

Developing care for a changing population: supporting patients with costly, complex needs

Discussion paper

Hubertus J.M. Vrijhoef and Ruth Thorlby

May 2016

About this report

This report was originally prepared as a working paper for the Nuffield Trust and The Commonwealth Fund's 15th international meeting on improving the quality and efficiency of health care. The meeting, which took place in July 2015, was designed to provoke and inform debate. The Commonwealth Fund is a private, non-partisan foundation that supports independent research on health and social issues. The 2015 meeting reflects a shared commitment to cross-national policy exchange and builds on a collaboration that began in 1999.

The meeting brought together leading medical professionals and senior policy-makers from the United Kingdom and the United States to compare front-line delivery system models and policy approaches aimed at improving care for high-cost and high-need patients. This paper is one of three UK papers commissioned for the meeting and subsequently published by the Nuffield Trust. It offers a review of the emerging evidence and practice in Europe, alongside 10 reflections for policy-makers as they consider how to reform health systems to meet the needs of this crucial group of patients.



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Key points

Responding to the needs of the growing numbers of people with complex, chronic illnesses is making new and testing demands of health systems worldwide. Policy-makers are increasingly focused on how to improve care for this group of patients, who often experience fragmented services that fail to meet all their needs, at the same time as reducing the amount of resources consumed in caring for these patients. This paper was commissioned to look at emerging evidence from Europe, to stand alongside an overview of new models and strategies from the United States (McCarthy and others, 2015). In the paper, we offer a summary of the evidence and set out 10 key reflections for policy-makers.

There are no specific 'European' answers to the problem of high cost/complexity, but a growing body of policy-relevant evidence is emerging

Academic reviews of interventions for complex patients draw on evidence from multiple industrialised countries. They find that projects to improve care for people while in hospital or after discharge show some promising strategies, but improving care in the community is more challenging. There are several pan-European initiatives to pool evidence from best practice, in a policy-relevant form.

Multifaceted interventions seem to work best for complex problems

Interventions targeted at complex patients achieve more of their goals if they are multifaceted rather than relying on one intervention, for example combining a range of professionally focused changes (such as specialist geriatricians or case management) with patient/carer-focused interventions (such as better information or self-management).

Identifying who is at risk of complexity is a crucial first step

Many data tools have been developed in the past decade, which are increasingly effective at identifying, from routine health datasets, patients at risk of developing high-cost needs. But unmet needs are often driven by non-medical social factors, and data tools need to find ways of incorporating a broader range of risk factors into their models.

The needs of patients identified as 'complex' are likely to vary considerably

The personal capacity and resources that patients have to manage their multiple illnesses vary considerably, with age and socioeconomic status. Researchers are finding ways of conceptualising and measuring the 'treatment burden' of people with complex needs so that care can be better tailored to meet these needs.

Good outcomes for complex patients need to be rooted in patient preferences and are likely to include non-medical goals

Once a person has several chronic illnesses, understanding what a positive outcome means becomes more complex. It may require trade-offs between best-practice

treatment goals for individual illnesses, and include non-medical outcomes, which need to be based on what is important to the patient themselves.

Interventions may not reduce high costs, at least in the short term

Although minimising costs, particularly the high costs of hospital care, is vital to all health systems, evaluations of interventions designed to improve care for complex patients point to very limited reductions in hospital costs in the short term, and sometimes increased investment in other services is required. Policy-makers need to have more realistic expectations about cost savings.

Chronic care models may not be fit for purpose for complex patients

Many models of care developed for individual chronic illnesses have a strong focus on improving the management of conditions by patients and professionals in the community, to reduce reliance on acute care. These models may need to be substantially adapted to meet the needs of people with multiple illnesses, for example where capacity for self-management is very limited, and deteriorating conditions require access to specialist acute care.

Although highly relevant, the implications for the workforce are often neglected in research studies/new interventions

Creating multidisciplinary, coordinated care has big implications for the make-up and professional roles of the workforce. As well as involving staff from non-medical backgrounds to meet people's social needs, interventions to improve care for complex patients might require a realignment of clinical roles, for example a rebalancing of generalists to specialists.

Designing an intervention starts by fully understanding the problem

Approaches to new models for complex patients need to bring all these elements together with a clear theoretical underpinning, informed by the best available evidence of patients' needs and preferences, rather than simply implementing the standard ingredients of integrated care, such as care navigators or case managers.

Evidence of change needs to be given adequate time and robust evaluation

The systematic reviews that informed this paper flagged up the striking brevity of evaluation timespans: many projects were evaluated after only two years. Implementing complex interventions, particularly those that require new or adapted clinical roles, takes time, and it can often take at least two years before projects improve outcomes or generate cost savings.

1. Introduction

It is hard to understate the scale of the challenge facing Europe in relation to the growth of costly and complex conditions. Most are the result of chronic diseases, which account for 86 per cent of all deaths in the European Union (EU) region and absorb between 70 and 80 per cent of total health care costs (EU, 2013). Although chronic diseases often start in younger age groups, their symptoms dominate older populations: more than 80 per cent of people aged over 65 in Europe have a chronic condition (EU, 2013).

As people age, they are more likely to have more than one chronic condition. There are an estimated 50 million people living in the EU with multiple chronic diseases (Struckmann and others, 2014) and the numbers of people aged over 65 are projected to rise from 87.5 million in 2010 to 152.6 million in 2060 (EU, 2013).

Providing effective, high-quality care for people with chronic conditions has been a priority for governments for the past three decades. Many countries have adopted variants of the chronic disease management and/or chronic care models, two approaches pioneered in the United States (Coleman and others, 2009; Conill and Horowitz, 1999). European countries have adopted best-practice clinical guidelines and invested in the essential components of chronic care management, including self-care and integrated, coordinated services (Epping-Jordan, 2005; Nolte and McKee, 2008).

The past five years have seen an increased sense of urgency, mainly driven by two factors. The first driver is a clearer understanding of the scale of multimorbidity, which increases with age, but is also strongly linked to socioeconomic deprivation (Barnett and others, 2012). This poses new challenges to health systems geared to the management of acute episodes and single-disease chronic conditions, both of which may only partially meet the needs of people with multiple chronic conditions.

The second driver is the need to contain the growth of public spending in many European states. The economic crisis in 2008 exposed the vulnerability of government spending on public services and the impact of rising demand for health care while health budgets stagnate or decline (Thomson and others, 2014).

This difficult economic environment has meant that the search for better care for people with chronic conditions is often framed as a key mechanism to contain, and perhaps even reverse, the growth of health care spending, particularly on hospital and emergency services. Many countries have focused on identifying the characteristics of 'super-users' of health services, on the assumption that the large costs that they incur are disproportionate and can be reduced by modifying aspects of current health systems through a range of strategies, such as the better use of information technology, the skills and range of health and care staff and facilities (Nolte and others, 2008; 2014).

There is now a renewed focus on sharing learning within and between countries in Europe. Examples of projects include:

- ‘Innovating Care for People with Multiple Chronic Conditions in Europe’ (ICARE4EU; see www.icare4eu.org/)
- ‘Developing and validating DISease Management EVALuation methods for European health care systems’ (DISMEVAL; see www.dismeval.eu/)
- ‘Benchmarking Integrated Care for Better Management of Chronic and Age-related Conditions in Europe’ (Project INTEGRATE; see <http://projectintegrate.eu/>).

Policy-makers in Europe are all too aware that they must enable the creation of new models of care, drawing on the best available evidence in order to make the most effective use of scarce resources.

2. Aim and methods

Aim

This paper has two aims: first, to examine literature reviews describing interventions managing patients with complex, costly conditions. We focus on strategies addressing so-called ‘super-users’ as part of system transformation in various European countries, to identify the target populations, measures, successful building blocks and outcomes.

Second, drawing on the insights from the literature reviews, we aim to highlight what can be learned from the current efforts to reform services in Europe, and provide some reflections in relation to:

- identifying target populations
- the essential building blocks of services to meet the needs of these populations
- what needs to be done to ensure successful implementation of strategies
- how success can be measured
- identifying gaps in information.

Methods

We used a modified integrative literature review technique in order to generate new knowledge through the synthesis of existing information (Whittemore and Knaf, 2005). Details of our approach are contained in Appendix A.

3. Results

Included studies and their characteristics

Our initial search resulted in 123 reviews of which nine met our inclusion criteria. The included reviews varied from a narrative review (Allen and others, 2013) and systematic reviews (Allen and others, 2014; Bakker and others, 2011; Smith and others, 2007; 2012a; 2012b), to systematic reviews with meta-analysis (Leppin and others, 2014; Tricco and others, 2014; Verhaegh and others, 2014).

Table A1 in Appendix B shows that the number of studies included in the reviews ranged from 10 to 42, while five reviews included 20 studies or fewer. Studies included in all the reviews together were performed in 22 different countries, including 13 European countries. In all but one review, most studies included were performed in the United States, while Australia and the UK were represented by at least one study in most reviews. Reviews either looked at studies with a randomised controlled trial (RCT) design only or allowed other designs. The total number of people participating in the studies included in the reviews ranged from 1,882 (Allen and others, 2013) to 17,283 (Leppin and others, 2014); only one review reported a total number of participants over 10,000 (Leppin and others, 2014).

Most of the reviewed interventions were tested in experimental settings and not implemented on a larger scale. The maximum length of the studies was about two years only and, as a result, no long-term outcomes (impacts) of the interventions were reported. The range of outcomes reported in the reviews varied from narrow (readmission rates), to broad (patient-related outcomes, utilisation and costs) to system-wide (quality, enabling contextual factors and constraints) outcomes (see Appendix B, Table A1).

Findings from the interventions or models

Although there was considerable variation in the types of interventions or models reviewed, the studies fell into three broad categories:

- studies on improving care for complex patients while in hospital (Bakker and others, 2011)
- studies of interventions designed to improve the transition for complex patients between hospital and other settings in order to reduce readmissions (Allen and others, 2013; 2014; Leppin and others, 2014; Verhaegh and others, 2014)
- studies of interventions designed to improve the care of complex patients in primary care and community settings (Smith and others, 2007; 2012a; 2012b; Tricco and others, 2014).

Table A2 in Appendix B gives the key findings and policy and research recommendations from each of the nine reviews.

Better care for complex patients in hospital

Bakker and others (2011) reviewed 20 studies of hospital-wide interventions (all RCTs or controlled clinical trials) designed to improve care for frail older inpatients. They found that there was no single best evidence-based practice for improving quality, safety or effectiveness. However, they found that some form of ‘geriatric consultation team’ was partially effective in improving some patient outcomes – including length of stay, mortality and mental/physical functioning – compared with control groups. Geriatric consultation teams had slightly different configurations between interventions, but generally comprised:

- a geriatrician
- a geriatric nurse (specialist/coordinator/discharge planning)
- a social worker
- additional team members in some cases, including physical therapists, dietitians, occupational and speech therapists, clinical pharmacists, gero-psychiatrists and home health nurses.

Better care for complex patients in the transition from hospital to other settings

Reducing the risk of potentially avoidable readmissions after hospital discharge for complex patients has been a longstanding goal for many health systems. Verhaegh and others (2014) identified and reviewed 26 RCTs of interventions explicitly aiming to reduce readmissions over the short, medium and long term for chronically ill patients. They concluded that short-term readmissions were the toughest to reduce, but that ‘high-intensity’ interventions, initiated during the hospital stay, could significantly reduce these readmissions. These interventions included:

- a home visit within three days
- care coordination by a registered nurse or advanced practice registered nurse
- communication between the hospital and primary care provider.

These were also core components of the definition of high-quality ‘transitional care’ identified by Naylor and others (2011).

Allen and others (2014) reviewed transitional care interventions against a broader range of outcomes (beyond readmissions) and delivered by a broader range of practitioners, including general practitioners (GPs) and practice nurses, and by older people and their carers themselves. The results were very mixed. GP and practice nurse interventions did not seem to reduce re-hospitalisations or length of stay but did improve patient and carer satisfaction. The authors commented that few studies report on the involvement of older people and their carers in the design of interventions. This remains a gap in the research literature, given that patients and families are expected to manage increasingly complex conditions and health systems after discharge.

The theme of actively assessing patients’/carers’ capacity to manage self-care, and supporting them to do so, was picked up by Leppin and others (2014) in their review of the efficacy of interventions to reduce early hospital readmissions. From 42 trials they concluded that interventions are effective at reducing readmissions, but more effective interventions are likely to be more complex and support the patient’s capacity for self-care, by contacting the patient frequently and using home visits.

Finally, Allen and others (2013) reviewed 15 studies of multiprofessional communication between health and social care professionals within transitional care for older people. They found that improved multiprofessional communication reduces rates of readmission and length of stay for older people, promising greater cost-effectiveness and efficiency for the health system.

Better care for complex patients in primary care and community settings

For more 'upstream' interventions to improve outcomes for complex patients, the evidence is more inconclusive. A Cochrane Review of 'shared care' of chronically ill patients between primary and secondary providers found positive outcomes for improved prescribing only, while the impact on all other outcomes was 'mixed' (Smith and others, 2007).

A multifaceted set of interventions aimed at improving the care of people with more than one chronic condition (multimorbidity) was reviewed by Smith and others (2012b). These interventions included case management and better care coordination as well as improvements to specific issues such as medication adherence. The authors concluded that the complexity of the interventions made it difficult to disentangle the impact of specific components on outcomes, but that the targeting of specific problems for patients, such as difficulties with medication management, could yield benefits.

Tricco and others (2014) considered the effects of quality improvement interventions closely related to care coordination (as defined by the expanded chronic care model) as well as patient navigators and outreach activities. They found that the following reduced hospital admissions among patients with chronic conditions (except for those with mental illness) and reduced emergency department visits among older patients:

- team changes (for instance, changes to the primary care team and routine visits to personnel other than the physician)
- case management
- promotion of self-management
- patient education.

Given the variability in contexts, it is challenging to generalise findings. Nonetheless, it was found that the majority of reviews reported that positive outcomes and multifaceted or comprehensive interventions are associated with better outcomes.

Overall, various knowledge gaps were reported. There is an urgent need for:

- a standardised, validated set of outcome measures
- more robust studies
- an analysis of data on the cost-effectiveness of interventions (this was rarely studied in the interventions).

Several reviews stressed:

- the need for future studies to include information about how interventions are implemented
- the untapped potential of the engagement of older people and their caregivers.

4. Discussion

In this section we draw out some reflections for policy-makers from our review of reviews and our scan of additional literature sources.

Reflection 1: There are no specific ‘European’ answers to the problem of high cost/complexity, but a growing body of policy-relevant evidence is emerging

This integrative review has shown that there is no set of approaches to the care of complex, high-cost patients that can be described as specifically ‘European’. The evidence base that has been assembled in these reviews, which involved the highest possible quality (RCTs and their meta-analysis), has drawn on experience from a range of countries with very different health systems, including the United States, which was the most cited country in the included reviews.

Policy-makers in Europe who wish to draw on the most systematic evidence of what appears to ‘work’, such as the examples collated in the reviews, including Cochrane reviews, need to bear in mind that although the interventions may have yielded robust results against control groups, the studies may not have fully captured important contextual details relating to organisational or professional differences or details about implementation (Tricco and others, 2014). This means that there needs to be some caution about the ‘replicability’ of interventions that look successful from the evidence base.

Nevertheless, alongside the gold-standard evidence from the academic literature, European policy-makers have a growing body of evidence from several pan-EU projects to draw on, which have focused on capturing and evaluating good practice in real-world settings, informed by the literature on experimental designs (see Table 4.1). All of these projects have been designed to illuminate the complexities of implementation as well as isolate the individual components of interventions. Project INTEGRATE, for example, has chosen its four case studies on the basis of broad health system ‘types’: Spain and Sweden as examples of Beveridgean/national health systems and Germany and the Netherlands as examples of Bismarckian/mixed insurance models.

Table 4.1: Examples of European initiatives on chronic/complex care

	DISMEVAL	ICARE4EU	Project INTEGRATE
Focus	Study of chronic disease management in 'real-world', population-wide settings and improving evaluation methods	Identification of best practice in care for people with multiple chronic conditions	Identification of best practice in integrated care for people with diabetes, geriatric-related conditions, chronic obstructive pulmonary disease (COPD) and mental health problems
Scope	Evaluation of projects in 12 EU countries	30 European countries	Four countries plus examination of international evidence
Duration	2009–11	2013–16	2013– (ongoing)
Website/ resources	www.dismeval.eu	www.icare4eu.org	www.projectintegrate.eu

Improving the quality of evaluations has been another common goal. For example, DISMEVAL, which ran between 2009 and 2011, was funded by the European Commission to generate new research methods and strengthen the evidence base for policy-makers to improve chronic disease management (Nolte and others, 2014). Evaluation is discussed in more detail in reflections 9 and 10 below.

Reflection 2: Multifaceted interventions seem to work best for complex problems

One of the common findings from our integrative review was that interventions targeted at complex patients achieve more of their goals if they are multifaceted, for example combining a range of professionally focused changes (such as specialist geriatricians or case management) with patient/carer-focused interventions (such as better information or self-management).

Part of the explanation for this may lie in the very heterogeneous nature of the needs that arise from complex co-morbidities. Recent studies have described the rapidly evolving scale of multimorbidity in populations. For example, Barnett and others in Scotland have shown that most people with any chronic condition are likely to have multiple chronic conditions (including younger and older people), but that multimorbidity increases with age. The majority of people aged over 75 have three or more conditions. Multimorbidity also occurs earlier in socioeconomically deprived communities (Barnett and others, 2012).

Globally, the development of clinical best practice for people with multimorbidity is in its infancy (Blozik and others, 2013; Goodman and others, 2014; Guthrie and others, 2012): the National Institute for Health and Care Excellence (NICE) is scheduled to publish its first set of guidance on multimorbidity in September 2016.¹ Until then, projects with the widest spectrum of activity need to be encouraged, especially those that have a population-wide focus, that can deliver targeted care to the 'super-users'

¹ See www.nice.org.uk/guidance/indevelopment/gid-cgwave0704.

but also act on preventing ill-health in the ‘still well’ population. An example of this approach is the *Gesundes Kinzigtal* programme in southern Germany (see Box 4.1).

Box 4.1: The *Gesundes Kinzigtal* programme – an example of a multifaceted, population-focused intervention

This programme was founded in 2005 by a group of physicians, and two insurance companies, who agreed to a cost-sharing arrangement. Physicians of patients with multimorbidity are given specialist (geriatric and pharmacist) input to manage the medications of their multimorbid and elderly patients six times a year and exchange information and data with their peers to compare case management and prescription approaches. The programme is also implementing a self-management training programme specifically aimed at multimorbid patients. Alongside this, *Gesundes Kinzigtal* also runs a wide range of health promotion activities. Matched control evaluation has found savings of 16 per cent per person, derived from lower hospital, pharmaceutical and care costs, and an increase in life expectancy of 1.5 per cent compared with matched controls in the same region.

Source: Struckmann and others (no date)

Reflection 3: Identifying who is at risk of complexity is a crucial first step

Targeting interventions at the right cohort of patients is recognised as a crucial step in improving outcomes for complex conditions (Tricco and others, 2014). Interventions that are focused on inpatients, or those about to be discharged, are conceptually and practically easier to design (the target group are identified by their presence as inpatients). But health systems worldwide have made increasing use of risk prediction models to identify patients in the community at risk of hospitalisation; Wallace and others (2014) identified 27 unique, validated models studied in the United States, Canada and Europe.

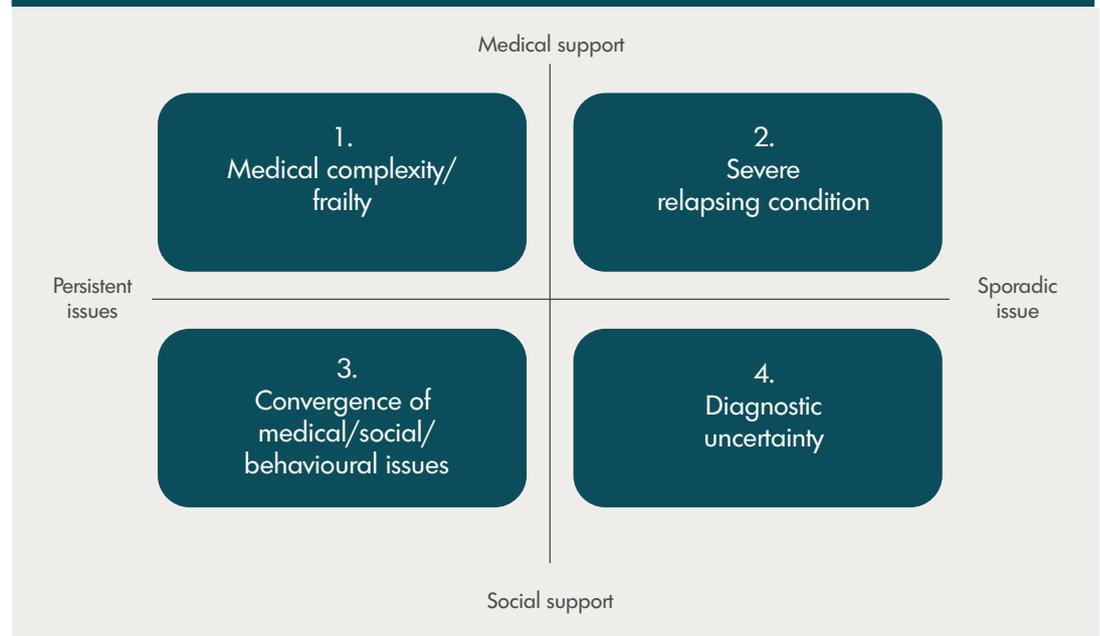
There are local examples of data analysis using similar concepts to understand the combination of factors that drive care costs in populations. For instance, the Symphony Project in Somerset (in South West England) analysed routine administrative data to describe the costs associated with conditions in the local population (Kasteridis and others, 2015). The study found that multimorbidity, not age, appeared to be the key driver of high care costs, with the highest costs concentrated among those with the most conditions rather than being associated with any specific conditions.

Reducing the costs associated with multimorbidity is a common policy goal, but the aspect that is least well understood is the role played by social, non-medical factors in raising individual risks. These factors are much less frequently incorporated into risk prediction models. Wallace and others (2014) found that only one-third of the risk prediction models included in their study attempted to incorporate non-medical factors.

Reflection 4: The needs of patients identified as ‘complex’ are likely to vary considerably

Some have argued that there needs to be an additional step beyond the identification of ‘at-risk’ complex patients to understand the type of complexity that they represent. Researchers in Canada (Vaillancourt and others, 2014) have proposed a set of ‘patient archetypes’ (see Figure 4.1) to better recognise and respond to the needs of complex patients, based on interviews and case note reviews of 142 patients who had visited the emergency department at least twice in the preceding six months. They argue that having a clearer understanding of patient characteristics is essential: patients in quadrant 3 of Figure 4.1, for example, need a broad range of services and a high level of support to build trust with providers. The researchers found that, in the absence of a clear understanding of needs, providers typically respond to complexity ‘by piling on more tests [or] intervening more aggressively’ (Vaillancourt and others, 2014, p. 40).

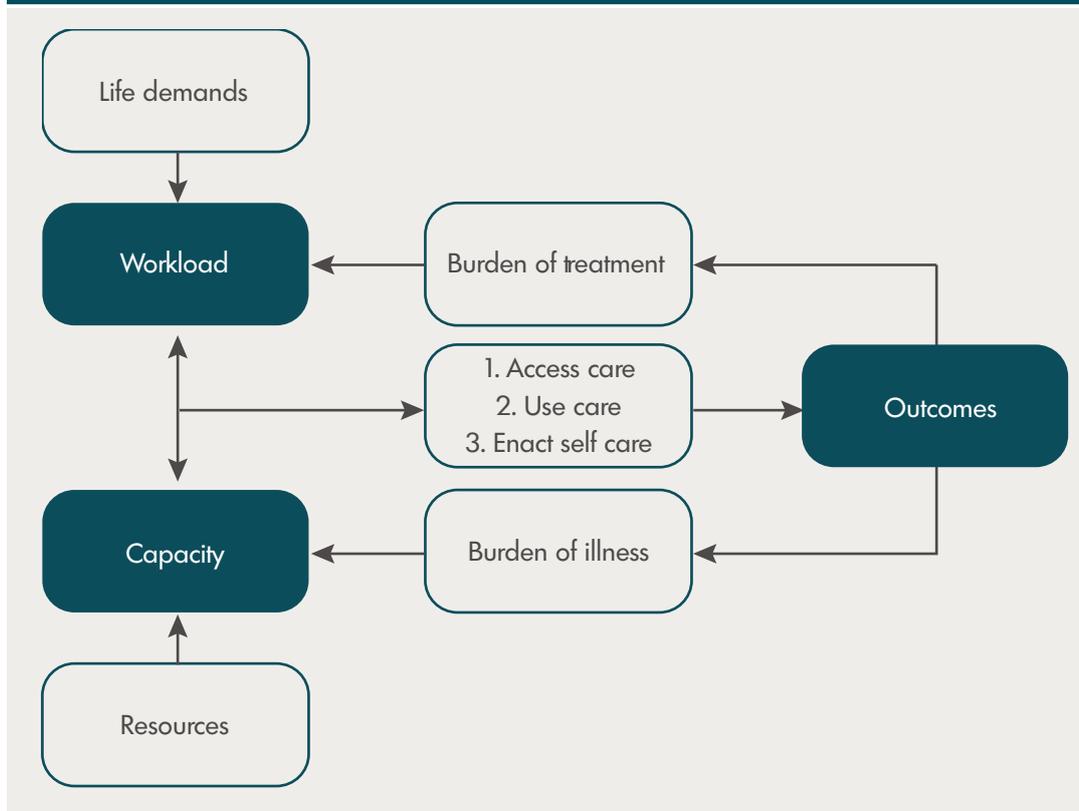
Figure 4.1: Archetypes of high users according to patterns and type of need



Source: adapted from Vaillancourt and others (2014)

A similar approach has been developed by Leppin and others (2014; 2015) in the United States, with their concept of the ‘work’ a patient with complex multimorbidity has to do in understanding and adhering to the medications and other demands of their illnesses. The outcomes of a patient with multiple illnesses depend not just on the nature of their illnesses, but also on their individual capacity and resources to manage both the demands of each illness and the demands of the treatment – the ‘burden of treatment’ (see Figure 4.2).

Figure 4.2: The 'cumulative complexity model' of the patient's ability to participate in treatments



Source: adapted from Leppin and others (2014)

Proponents of this approach believe that paying attention to understanding and responding to the 'treatment burden' is essential to delivering better outcomes for complex patients, and that it is best done by generalists in primary care (May and others, 2009).

A research team based in France has successfully developed and tested an instrument designed to measure treatment burden on a sample of patients in France (Tran and others, 2012). This explored patient perceptions of taking medications, managing appointments and the impact of illness on their social lives. Tools such as these are useful additions to the body of literature on health literacy (Martin and others, 2009), and could be valuable in the design of interventions and the development of clinical guidance for complex, multimorbid patients.

Reflection 5: Good outcomes for complex patients need to be rooted in patient preferences and are likely to include non-medical goals

As knowledge about the distribution of multimorbidity in populations increases and methods to identify those at risk of complexity arising from these conditions improve, there needs to be a parallel process of understanding what good 'outcomes' mean for the patients concerned. Smith and others (2012a; 2012b), in their review of interventions, found that for many complex, multimorbid patients, there might be competing outcomes or ones that are relevant across conditions, for example 'nutrition, living

situations, function, symptom burden, survival and average life expectancy' (Smith and others, 2012a, p. 13). They recommend that patients participating in setting their own priorities is the only 'rational and ethical' approach to such complexity.

There are examples of this approach in action in England: the creation of user-generated priorities or goals lies behind the 'Narrative' drawn up by National Voices, a coalition of patient groups, to underpin a common definition of integration (National Collaboration for Integrated Care and Support, 2013), Variants of the 'I' statements that are contained within the Narrative are in use in integrated care pilot sites. An example from Cornwall is given in Box 4.2.

Box 4.2: User-generated care goals – the example of a 'guided conversation' from Cornwall

The government is funding a number of innovative integrated care projects in England. One of them, based in Cornwall in South West England, sets user-oriented goals through a 'guided conversation' with users, covering aspects of their medical conditions, social circumstances and what their goals might be. Information is collected under the headings of:

- About me
- How I manage my health condition(s)
- My medications
- Things I'd like to change and what might prevent me or help me
- Goals

Goals can be social or non-medical. The project uses an illustrative example of an older man with health problems and anxiety who was unable to leave the house. Targeted support allowed him to once again walk his dog on the beach, which was one of his main goals.

The measurement of integrated care is still an evolving field, with many health systems adapting and combining measures used in single institutional or disease-specific settings (PIRU, 2014). In their overview study of care coordination measurement instruments, Schultz and others (2013) found very few measures that assess care coordination as coordination needs change. Most measures focus on aspects of communication, in particular the transfer of information. Other gaps identified were:

- measures of health care professionals' view of care coordination
- measures applicable to the home health setting
- measures for patients at the end of life (Schultz and others, 2013).

Reflection 6: Interventions may not reduce high costs, at least in the short term

Taking a user-based approach to setting outcomes in complex, multimorbid patients is potentially very challenging for health systems as it requires that the care system can effectively identify the nature of their complexity and deliver a potentially broad range of tailored services, which may include non-medical services and support.

Meeting these needs does not necessarily imply that complex patients will incur fewer costs on the health side: evaluations of complex interventions in England have found that the majority do not reduce emergency hospital admissions as expected and, in some cases result in higher admissions (Bardsley and others, 2013). This finding mirrors the review of coordinated care conducted by the Agency for Healthcare Research and Quality in the United States in 2007, which found:

- insufficient evidence of cost-effectiveness overall
- only one review (out of 43) showing evidence of cost-effectiveness in relation to coordination for patients with depression
- some examples of increased utilisation of services in the coordination intervention groups (McDonald and others, 2007).

More recently, Nolte and Pitchforth (2014) examined 19 systematic reviews on the economic impacts of integrated care. They also found that evidence of reduced utilisation of hospital services, cost-effectiveness and cost/expenditure reductions was weak, very mixed and difficult to interpret. They noted that many of the reviews were unable to consider costs beyond the health systems (such as the impact of unemployment or loss of income because of illness). They concluded by asking whether integrated care is an intervention that ought to be considered cost-effective at all, or ‘whether it is a complex strategy to innovate and implement long-lasting change in the way services in the health and social care sectors are being delivered and that involve multiple changes at multiple levels’ (Nolte and Pitchforth, 2014, p. 39).

The message for policy-makers is that there should be a greater degree of realism about the degree to which the ‘high-cost’ element of complex care can be reduced at a health system level and over what sort of time period.

Reflection 7: Chronic care models may not be fit for purpose for complex patients

Another possible explanation for the disappointing results of ‘integration’ initiatives that are designed to lessen reliance on the acute sector is that they focus attention on unmet need in patients. Mason and others (2014) reviewed the evidence for schemes that integrated the financing of health and social care providers with the aim of better meeting the needs of complex, ‘high-cost’ users and reducing the use of acute hospital care. They concluded that integrated schemes seldom led to improved health outcomes and none of them reduced hospital use in the long term. The authors suggested that better coordination may ‘reveal rather than resolve’ unmet need (Mason and others, 2014, p. v).

In the light of the emerging evidence on the scale and distribution of multimorbidity, and its interaction with social factors and individual patients’ varying capacity to manage the burden of their own complex illnesses, there may be a need to revisit and rethink aspects of the chronic care model itself, including the notion of what might or might not be an ‘avoidable’ admission to hospital.

In their review of self-management models for COPD (a chronic condition where the evidence for supported self-management is strong), Bourbeau and Saad (2012) reproduced the characteristics of the two models of care – the acute care approach and the chronic care approach (see Table 4.2) – that have underpinned many of the policies towards more integration.

Table 4.2: Characteristics of care approaches

	Acute care approach	Chronic care approach	Complex care approach?
Focus	Diagnostic, treatment of acute condition and symptoms	Health promotion, disease self-management	Elements of both?
Outcomes	Short term, reduction in symptoms	Long term, prevention of complications, quality of life	Elements of both?
Health professional	Control of patient, decision-maker	Facilitator, partner with patient	Dependent on context
Patient/family	Passive	Active	Dependent on patient/family capacity?

Source: adapted from Bourbeau and Saad (2012, p. 100)

Many health systems characterise their trajectories in similar terms, as shifting the focus from an acute approach – a short-term, professionally dominant model aimed at reducing symptoms – to a long-term, community-based approach characterised by partnership between service users and professionals. However, the logic of multimorbidity suggests that patients might need to access both systems at once, as individual conditions develop and worsen or improve at different rates.

This underlines the importance for policy-makers to ensure that health systems are in a position to collect the most complete data as possible on the full range of conditions that patients are experiencing when they access hospital and other forms of care, so that realistic goals of avoidable admissions for ambulatory care sensitive conditions can be set.

Reflection 8: Although highly relevant, the implications for the workforce are often neglected in research studies/new interventions

An important condition for managing patients with complex needs is an adequate workforce. Notwithstanding its relevance to policy-makers, it remains a misty area for many, as reported by Project INTEGRATE. This is an EU-funded project aiming to gain insights into the delivery of integrated care to support European care systems to respond to the challenges of ageing populations and the rise of people living with long-term chronic conditions (Busetto and others, 2015).

A review of the literature and additional expert interviews resulted in the identification of eight key workforce changes needed for the implementation of multifaceted interventions:

- multidisciplinary protocols/pathways
- multidisciplinary staff
- nurse involvement
- team meetings
- provider training

- new positions
- task redistribution
- a case manager/care coordinator.

The review found that barriers to the implementation of workforce changes were often rooted in unclear delineation of responsibilities. Health professionals' lack of knowledge, skills and expertise were frequently perceived as problematic. Moreover, a culture of mistrust, an unwillingness to share care and a preference for old routines hindered the implementation of workforce changes. Lastly, problematic communication tools and resistance to cooperation also hindered the implementation of workforce changes (Busetto and others, 2015).

Facilitators of change hinged on the enthusiasm and motivation of leaders, managers and staff, supported by adequate resources, and nurse-led care. A patient-centred approach to care and patients' own support, awareness and motivation were conducive to the workforce changes. Frequent communication via good communication channels, easy access to all relevant patient data and the possibility to share data with all health professionals (and sometimes patients) involved were also identified as enablers of workforce changes (Busetto and others, 2015).

Busetto and others (2015, p. 54) concluded that 'advancing knowledge in this area would help decision makers to design more appropriate integrated care interventions and foster health systems' capacity to cope with the challenges associated with the current demographic and epidemiologic trends'.

Part of the challenge in designing a workforce to meet the needs of complex patients may lie in the nature of the complexity itself. Intelligent use of the workforce in managing single-condition chronic illnesses may involve assigning the routine monitoring and health-coaching tasks to non-physicians while the patient is stable (Nolte and McKee, 2008). But as complexity grows, for example as people are diagnosed with new chronic illnesses as they age, the role of clinical judgement grows in importance, especially in the absence of clinical guidelines for multimorbidity.

This implies that care must be more than simply coordinated. It also needs to be directed by a clinician (or team of clinicians) with the authority to negotiate with the increasing array of specialists with whom the patient will come into contact and ensure that the patient receives the most appropriate care, in accordance with the patient's own preferences. This may be harder to achieve where there are imbalances in professional power, for example between generalist/primary care and secondary care specialists. It is likely that the design of interventions needs to take into account how the realities of professional and organisational culture and practice need to adapt in the face of this complexity.

Reflection 9: Designing an intervention starts by fully understanding the problem

In their landmark study of care coordination, McDonald and others (2007) examined theoretical frameworks that might help decision-makers (both system- and clinician-level) to better design and evaluate interventions to improve care coordination for patients. Their aim was to look behind the standard ingredients of integrated or coordinated care (for example, case management, self-management for patients or

care navigators) to understand the essential purpose and structures of interventions to improve care for complex and chronically ill patients.

Drawing on frameworks from behavioural science, organisational design and management sciences, McDonald and others (2007) proposed that all interventions need to encompass the following concepts:

- assessment of the needs for coordination by reviewing baseline characteristics for a given practice setting and patient population
- identification of the options for improving coordination by reviewing potential coordination mechanisms and considering their fit with the needs for coordination
- prioritisation and implementation of one or more of the alternatives
- evaluation to determine the effects of coordination and outcomes of care
- iteration if needed to test alternative solutions.

Those designing new models need to be able to answer questions relating to the behaviour and motivation of participants (including patients and carers) in all domains. So, for example, under the first point – assessment – there must be agreement on what the needs of a patient or population are, and what the nature and impact of the fragmented care that the intervention is trying to correct are.

As we have been arguing in this paper, the emerging evidence on the scale and distribution of complex multimorbidity, coupled with the absence of guidelines that encompass more than one condition and the variable nature of patients' preferences and capacity to manage, mean that there may well be confusion among those designing and implementing care coordination about goals and how to best measure them. Van Houdt and others (2013) have since contributed to the scope of theoretical frameworks, adding important concepts such as 'cultural factors' and 'information exchange', but the essential logic of McDonald and others' (2007) framework still stands: information exchange, for example, will not be sufficient to enable care coordination if there is a lack of clarity about how to act on the information.

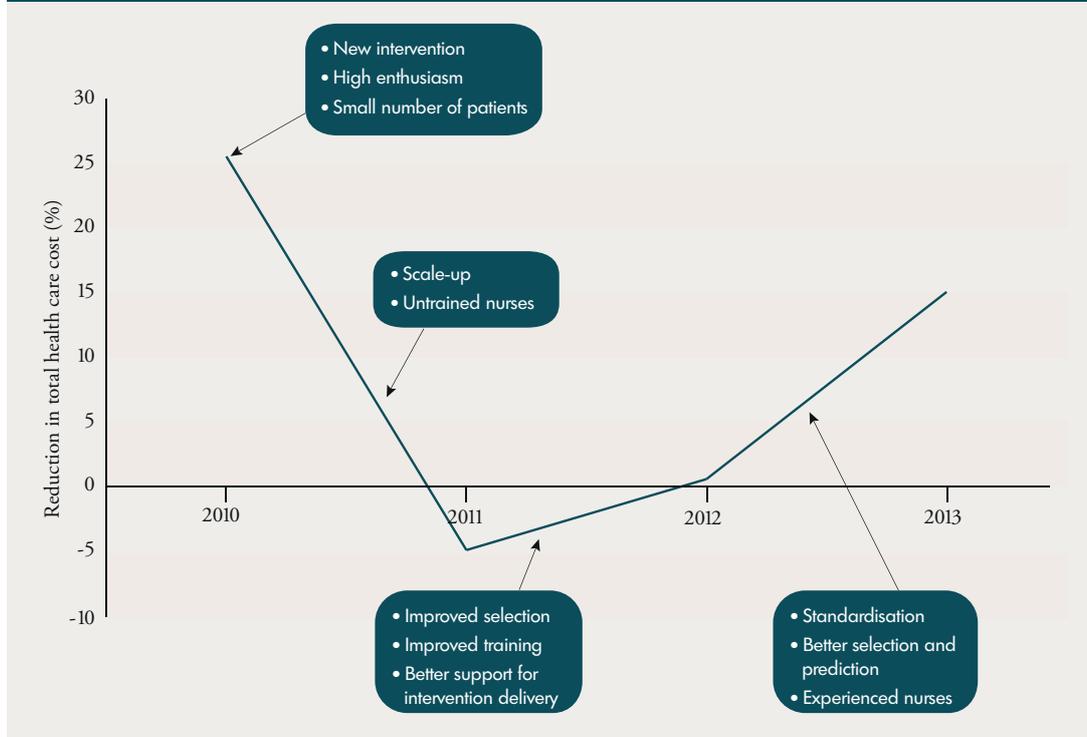
Reflection 10: Evidence of change needs to be given adequate time and robust evaluation

Many of the reviews drew attention to the absence of high-quality studies, which is partly rooted in the complexity of the interventions themselves, which makes randomised controlled designs difficult. The other limitation highlighted in the reviews was the short timespans over which projects were evaluated, often no more than two years.

An illustration of the risks of over-hasty evaluation can be seen in an example from Sweden of the effects of time and scaling up on the 'success' of a project by Health Navigator to reduce emergency readmissions (Reinius and others, 2013). The project, which involves using nurse 'navigators' to assist after discharge, is running over five years, working with 12,000 patients in five county councils. It is using a form of RCT. The initial high savings rate when the project was first piloted in 2010 by a small group of nurses was not sustained when the project was scaled up and extended by new members of staff. However, as can be seen from Figure 4.3, as familiarity with the project increased, the savings rate began to climb back towards the initial point in

2010. If the project had been evaluated over a shorter timeframe, between 2010 and 2012, it may well have been deemed a failure.

Figure 4.3: Effects of time on savings for the Health Navigator project, Stockholm, Sweden



Source: Dr Gustav Edgren, Karolinska Institute, Health Navigator Ltd, <http://healthnavigator.se/en/omoss/>

As well as having longer timescales, many evaluations need to take a broader focus, to include perspectives on implementation, and what needs to change at different levels of the health system in order to enable progress towards desired goals. The DISMEVAL study included this wider perspective: from their examination of 50 projects across 12 European countries, the authors observed that the institutional backdrop to new projects is important. They noted that many of the projects

'tend to be implemented within existing organisational and governance structures without necessarily overcoming existing structural or sectoral boundaries. Such approaches may still be effective in enhancing coordination, through, for example, the use of structured referral pathways, but structural barriers between sectors remain, potentially impeding further progress in advancing service delivery towards one better suited to meet complex chronic care needs.' (Nolte and others, 2014, p. 71)

Study limitations

This integrative review does not control for sources of bias as a systematic review would have done. We purposefully conducted an integrative review of independent reviews supplemented by other sources of relevant information. The relevance was judged by our professional expertise in the field of study. Our systematic search in PubMed and the Cochrane Library resulted in a selection of nine reviews. There were more reviews on the effectiveness and/or efficiency of interventions to manage patients with costly, complex conditions, but did not include results from studies performed in European countries, which were relatively underrepresented in our selection. Reasons for the small number of studies from European countries published during the year range we looked at – between 2005 and 2015 – could be that studies are ongoing and/or not (yet) published in scientific journals. By including additional information from different resources and synthesising all findings, we tried to overcome this information gap in the search for general reflections relevant to policy-makers in Europe.

We have not reported on the methodological quality of the reviews: a mismatch seems to exist between traditional appraisal criteria and the complexity of evaluating multifaceted interventions in real-life settings. To take this point one step further, study design alone is an inadequate marker of the quality of evidence in an evaluation of a complex intervention. The success or failure of the intervention itself should also be part of its appraisal (Rychetnik and others, 2002). However, the difficulty of such appraisal is that information about the implementation of the intervention often goes unreported in scientific publications.

5. Concluding thoughts

Health systems in all developed countries, including European countries, are encountering a rapidly evolving challenge to meet the needs of people with increasingly complex conditions, most often the product of multiple chronic illnesses. The clinical models of both acute care and single chronic disease management may be ill-equipped to respond to this challenge, as clinical guidelines, practice and the workforce have been developed from the experience of single conditions. Furthermore, our understanding of what ‘best practice’ might look like for people with complex, multiple conditions is still in its infancy.

The implications of the evidence reviewed in this paper suggest that health systems that can fully respond to the needs of complex patients might require a conceptual leap similar in magnitude to the efforts to articulate ‘chronic care’ compared with acute, episodic care in the 1980s and 1990s. New models are likely to involve blending elements of both acute and chronic care models, rather than assuming that health systems will shift away from acute towards chronic care archetypes.

New models will need to be:

- based on a much more sophisticated understanding of what patients (and carers) can manage in terms of their own treatment
- able to offer access to both medical and non-medical support
- rooted firmly, above all, in what patients have themselves expressed as their desired outcomes.

Based on these patient preferences, care will need to be intelligently coordinated by a clinician able to navigate, and on occasions override, the single-condition-derived best practice from specialist care.

It is far from clear to what extent these new models will reduce costs or generate savings. It might be necessary to decouple high expectations about reduced hospital use from these interventions while new knowledge is being generated, in order that they are not deemed failures too quickly. It will require sustained efforts from clinicians and researchers to improve the evidence base about:

- what good outcomes look like for people with complex, multimorbid conditions
- what the markers of quality look like
- what implications this has for professionals, providers and health systems.

In the meantime, the available evidence suggests that policy-makers should enable multifaceted interventions that pull together a range of health and non-health services. However, they should also be realistic about the impact on acute hospital use, in order that promising interventions (at least in terms of user wellbeing) are not abandoned if they do not reduce demand for hospital care within a short timeframe.

Appendix A: Methods

We used a modified integrative literature review technique in order to generate new knowledge through the synthesis of existing information (Whittemore and Knafl, 2005). The existing information was retrieved from reviews published in PubMed and the Cochrane Library between January 2005 and June 2015. We combined 'older', 'chronic', 'frail', 'multimorbidity' or 'hospitalization(s)' with 'complex AND delivery AND outcomes' or with 'complex AND delivery AND effectiveness'. Additionally, we combined 'older', 'chronic', 'frail' or 'multimorbidity' with 'transitional care AND outcomes' or with 'transitional care AND effectiveness'. The title and abstract of all papers were screened and only those addressing older patients with complex, costly conditions, reporting on studies performed in European and other countries and reporting on the outcomes of interventions targeting these 'super-users' were included in our final selection.

Appendix B: Details on the nine literature reviews examined for this discussion paper

Table A1: Characteristics of the nine literature reviews

Reference	Target intervention	Target people	Number of studies	Type(s) of studies*	Countries (number)	Number of people (group)	Measures (primary; other)
Verhaegh and others (2014)	Transitional care: bundle of discharge interventions initiated during hospital admission and continued after discharge through home visits or telephone follow-up for a minimum of one month	Chronically ill adults and patients at risk of poor outcomes after discharge and their informal caregivers	26	RCT	<ul style="list-style-type: none"> • United States (11) • Hong Kong (3) • Australia (2) • Canada (1) • China (1) • Germany (1) • Ireland (1) • Italy (1) • Spain (1) • Spain and Belgium (1) • Sweden (1) • Taiwan (1) • UK (1) 	7,932 (intervention group: 3,992; control group: 3,940)	<p>All-cause hospital readmission:</p> <ul style="list-style-type: none"> • Primary • Short term (30 days or less), intermediate term (31–180 days), long term (181–365 days) <p>Other</p> <ul style="list-style-type: none"> • Intensity of interventions • Patient's age • Patient's primary disease • Health care system • Date of publication • Total number of included patients

Smith and others (2012a; 2012b)	Interventions to improve outcomes for people with multimorbidity in primary care and community settings	Patients with multimorbidity in primary care and community settings	10	RCT	<ul style="list-style-type: none"> • United States (8) • Canada (1) • UK (1) 	3,407	<p>Primary</p> <ul style="list-style-type: none"> • Physical or mental health and psychosocial status <p>Other</p> <ul style="list-style-type: none"> • Patient and provider behaviour • Utilisation of health services • Acceptability of services • Costs
Allen and others (2014)	Transitional care involving discharge care in hospital and follow-up support in the home	People aged 60 or over living in their own homes	12	RCT	<ul style="list-style-type: none"> • United States (7) • Australia (3) • Denmark (1) • France (1) 	5,269	<p>Primary</p> <ul style="list-style-type: none"> • Effectiveness • Efficiency • Timeliness • Safety and risk • Equity • Person- and family-centred care
Bakker and others (2011)	Hospital-wide interventions, i.e. system interventions not restricted to medical specialties or departments and available for all hospitalised older patients	Patients aged 65 or older and admitted to the hospital	20	CCT, RCT	<ul style="list-style-type: none"> • Australia (1) • Canada (1) • Sweden (1) 	8,752 (intervention group: 4,379; control group: 4,373)	<p>Primary</p> <ul style="list-style-type: none"> • Patient-related outcomes • Quality of care • Patient safety • Resource use • Costs
Smith and others (2007)	Shared care interventions for chronic disease management	People or patients with specified chronic disease, primary care providers and specialty care providers	20	CBA, RCT	<ul style="list-style-type: none"> • UK (7) • United States (5) • New Zealand (3) • Australia (2) • Denmark (1) • Ireland (1) • Sweden (1) 	8,737	<p>Primary</p> <ul style="list-style-type: none"> • Patient outcomes • Process of care • Economic outcomes

Allen and others (2013)	Multi-professional team communication pathway to deliver transitional care across health and social care services	People aged 60 or older	15	Various	<ul style="list-style-type: none"> Australia (8) UK (3) Canada (1) Finland (1) Ireland (1) The Netherlands (1) 	1,882	<p>Primary</p> <ul style="list-style-type: none"> Outcomes <p>Other</p> <ul style="list-style-type: none"> Enabling and contextual factors Constraints
Leppin and others (2014)	Intervention to reduce early hospital admissions	Adult patients admitted from the community to an inpatient ward for at least 24 hours with a medical or surgical course	42	RCT	<ul style="list-style-type: none"> United States (23) Hong Kong (3) Australia (3) Sweden (2) Croatia (1) Denmark (1) England (1) Germany (1) Israel (1) New Zealand (1) Spain (1) Spain and Belgium (1) Switzerland (1) Taiwan (1) The Netherlands (1) 	17,283	<p>Primary</p> <ul style="list-style-type: none"> Relative risk of all-cause or unplanned readmission with or without out-of-hospital deaths at 30 days post-discharge
Tricco and others (2014)	Quality improvement strategies for care coordination for patients who are frequent users of the health care system	Adult patients (aged 18 or older) who are frequent users of the health care system	36	RCT	<ul style="list-style-type: none"> United States (22) Europe (8) Australia (2) Canada (2) Israel (1) South Africa (1) 	7,494	<p>Primary</p> <ul style="list-style-type: none"> Overall health care utilisations, including hospital admissions, emergency department visits, clinic visits and length of stay

* CBA = cost-benefit analysis, CCT = controlled clinical trial, RCT = randomised controlled trial.

Table A2: Key findings and policy and research recommendations from each of the nine literature reviews

Reference	Recommendations	
	Policy	Research
Verhaegh and others (2014)	<ul style="list-style-type: none"> • Transitional care is associated with an absolute risk reduction of 5 per cent in intermediate-term readmissions and 13 per cent in long-term readmissions. • Transitional care is not effective in reducing short-term readmissions, while subgroup analysis shows that only high-intensity interventions are associated with reduced short-term readmissions. • Transitional care is most effective among people older than 60 and those admitted to general internal medicine units. • A home visit within three days, care coordination by a nurse and communication between the hospital and primary care provider are components most often associated with reduced short-term readmission rates. 	<p>Future studies should focus on:</p> <ul style="list-style-type: none"> • bundled payments and shared savings from a systems perspective. • the effect of intermediate and long-term interventions on short-term outcomes • the development and testing of methods to measure the preventability of a readmission, to evaluate the effect of telehealth interventions, and to evaluate the cost-effectiveness of transitional care interventions.
Allen and others (2012a; 2012b)	<ul style="list-style-type: none"> • Interventions are multifaceted and either predominantly organisational (i.e. case management and coordination of care or enhanced multidisciplinary team work) or predominantly patient oriented. Overall, results are mixed with a trend towards improved prescribing and drug adherence. • Organisational interventions focusing on particular risk factors in co-morbid conditions or functional difficulties in morbidity may be more effective. • Patient-oriented interventions not linked to health care delivery seem less effective. 	<ul style="list-style-type: none"> • A set of generic outcome measures that incorporate physical functioning and quality of life and that are responsive to change over time needs to be developed. • Future research should ensure the applicability and successful integration of intervention into current delivery systems. • Studies must include clear definitions of multimorbidity.
Allen and others (2014)	<ul style="list-style-type: none"> • There is a need to clearly identify patients with multimorbidity and to develop cost-effective and specifically targeted interventions that can improve health outcomes. • A clear theoretical framework guiding interventions for multimorbidity needs to be developed. 	<ul style="list-style-type: none"> • There is a need for improved understanding and evidence about the quality of transitional care for older people and their carers in the domains of person- and family-centred care, equity and timeliness.
	<ul style="list-style-type: none"> • Gaps exist in the evidence base regarding the quality of transitional care for older people and their families and carers where quality is assessed in a holistic way. • Older people and their families should be involved in planning and decisions about their care. 	

<p>Bakker and others (2011)</p>	<ul style="list-style-type: none"> • No single, best, evidence-based practice can be identified. • Different forms of geriatric consultation teams are partly effective in improving patient-related outcomes and process quality measures. • Other forms show heterogeneous effects in different settings. 	<ul style="list-style-type: none"> • More experimentation with comprehensive interventions is urgently needed to improve care for all frail older patients throughout the hospital. 	<ul style="list-style-type: none"> • Future studies should focus on what works best in a specific hospital by using a stepwise procedure.
<p>Smith and others (2007)</p>	<ul style="list-style-type: none"> • Consistent evidence for the effectiveness of shared care is lacking. • Clear evidence of benefit is found for improved prescribing, medication adherence and use. 	<ul style="list-style-type: none"> • Consumer involvement in designing or introducing shared care services is very limited. • Questions remain regarding the effectiveness of shared care. • Genuine involvement of all sectors needs to be secured. • Limited use is made of the potential of information technology. 	<ul style="list-style-type: none"> • There is a need for more sophisticated economic analysis in this area. • Future studies should incorporate qualitative evaluations and a consideration of treatment fidelity. • Future studies need to be longer than two years in duration.
<p>Allen and others (2013)</p>	<ul style="list-style-type: none"> • Specified discharge worker roles, multiprofessional care coordination teams and information technology systems provide better service satisfaction and subjective quality of life for older people. • Improved multiprofessional communication reduces rates of readmission and length of stay for older people, indicating greater efficiency for the health system. • Systems of care emphasising information exchange, education and negotiation between stakeholders facilitate communication in transitional care contexts. 	<ul style="list-style-type: none"> • Enhanced multiprofessional communication, transitional pathways and role clarity are required to improve the quality, sustainability and responsiveness of aged care into the future. 	<p>Future studies should focus on:</p> <ul style="list-style-type: none"> • the investigation of pathways promoting person-centred care planning, including the older person, family and relevant practitioners • the development of interventions aimed at marginalised and socially disadvantaged older people with indicators of equity and access • the investigation of changing roles for practitioners in multiprofessional teams with a focus on community-based teams, including nurses specialising in aged care and general practice.
<p>Leppin and others (2014)</p>	<ul style="list-style-type: none"> • Interventions included one to seven unique activities, with case management, patient education, home visit support and self-management being commonly present. • Interventions reduce the relative risk of readmissions within 30 days. • Effective interventions are more complex and seek to enhance patient capacity. 	<ul style="list-style-type: none"> • Future work may benefit from consideration of the demands that health care interventions place on recently discharged patients and their caregivers and the extent to which these demands are offset by comprehensive support for implementation. 	<ul style="list-style-type: none"> • More recently tested interventions were less effective and future research is needed to determine the implications of this finding.
<p>Tricco and others (2014)</p>	<ul style="list-style-type: none"> • Quality improvement strategies focused on the coordination of care reduce hospital admissions among patients with chronic conditions other than mental illness and reduce emergency department visits among older patients. • Team changes, case management, self-management and patient education have a significant effect on reducing hospital admissions. 	<ul style="list-style-type: none"> • Quality improvement strategies targeting patients (as opposed to clinicians) might be an efficient use of resources. • Novel strategies are required for patients with mental health conditions. 	<ul style="list-style-type: none"> • Further research is needed to determine how to optimise care coordination strategies for specific patient subgroups and settings and how to evaluate them.

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About the authors

Hubertus J.M. Vrijhoef is Professor at the School of Public Health, National University of Singapore, and the National University Health System, Singapore; Senior Principal Investigator at the Department of Patient and Care, Maastricht University Medical Center, the Netherlands; and Guest Professor at the Department of Family Medicine and Chronic Care, Free University of Brussels, Belgium. He was a 2008–09 Harkness Fellow, based at MacColl Center for Health Care Innovation, Group Health Research Institute, where he researched the concept of fragmentation of chronic care. Bert has an MSc in Health, Policy and management from Erasmus University and a PhD in Medical Sociology from Maastricht University.

Ruth Thorlby is Deputy Director of Policy at the Nuffield Trust. Her research interests include NHS reform, GP commissioning, accountability, international comparisons and health inequalities. Before joining the Trust she was a senior fellow at The King's Fund, where her publications included two major reviews of NHS performance as well as a range of briefing and research papers. She was a 2008–09 Harkness Fellow, based at Harvard Medical School, where she researched how physicians and health care organisations in the United States understood and tackled racial inequalities in the quality of health services. Ruth has an MSc in Social Policy from the London School of Economics. Before moving into health policy research, Ruth was a broadcast journalist, working for BBC World Service and BBC News and Current Affairs, including *Panorama*.

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59 New Cavendish Street
London W1G 7LP
Telephone: 020 7631 8450
Facsimile: 020 7631 8451
Email: info@nuffieldtrust.org.uk

 www.nuffieldtrust.org.uk