-reach service reduced average length of stay by 2.53 days. Readmissions within 30 days were reduced from 8.1 per month in 2012/13 to 3.9 in 2013/14. Numbers discharged to the early assisted discharge service increased from 9 to 79, representing 17% of admitted patients. Authors stated that the in-reach service model would be applicable to other long-term conditions and hospital sites.</td>
</tr>
<tr>
<td>Wilkinson (2014)</td>
<td>COPD</td>
<td>Uncontrolled observational</td>
<td>Thirty-four patients were found to be responsible for 176 admissions (22% of total COPD admissions) to the hospital. These patients required 185 active interventions during the 12-Authors concluded that the use of medical intelligence data to identify factors underlying frequent admission allowed an effective intervention to be delivered in a consultant-led model.</td>
</tr>
<tr>
<td>Population/condition</td>
<td>COPD</td>
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<tr>
<td>month study period but only 39 hospital admissions. The 30-day readmission rate dropped from 13.4 to 1.9% (p&lt;0.01).</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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