

Evidence:

Do changes to patient-provider relationships improve quality and save money?

A review of evidence about value improvements made by changing communication, collaboration and support for self-care

Dr John Øvretveit

June 2012



Identify Innovate Demonstrate Encourage

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Health Foundation commentary

This review of the evidence about how involving patients more in their care can improve quality and save costs is timely: the NHS in England is grappling with the twin challenges of implementing the Health and Social Care Act 2012 and the financial constraints on health service budgets that looks set to continue well beyond 2015. The Act has at its heart new duties for the health service to fully involve patients in decisions about their treatment and care. In seeking to implement this, managers and clinicians will also need to understand the possible impact on the costs of care as well as the benefits of delivering services differently. It is therefore critical that there is more understanding of the likely costs and benefits that may result from the implementation of policies to advance approaches such as shared decision making and self management support.

The Health Foundation wants to understand better whether changes which aim to improve quality can also achieve better value. This is the third evidence review in a series which has specifically sought out information on the costs and benefits of initiatives to improve services. The first two reviews were also carried out by Dr John Øvretveit. *Does improving quality save money?* considered very broadly approaches to improving safety, reducing waste and improving patient experience and the extent to which there was evidence that these save costs. The report was influential in highlighting the lack of such evidence and stimulating debate on the need for more research into the costs and value of improvement interventions at a time of reduced budgets and increasing demand on health services.

Does clinical coordination improve quality and save money? looked more specifically at changes to the organisation of patient care which can improve continuity of care and also increase value of care by reducing waste and duplication.

We are also committed to a programme of work concerned with changing the relationships between healthcare providers and patients, as we believe that this is vital to ensuring a better experience of using healthcare services and better outcomes: it is surely better to spend money on services that patients value than it is to spend money on services that they don't want, don't use or use ineffectively. We were therefore pleased to support the third review in this series; to examine the extent to which the published evidence on a wide range of approaches to changing patient-provider relationships supports the assertion that these approaches can both improve quality and save money. This review therefore also complements our other reviews of evidence in this field: *Helping people help themselves*, looking at the evidence for the effectiveness of self-management support, and *Helping people share decision making*, examining the evidence for shared decision making in improving people's experience of care.

The findings report on a field of scientific knowledge about patient-provider relationships and support for self care which is in its early stages, with a preponderance of conceptual literature over empirical studies. Although there is a growing body of literature about patient-provider relations, little of it has studied the impact on costs. Even where

costs are considered, these are often limited to the immediate intervention cost, rather than any assessment of return on investment in relation to the longer term costs of care. Nevertheless there are empirical studies which do provide evidence about how poor communication and lack of information impact adversely on patient care and also provide some evidence of effective interventions to improve communication and care.

The Health Foundation has published a number of reviews of the evidence about the effects of changing the relationships between patients and service providers, through improved communication and collaborative approaches such as shared decision making and supported self-management. The emerging picture is one that emphasises the importance of such interventions being considered as part of re-design to care pathways and changing models of clinical practice rather than as 'add-ons' to current models of care.

As with previous work in this series, a major finding is of the lack of research which has considered the cost implications of implementing interventions that aim to change the relationship. The review gives a clear message for researchers on the need to look further into how poor communication and inequitable relationships between patients and healthcare professionals add to the costs of healthcare provision. Research is needed which provides greater specificity in the descriptions of the interventions being studied, the underpinning logic models and how changes in the relationship improves quality and impacts upon costs. This needs to consider the different stakeholders and account for those costs over time, in particular, considering how effective implementation of an intervention links to the later experience and outcomes of a patient's care.

The report highlights where there are gaps in the evidence and where new research could provide valuable knowledge that could help decision-makers and practitioners to make evidence-based decisions about interventions which have the most likelihood of improving quality and saving costs.

We cannot make change without considering the resource implications. This message is particularly relevant at a time when UK healthcare and others are facing significant constraints on finance. The challenge is to prioritise the use of resources to provide high value healthcare. This is particularly relevant at a time when many providers and patient groups are exploring ways to enable patients to be more independent and take a greater part in their own care.

The Health Foundation will use the findings of this review to inform our thinking about future research into the benefits, effectiveness and cost effectiveness of approaches to changing relationships between patients and providers.

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Preface

Patients often experience relationships with nurses, doctors and providers that are more typical of the last century, and sometimes of the one before. Professionals and healthcare organisations have not changed as fast as other industries in the way they relate to patients. As a patient, I sometimes think this is a good thing, as not all changes in banks, travel and other services have been for the good. But in health services, many patients find the way their providers relate to them is frustrating, sometimes demeaning, and occasionally harmful to their health. This is not what most providers want. But many find their work situation prevents them from relating to patients in ways that would benefit the patient more. Some do not have the skills, and a few do not know they do not have the skills.

Research shows widespread problems in communication, collaboration and lack of support for self-care. Research also shows there are effective changes that can be made, but knowing which changes to make is only part of the solution. Giving more time for patient questions or education often means seeing fewer patients, even if it saves time in the long run. A change will need time and resources to carry out – will the new way take up more time and resources than we use at present? What stands between the knowing, and making a real difference for patients, is belief in the value of the change and our ability to make the change, and then working to implement the change.

This is why this report considers the cost of making the change and the costs of the new way of working. It compares these two costs with the cost of sub-optimal relationships at present – both the resources wasted and the needless suffering caused to patients.

We cannot afford to ignore the relationship between quality and costs. To do so leaves quality improvement as an enthusiast movement rather than an integral part of professional and organisational practice. The work of improving quality consumes resources. These resources could be used in other ways that may be more effective for patients. It is both an ethical and a business imperative to consider how much time and money a quality improvement costs and the consequences of using health resources in this way rather than another. This review advocates looking at whether quality really does improve, but also at whether resources are used more efficiently as a result of the improvement, and at the cost of the change.

This report is part of a programme of research which asserts that more progress will be made if we consider both the resource and the quality implications of proposed improvements. Bringing quality and resources together makes a unity of purpose more likely, which is necessary for the type of changes being considered here; changes in relationships which are central to our working and life experiences.

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Chapter 1

Summary

Do any of these new ways of working use fewer resources? Are any better for patients? Does the cost of change pay for itself?

A separate executive summary to this report gives the main findings and practical implications (Øvretveit 2012a).

Two research reviews: *Does clinical coordination improve quality and save money?* (Øvretveit 2011a) and *Does improving quality save money?* (Øvretveit 2009) found evidence of adverse events and quality problems for patients that were caused wholly or partly by incomplete communication and collaboration between caregivers and patients. They also found research into interventions to change the way providers relate to patients and support self-care. There was some evidence suggesting improved outcomes and cost savings were possible, from some interventions, but these previous research reviews could not examine this subject in detail. Consequently, a review of research specifically into this subject was undertaken, and this report presents findings from that review.

1.1 Problems

The report first presents evidence of the suffering and costs associated with sub-optimal communication and collaboration between health professionals and patients, and sub-optimal support for self-care. The review found there was evidence of negative health consequences for patients when health professionals failed sufficiently to consider patients' preferences and lifestyle and also when they did not agree assessment and treatment plans in a collaborative way. Additionally, there is

research that shows that many patients and their carers feel unsupported in their efforts to take care of their health conditions, and that there is a high cost to the health system of failure to provide adequate support for self-care. Research also shows factors outside the health system that affect people's ability to care for their health conditions.

1.2 Solutions

The research also provides some evidence of solutions. These are interventions and changes to promote patient–professional communication and collaboration to bring about a more active role for patients and to support self-care. There is little high-quality evidence of the effectiveness of different interventions and even less evidence of the costs and possible savings to different parties. This does not mean that some interventions might not improve quality and save money. It means only that there is uncertainty about their effectiveness, if traditional systematic review standards of evidence of effectiveness are used to judge the strength of evidence. The review was able to give useful information about changes that are likely to improve quality and reduce provider costs, and these are listed in this report and summarised in *Summary of 'Do changes to patient–provider relationships improve quality and save money?* (Øvretveit 2012a).

1.3 Value improvements giving savings

The method for estimating possible value improvement savings or 'quality and cost return on investment' (Q+C ROI) for a health system is described in the report, together with the limitations of such assessments.

Whether interventions are effective and save money depends on:

- targeting the patients most likely to be helped,
- implementing the intervention effectively,
- factoring in the provider and patient environments that help and hinder the intervention.

This review proposes that changes that both save money and improve outcomes are more likely to gain the widespread support needed to work through the challenges of implementation.

Chapter 2

Summary of the eight practical findings

Which changes to patient–provider relationships improve quality and save money?

1. Some changes do, some do not, and none will do so everywhere, with every patient.
2. Making a change to save resources will not always save money for a provider. Saved provider time cannot always be used to generate more income. Saving patient visits may even reduce income for a provider, depending on how providers are paid. Also, although a change may lower the running costs of a service, the cost to make the change may not be ‘paid back’ by the lower running costs.
3. For a health system, saving resources in one provider may lead to using disproportionately more resources in another. Whether the health system saves money depends on how costs and savings can be balanced across the system. It also depends on whether and when the change is paid back by lower running costs overall.
4. Whether a change saves money depends on who pays for the change, the financing system, which time span we consider and the implementation capability of the provider or health system.
5. Specific changes with the categories noted below are ‘likely’ to reduce waste and suffering for most patients if they are well implemented and a health system perspective is taken.
 - Some aids to help patients choose between treatments or not to use a treatment.
 - Simplifying medication dosing regimens.
 - Interventions to enable patients and providers to check the accuracy of their prescribed medication together when moving from one provider or unit to another.
6. Specific changes of the type listed below will ‘possibly’ reduce waste and suffering for certain patients, if a health system perspective is taken.
 - ‘Calendar packaging’, ideally with education and reminder strategies, to improve medication adherence.
 - Mailed and telephone reminders to reduce non-attendance or to move non-attenders to the bottom of the waiting list.
 - Most types of self-care programmes for patients with chronic illnesses, but specifically patients with the highest risk of avoidable admission and with the desire and capacity for self-care.
 - Some types of self-care education for people with type 2 diabetes mellitus, asthma or osteoarthritis.
 - Post-hospital discharge self-care support programmes for older people with congestive heart failure, and self-management training and follow-up on request for patients with ulcerative colitis.
 - Peer-facilitated self-management education for patients with heart disease, lung disease, stroke or arthritis.

- Appropriate high-quality training for physicians in patient communication skills that use role-play, feedback and small group discussions.
 - Mobile phone text messaging to give reminders for attendance at scheduled healthcare appointments, to communicate results of medical investigations, and feedback on treatment success – especially for patients with chronic illnesses.
 - Appropriate interventions to enable patients from low-income ethnic minority groups to ask their doctors more and better questions and to recognise the importance of asking questions in decision making.
 - Visual feedback of medical imaging results for patients who smoke or who are at risk of UV-related skin cancer, or providing a DNA test to estimate patients' genetic predisposition to diseases such as heart disease or lung cancer.
 - Offering email access to physicians or specialist nurses to specific patients for specific purposes.
 - Internet-based patient sites established by the provider or the health system with patient access and ability to comment on personal health information (test results, problem summaries, medication lists and side effects).
 - Interventions to enable selected patients to use internet-based personal health record systems (PHRs) to create their own medical record and health diaries.
 - An intervention to improve physicians' communication skills and activate patients to participate in their care, for patients from low-income ethnic minority groups.
 - Allowing patients or relatives to call a hospital rapid response team in specific situations.
 - Patient/family and provider collaboration to give home-based care at the end of life.
 - Incentives for treatment compliance for low-income patients with tuberculosis.
 - 'Patient re-enforcement and reminding' for increasing adherence to lipid-lowering medications and/or simplification of the drug regimen.
 - Simple specific interventions to enable patients to speak up about known safety risks (for example, signs in rooms and staff wearing reminder buttons).
 - Patient/family-provider collaboration to provide palliative care as an alternative to other treatments which may not be wanted by the patient.
 - Advanced directives (ADs) or advanced care planning support programmes with independent regulated experts facilitating patients to prepare ADs.
 - Interventions to improve patient participation in health consultations that use patient-directed coaching, educational materials and feedback to providers of patient-reported outcome measures, or certain communication skills training.
 - Multiple-intervention self-care programmes for targeted patients, combined with interventions to change providers' attitudes and abilities to support the self-care programmes and supported by information technology services.
7. These changes are unlikely to improve quality and reduce costs.
- Offering patients email communication direct to their physician.
 - Educational interventions to providers in patient communication or collaboration skills that use only oral presentations with no opportunity to practice the skills and gain feedback.
 - Providing poorly selected safety recommendations to patients.
 - Training physicians in shared decision making, without other changes to the context of their practice.
 - One type of osteoarthritis self-management programme and some other self-care group education programmes for patients with different types of health conditions in the same education group.
8. The research knowledge for selecting value improvements is limited. It will take time for more research to consider cost issues. Meanwhile, it is possible to estimate the likely quality and cost return on investment of some interventions from the research which has been done.

Part 1: Introduction and methods

Chapter 3

Introduction

The question addressed by reference to research evidence is:

‘Can we improve quality and save money by changing the way we communicate and collaborate with patients, or by supporting self-care?’

Two previous research reviews found some evidence of adverse events and quality problems for patients that were caused wholly or partially by incomplete communication and collaboration between caregivers and patients (Øvretveit 2009, 2011a). These reviews also found research into interventions to change how providers relate to patients and to support self-care. There was some evidence to suggest that both improved outcomes and cost savings were possible from some interventions of this type, but these reviews were not able to examine this subject in detail. Consequently, a review of research specifically into this subject was undertaken and this report sets out findings from that review.

3.1 Four sub-questions

The review sought to answer the overall question through answering sub-questions that also form the structure for the findings section of this report:

1. Is there a problem? Is there any evidence of sub-optimal relationships?
2. What are the solutions? Which changes to improve relationships have been described in empirical research?
3. What is the evidence of relationship-changing interventions that improve quality and could save money, or which cost more than they save?

The review found some evidence, but not much strong evidence, that changes could improve quality and save resources. However, there is research that could help decision makers decide whether, or how, to make such changes. Thus, a fourth sub-question was added to make use of this research and help better informed decisions:

4. What does research suggest about which interventions are ‘likely to’, or ‘possibly may’, improve quality and save money and what is the evidence and theory supporting this?

To answer this last question, a method was developed for estimating, from available evidence, whether an intervention could be a value improvement if carried out in a local, routine healthcare setting. The method used to make this estimate is described later in the methods section and can be used by health personnel.

3.2 Limitations of the evidence

At the outset, it is important to state the two primary limitations to this review of research. First, the economic perspective is that of a healthcare provider system over three years. The three-year period was used because many of the interventions described initially cost money and time to be implemented, and any savings achieved will take time to repay implementation costs. The ‘healthcare provider system’ perspective is used because the type of changes considered (patient–provider communication, collaboration and support for self-care) result in different savings and costs for

different providers. A hospital spending time and money on educating patients to take care of their health condition will not save money if it is not paid to do so, but others will.

If the hospital is part of a provider system, then the system overall may save money. The review does not consider wider social costs and savings, or those for patients, their informal carers or other stakeholders.

A second limitation concerns the generalisability of the findings reported. Most of the evidence concerns interventions or changes carried out in one setting and often for one type of patient group. Whether the same intervention would produce the same outcomes elsewhere, or for other patients, is unknown.

Reviews and multi-centre studies may give more generalisable findings if the same intervention has been studied in different settings for different patients. The results that could be expected in our own service, with our patients, is uncertain, because we may not be able to implement the change in the same way as those in the research.

Other limitations are described in the methods and practical implications sections. The general point is that the research and the evidence can help practical improvements, but can be misleading if local decision makers do not recognise the limitations of the evidence and make their own assessments.

Chapter 4

Methods

The search aim was to find if there was evidence of:

1. Harm, dissatisfaction and/or wasted resources (or costs) attributable to sub-optimal patient-provider relations.
2. Improved quality and use of resources attributable to interventions or programmes to change patient-provider relations.

Given the objectives and the diverse literature on the subject, a management research review method was used to carry out a search and perform a timely synthesis of the many types of evidence. This used databases of published research, already completed evidence reviews, and the author's existing knowledge of research on the subject, in an iterative approach to combine different sources and types of evidence (Greenhalgh *et al* 2004; Greenhalgh and Peacock 2005; Øvretveit 2003, 2005a,b, 2009, 2010, 2011a,b).

The two parts of the review method were:

- Searching and organising the evidence to answer the questions.
- Estimating from available evidence the return on an investment from making a change which research suggests could improve quality and save resources.

4.1 Steps of the method

The steps were as follows:

1. Broad scan. Define the objectives and search terms for the review, find and note the literature on the subject.

2. Narrow the focus on previous reviews. Identify and select previous reviews, assess these for answers to the review questions.
3. Open up inclusion. Bring in high-quality individual studies in order to provide additional evidence to answer the review questions, noting the strength of evidence of the findings and assigning a grade score (see Figure 3: How was the evidence graded, on page 20).
4. Open inclusion more widely. Add other research (of acceptable evidence strength) to fill in the evidence for the questions, noting that the evidence at this level is weaker, and using a snowball approach to identify relevant studies (Greenhalgh and Peacock 2005).
5. Review and synthesise. Combine the evidence in order to answer the questions, noting the degree of certainty (through the grading system). Identify unanswered questions and priorities for research, and provide any recommendations that are supported by the evidence.
6. Make a Q+C ROI value improvement estimate to indicate the likely or possible quality and cost return on investment, if the intervention is carried out in a local, routine healthcare setting (this step is summarised later in this chapter).

Search, selection and abstraction

The first step was to define the concepts and search terms because these decide which research is to be included in the review (see Figure 1 on the following page).

Figure 1: Concepts

The definitions below were used to choose the terms for searching databases and to focus the review on the items in the review question:

- **Patient:** a person receiving healthcare diagnosis, treatment or other support from a healthcare provider to help them with a health problem. Another definition is ‘capable of waiting or persevering’.
- **Provider:** an individual receiving payment for services to a patient (typically a clinician), or healthcare service organisation providing care, diagnosis, treatment or health information (the review excluded studies of provider–carer relations).
- **Provider–patient relationships:** in terms of communication, collaboration and support for self-care. These represented the main ways provider–patient relations and roles had been conceptualised in research.
- **Healthcare illness services:** services for people who request help with an illness, mostly services providing diagnosis, treatment and information for self-care. This excludes public health promotion and preventative services before a patient perceives symptoms, although there is a grey area for patients assessed to be at risk of an illness.
- **Quality improvement:** an intervention or a change to patient–provider relations, or healthcare practice or services that result in better intermediate or final outcomes (as shown in changes to process quality indicators or outcome quality measures, such as patient satisfaction or clinical outcomes).
- **Healthcare system resources:** those considered in this review were: a) resources used to make and sustain the change in question; and b) the resources saved across the system (not to individual providers). Resources are often quantified in terms of provider time, visits, length of stay or in money value.
- **Cost:** the monetary value of resources consumed that could have been used in other ways, or the loss to a patient, using methods to help patients express their valuations.
- **Waste:** time or resources consumed that do not contribute to meeting a human need and could be used in other ways.
- **Value improvement:** a change to healthcare that results in: a) improved quality and less waste, and less use of resources; or b) improved quality using more resources but the higher quality is valued proportionately more relative to the extra resources used (‘it is worth the extra’). This review focuses on type a.
- **Quality and cost return on investment (Q+C ROI):** a value improvement intervention that provides a positive return on the investment in terms of higher quality and less waste that can be translated into lower costs. An intervention with a negative Q+C ROI is one where the intervention uses more resources to make and sustain the change than the resources saved by it and also results in lower quality.
- **Time span of Q+C ROI and time to pay-off:** how much time and money the health system saves or loses with a quality improvement, compared to the alternative, after one year, three years and five years.
- **Cost flow budget analysis:** analysis of annual spends and savings to each of the budgets involved in investing and benefiting from an improvement.

The concepts were those used in the review question:

- ‘changes’ (and ‘interventions’)
- ‘patient–provider relationships’
- ‘improve quality’
- ‘save money’.

The definitions informing the search and the review are shown in Figure 1. After step 1, the initial scan of studies about provider–patient relations, a decision was made to limit the review to those studies that provided evidence about communication, collaboration and self-care involving an individual patient and an individual or organisation providing a health service. This gives a more precise definition for the search and covers many of the studies in this subject area – but not all. Time and resource limitations prevented including provider–carer relations research in the review, and relations other than individual patient relations, such as patient advisory groups.

More specific concepts were needed to carry out the search of titles and abstracts in databases. The search terms used were different combinations of: patient, physician, nurse, clinician, provider, and relations, communication, collaboration and shared decision making.

A recent review of patient-centred care eliminated the need to include terms related to this concept. Terms that had already been searched were: self-management, self-care, self-efficacy, self-help, self-treatment, self-monitoring, home-monitoring, self-medication, support, social support, peer support, mutual support, self-management education, long-term conditions, chronic care, coping skills, behaviour change, care plans, patient-held records, home care, telemedicine and telecare (de Silva 2011).

Search terms used and databases to be searched were selected to identify reviews and primary studies that were relevant to the questions and capable of producing evidence reaching grade E4 or higher (see Figure 3). Searches were carried out as follows:

1. Reviews of research in the DARE database.
2. Health economics studies in the NHS economic evaluations database (few were found that provided costings).

3. Reviews and primary studies listed in the Cochrane Library, EPOC database, EMBASE, CINAHL PsycINFO, PubMed and the NLM gateway, for 1995 to July 2011.
4. The review also followed up references in some studies which referred to other research that had not been identified in the formal search, and looked for unpublished or early findings presented at conferences and in the ‘grey literature’.

The method used a staged approach to identify and filter the studies that would then be summarised and presented (step 1 to step 4). Studies were excluded if they were: non-empirical studies; below strength of evidence grade E4; not describing patient–provider communication, collaboration or support for self-care; judged as not providing sufficient certainty about outcomes of both higher quality and resource use.

Included studies were: systematic reviews and empirical studies of deficiencies in patient–provider communications, collaboration and support for self-care, and of interventions to make improvements in these aspects of the relationship with designs or evidence classified by this review as E4 and above. For the intervention studies, those that provided evidence about one or more of the following outcomes of interest were included.

1. Intermediate outcomes: patient or provider knowledge, skills, behaviour change, changes to care processes, and quality and safety process indicators; and for resources utilisation of services, medications or other consumables, and length of stay.
2. Patient end outcomes: patient satisfaction, clinical outcomes and other health and functional outcomes.
3. Quantifications of resources used to make the change: provider time, materials, money value costs.

4.2 Summary of search results

Five relevant systematic reviews of reviews were found, each including reviews or primary studies of different types of patient–provider relations. The most relevant and comprehensive in relation to patient–provider communication, collaboration and support for self-care were:

- Coulter A and Ellins J 2006 (updated and summarised in Picker 2011, and summarised in Coulter and Ellins 2007)
- de Silva D 2011
- Pearson ML *et al* 2007
- Challis D *et al* 2010
- Graffy J *et al* 2009.

Nine general overviews were found, which included summaries of some relevant studies, which were also used to find the primary studies:

- Bodenheimer T *et al* 2002
- Canadian Health Services Research Foundation (CHSRF) 2007
- Department of Health 2007
- Foot C and Maybin JO 2010
- Goodrich J and Cornwell J 2008
- Meyer J and Smith B 2008
- Robert Wood Johnson Foundation 2011
- SBU 2009
- Wallerstein N 2006.

Thirty one relevant specific Cochrane reviews were included as they provided relevant data about an aspect of communication, collaboration and support for self-care (for example, a review of research into patient-provider communications regarding medication adherence):

- Bailey JV *et al* 2010
- Bosch-Capblanch X *et al* 2010
- Brown HC and Smith HJ 2004
- Car J *et al* 2008
- Chan R and Webster J 2010
- de Jongh T *et al* 2008
- Deakin T *et al* 2005
- Duncan E *et al* 2010
- Effing T *et al* 2007
- Foster G *et al* 2007
- Gagnon M-P *et al* 2009
- Gravalin M *et al* 2007
- Gurol-Urganci I *et al* 2008
- Haynes R *et al* 2005

- Haynes RB 2008
- Henderson C and Laugharne R *et al* 1999
- Heneghan CJ *et al* 2006
- Hollands GJ *et al* 2010
- Johnson A *et al* 2003
- Kinnersley P *et al* 2007
- Lewin SA *et al* 2005
- Marteau TM *et al* 2010
- Monninkhof E *et al* 2003
- Murray E *et al* 2005
- Nicolson D *et al* 2009
- O'Connor PJ 2006
- Pitkethly M *et al* 2008
- Ranmal R *et al* 2008
- Ryan R *et al* 2011
- Schedlbauer A *et al* 2010
- Shepperd S *et al* 2011.

Twenty one non-Cochrane reviews of this type were included:

- Beck RS *et al* 2002
- Berkhof M *et al* 2011
- Claxton AJ *et al* 2001
- DiMatteo MR 2004
- George A and Rubin A 2003
- Giuffrida A and Torgerson D 1997
- Graffy J *et al* 2009
- Griffin SJ *et al* 2004
- Hall J *et al* 2010
- Haywood K *et al* 2006
- Heneghan CJ *et al* 2006
- Higginson IJ *et al* 2000
- Johansson K *et al* 2005
- Monninkhof E *et al* 2003
- Peat M *et al* 2010
- Richardson G *et al* 2005
- Schwappach DL 2010
- Stewart MA 1995

- Stevenson F *et al* 2004
- Wilson A and Childs S 2002
- Zedler BK *et al* 2011.

The reviews and the search were used to show which primary studies (for example, a single RCT study of training physicians in communication skills) might include evidence relevant to the review questions. Where reviews did not provide sufficient information, the primary studies were found and summarised in a table (n=47).

Studies were selected, graded and organised into tables and summarised, then the first draft outline was made with headings for answering the main questions.

A first full draft was written, drawing on the study summaries and tables to find evidence to answer the questions and to identify which papers would need more detailed analysis for possible evidence to answer them.

4.3 Assessing ‘strength of evidence’

The phrase ‘strength of evidence’ can mean different things. Decision makers need to be clear which meaning is being used so that they can assess whether the label ‘strong evidence’ means similar results are likely to be achieved in a local setting.

In this review it refers to the following criteria:

- how much the design excluded or assessed other factors, apart from communication, collaboration or support for self-care, that could have contributed to the data about problems, as well as,
- whether there are consistent findings across many studies.

Similarly, in the case of interventions, it refers to how much the design excluded or assessed other factors, apart from the intervention, that could have contributed to the data reported about outcomes and whether there are consistent findings across many studies.

Strong evidence does not guarantee that the same findings could be expected in a local setting, especially in another country, for a number of reasons which are considered later. In relation to

the two criteria used here, the design may have been carried out other than as described, or the studies may have been of services different to a decision maker’s local one, or involve different types of patients. Note that most studies are short term and few follow up results of interventions beyond 12 months. This is relevant to considering returns on investment over three years and interventions for chronic illness support.

Grading the evidence

A grading system was chosen, following the two criteria of consistent findings and design, that would give a simple indication of the degree of certainty of statements in this review about the size of the problems and the effects of interventions (see Figure 3, page 20). The grading was based on the type of research design and how many research studies have been carried out that gave similar results. The grading system was based on a combination of a modified GRADE evidence scale and a grading system used in earlier reviews of health management subjects (Øvretveit 2003b and by Greenhalgh *et al* 2004).

Figure 2: Definitions of ‘strong evidence’ (Øvretveit 2011a)

Different meanings of ‘strong evidence’: (Øvretveit 2011a)

- accuracy (that is, the data from measures were collected reliably, using valid measures),
- strength of effect in one study,
- strength of effect in a study where other explanations are excluded (for example, RCT),
- predominant aggregated effect from summation of many studies (for example, some with no effect, some with large effect),
- a consistent pattern of the same findings across many studies (which may or may not be in very different settings or for different populations).

The degree of certainty of the findings of a study was categorised as strong, moderate, limited and low strength of evidence (categories E1, E2, E3, E4). For findings about problems, this evidence rating

referred to how certain we can be that the problem reported (for example, patient dissatisfaction or adverse drug event) was caused in part or in whole by under-performance in communication, collaboration or support for self-care, rather than by something else. For findings about the effects of solutions, the grade refers to how certain we can be that these effects (for example, a change in provider behaviour, better treatment adherence or reduction in waste) are due in part or whole to the solution and not to something else. The assessment was made in terms of consistency of findings across studies and how well the research design was able to exclude influences other than the problem or the solution on the variables studied.

These findings were used as a basis for later estimating whether an intervention would result in a value improvement (higher quality and waste/cost reduction).

4.4 Value improvement saving estimation method

‘No strong evidence’ is a frequent conclusion from systematic reviews of research. This is especially so for reviews of evaluations of social interventions, but it need not and should not end there. Such conclusions do not mean the research that has been done, and the theories that do exist, cannot be used to inform action in routine healthcare.

The evidence from this review’s search did not allow definitive statements about changes that would result in a value improvement. However, the search findings could be used as a basis for estimating whether an intervention might result in a value improvement giving a higher quality and a waste/cost reduction (Q+C ROI).

What is a value improvement?

A value improvement is a change that improves quality and the use of resources. Not all value improvements save money. Some cost more but are judged to be worth it. Some new pharmaceuticals use more resources but the quality for the patient is significantly higher – that is, they have high cost-effectiveness.

This review considers one type of value improvement: one that improves or maintains quality but also saves resources – a ‘saving value improvement’. An example is training for clinicians to communicate with patients that results in less use of health resources and improved satisfaction and clinical outcomes, but where the cost of the training is paid for by the resources saved.

Another example is restricting or stopping the use of a treatment method or other activity that has proven ineffective for certain patients, where the savings are more than the cost of the disinvestment programme.

This review only lists those interventions estimated as likely or possibly giving a three-year Q+C ROI in an integrated health system – where the fourth and subsequent years would see savings. This perspective is taken, rather than that of an individual provider, because the resources expended by a provider may not be returned to that provider and another provider may make the savings. A health system perspective is taken assuming that the system can redistribute the costs and savings across providers. A three-year timescale is adopted because this is the minimum time to allow for the savings to start after ‘paying off’ the initial investment, but also the maximum time for many investors to see some return – usually the longer the timescale the more likely a ROI if the provider or health system has a stable patient population. Thus, the list in the findings would be shorter if a two- or one- year ROI was used and longer for a five-year ROI.

Time limited carrying out an annual cash flow budget analysis for different providers and for a health system overall, for those few interventions where cost data might have been available.

Figure 3: How was the evidence graded?

E1: Strong evidence

- Consistent findings of results in two or more high-quality RCTs (eg from a systematic review).
- This corresponds to the GRADE scale A: ‘Several high-quality studies with consistent results. Further research is very unlikely to change our confidence in the estimate of effect’ (Guyatt *et al* 2008).
- E1 does not refer to positive evidence of effectiveness but to the certainty of the findings, and could refer to high certainty that the intervention has no effect.

E2: Moderate evidence

- Consistent findings of results in two or more scientific studies of acceptable quality (eg from one RCT and other studies, or from two or more non-randomised controlled trials or from two or more before- after time series designs with no control).
- This corresponds to the GRADE scale B: ‘One high-quality study or several studies with some limitations. Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate’.

E3: Limited evidence

- Only one study giving results, or inconsistent findings of results of several studies. Studies reporting only informants’ perceptions of results are graded E3 if they were collected and analysed according to accepted scientific methods for gathering perception assessments, show a consistent pattern and use an appropriate design.
- Corresponds to GRADE scale C: ‘One high-quality study. Several studies with some limitations. Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate’.

E4: Very low strength of evidence

- Any estimate of effect is very uncertain. One or more studies with severe limitations or expert opinions using a standard consensus process.

The Q+C ROI value improvement estimation method

The method used to make saving value improvement estimates can also be used by health service personnel and was carried as follows.

Problems: waste and costs

1. For studies with evidence of problems, select those that quantify the problems.

Use these to estimate the possible waste or cost to a provider or health system (or other stakeholder), showing the basis for the estimate and the limitations. If possible, give a range estimate – that is, ‘unlikely that this would cost a provider less than ... or more than...’

Solutions: their cost, and likely savings (or loss)

2. For intervention studies, exclude those with inadequate evidence of quality improvements.

These are those for which evidence is not sufficiently strong, or there is strong evidence of no improvement, for intermediate outcomes such as patient experience/satisfaction and effective care practices/process, or for final outcomes.

3. Identify studies with acceptable evidence of quality improvement and also some evidence of resources or cost, and include and summarise these in the review. These are the studies presented in the ‘Findings 2’ of this report.

4 For studies with evidence of quality improvements only, identify whether they provide any data that would allow some estimate of the resources used for the intervention and/or resources saved (for example, number of emergency department visits, physician office visits, hospital days or lengths of stay, medications supplied, or other consumable or equipment costs). Then make an estimate of the extra time saved or spent at year one after starting the investment, and years three and five. These are the studies presented in the 'Findings 3' of this report.

Either simple or sophisticated estimates can be made. Simple estimates consider the likely cost of implementation and sustaining the change, compared with the likely savings which can be realised as cash in one or more budgets. These can and should be questioned by evidence. Sophisticated estimates use theories positing specific mechanisms linking interventions to final cost and quality outcomes.

Differences from cost-effectiveness and business case analysis

A Q+C ROI analysis is different to a business case analysis, but it can be a core part of such an analysis. A business case analysis starts from the strategic objectives of the organisation and its business plan, and then shows how an investment can contribute to this. A Q+C ROI estimate could be used to show how the intervention contributes to the business strategy, and how it represents a better use of resources than other potential investments.

If a treatment costs less than £30,000 and results in one year of perfect extra life, it is judged cost-effective for the NHS by the UK's National Institute for Health and Clinical Excellence (NICE); this use highlights one meaning of the term 'cost-effective'. It differs from the meaning of Q+C ROI – whether the cost of the intervention to a health system results in savings to the health system which pay for the cost within three years and at the same time give higher or equal quality on one or more quality outcomes.

To state this in more detail: cost-effectiveness analyses are of different types. The most well known are where effects are estimated in terms of quality adjusted life years (QALY). This means how many extra years in adjusted quality of life would be provided by the treatment: two years in perfect health is equal to four years of 0.5 level of health (where 0=death, 1=perfect health). NICE generally views one QALY to be worth £20,000-£30,000 (Schlander 2007), so a treatment resulting in one year of perfect life extra is worth the NHS paying up to £30,000 (Devlin and Parkin 2004).

Q+C ROI analyses are different from such cost-effectiveness as they do not value the outcomes in terms of quality of life years gained. They value outcomes in terms of: a) whether the quality of care is greater in some way, and b) a health provider or health system saves resources.

Then the question is whether the saving is greater than the cost of the intervention. Cost effectiveness estimates are usually more precise in their valuing of the quality of outcomes for the patient, but do not consider budget impact for a health system or provider in the same way.

Part 2: Findings

Chapter 5

Findings – overview of the subject

5.1 What research exists on this subject?

There is a significant amount of research outside healthcare that documents and evaluates how other service industries have changed their relationships with customers, especially through new technology (Christensen *et al* 2008). It is not possible to conclude from the evidence that healthcare lags behind other industries in changing customer relations. It is possible that in other industries there are influences driving faster innovation in customer relations and customer self-service. The survival and profit of most non-healthcare industries is perhaps more dependent on customer-provider communication, collaboration and self-service. Regarding the economics of quality and improvement research, other industries appear to give more attention to methods for calculating and evidence of return on investment, with the exception in the health sector of the pharmaceutical industry. The few health economic analyses that have been carried out on interventions to providers and to processes of care have limitations in their assessments of the cost of implementation.

Overall, this review found that the field of scientific knowledge about patient-provider relationships and support for self-care is in early stages, with many different but related and overlapping terms. Studies are published in many different journals, indexed in different databases and use a wide range of research methods. Some are designed to investigate either patient self-care, or communication, or collaboration as a primary subject. Some provide evidence of these aspects of care or patient experience as part of a larger study.

There is a preponderance of conceptual and advocacy literature over empirical studies. The former two explore different perspectives and ways of studying the subject, or emphasise the possible benefits of new relationships. The latter empirical studies seek to operationalise the concepts, and discover and provide evidence of the effects of different types of relationships and roles.

Some of the literature could be labelled as the ‘philosophy of patient participation’. This literature includes Illich’s medicalisation study and other critiques of how health professions, services and the state create dependencies and affect attitudes about responsibility for health (Illich 1976). It also includes consumerist and neo-liberal literature about patients’ rights. The increasing volume of literature about self-care may represent fundamental shifts in attitudes about patient and provider roles and relationships over the last 20 years, as well as the potential for saving healthcare resources, expenditure for patients and costs for employers.

Overall, this review found evidence of sub-optimal communication and evidence of some effective interventions to providers or to patients to improve communication. There is a small amount of evidence of cost-savings and waste reduction as a result of some interventions. This is similar for collaboration: evidence of problems and of some effective solution interventions, with a small amount of evidence of cost-savings and waste reduction. There is also evidence of sub-optimal support for patient self-care, and of cost-effective interventions to providers and patients to enable patients appropriately to do more to reduce health deterioration and to improve their health.

The initial hypothesis of the review was part supported by the research: that relations between patients and providers, and the communication and collaboration dimensions of this relationship, are important influences over whether a patient takes a more or less active role in caring for their health condition. However, the evidence shows that provider–patient relations are only one influence over whether this occurs. There is a growing body of empirical social science research that shows the importance of a patient’s social and financial environment to the role they take, as well as their personality and psychological characteristics. Evaluations of multi-component interventions to modify context factors that affect self-care are relatively recent and involve methodological challenges in attributing improvements to the interventions.

The range of studies examined for this review revealed many developments in this growing field. Most studies were not included because they did not provide the evidence that was sought, but some of the strands of research are noted here. Some research emphasises the importance of addressing barriers and facilitators that patients and providers experience when they seek to take a different role in care (Auslander *et al* 2010).

Related to this is a stream of research into the skills all providers may need to enable people to change, or whether a division of labour may emerge with self-help support being provided by a distinct occupation (Merelle *et al* 2010). Some research is examining ways to increase motivation for new roles and relationships and for behaviour change (Crowe *et al* 2010).

Much of this research also highlights the change in attitudes towards the professional role, the culture change that would be required in healthcare and the change in power between patients and providers, which is not necessarily a loss/gain or zero-sum change (Hibbard *et al* 2010; Blakeman *et al* 2010). One issue that would make interventions more complex is patients’ preferences and abilities, which appear to differ by person, type of illness and disease stage, which are affected by their educational and economic status and social environment, notably ethnic culture and religious affiliations.

Chapter 6

Findings 1 – problems

6.1 Sub-optimal communication

The evidence of sub-optimal communication found in the search and review is listed below. Only those types most likely to be associated with lower quality and avoidable waste are listed, and only studies of reasonably widespread problems, rather than the occasional instance, are cited.

‘What bothers doctors most is when patients say they’re following treatment and they’re not really doing it. Often, we’re just not being straightforward with each other.’

*Robert Arnold, MD,
Director of the University of Pittsburgh
Institute for Doctor–Patient
Communication (from Adams 2007)*

Problems in patient communication to provider

Table 1: Problems in patient communication to provider

Problem	Evidence
Patient demands judged by doctors as inappropriate	<p>40% of US doctors surveyed agreed that ‘patients often come with poor information from the internet’, in a 2006 US survey of primary care physicians (n=335) (Adams 2007).</p> <p>In the same survey, 78% agreed ‘patients occasionally ask to prescribe drugs they saw advertised on television’ 31% ‘patients often ask for unnecessary tests’, 28% ‘often ask for unnecessary prescriptions’ (Adams 2007).</p>
Patients withholding information necessary to the provider	<p>Some studies suggest that providers fail to provide a physical and time environment that allows effective patient–provider communication (Dugdale <i>et al</i> 1999).</p> <p>32% of US doctors surveyed agreed that patients ‘are often reluctant to discuss symptoms’ (Adams 2007).</p> <p>There is some evidence that some patients withhold information about not following treatment or about following other treatments. Some also consult other doctors or alternative therapy providers and carry out treatments they prescribe without telling their primary doctor (Adams 2007).</p>
Emails from patients	<p>59% of the US public agreed that ‘patients should be able to share information with their doctors electronically’; 74% of doctors agreed (margin of error $\pm 3.0\%$) (Markle 2011).</p> <p>62% of US patients with the ability to choose their doctor agreed with the statement that they are influenced in their choice by whether the doctor is contactable via email (Harris 2006).</p> <p>11% of UK and 20% of US patients agreed that they ‘can communicate with regular place of care by email’ in 2008 (Schoen <i>et al</i> 2008).</p> <p>Few service providers give email communication services, apart from internet services solely dedicated to providing this service. The literature shows many physicians concerned about ‘being overwhelmed by demands’ by emails, about potential malpractice liability, and about the loss of information and rapport which comes from more reliance on email communication with patients or replacement of consultation with emails (Markle 2011).</p>

Problems in provider communication to patient

Table 2: Problems in provider communication to patient

Problem	Evidence
Leaving hospital	<p>72% of UK patients and 87% of US patients agreed they ‘received clear instructions about symptoms to watch for and when to seek further care when leaving the hospital’, (n=1,500 UK; 2,500 US of ‘sicker patients’) (Schoen <i>et al</i> 2008).</p> <p>62% of UK and 89% of US patients agreed they ‘received written plan for care after discharge’ (of those hospitalised in the last two years) (Schoen <i>et al</i> 2008).</p> <p>80% of UK and 92% of US patients agreed they ‘know whom to contact for questions about condition or treatment’ (of those hospitalised in last two years) (Schoen <i>et al</i> 2008).</p> <p>33% of patients said they were not told about ‘danger signals to watch for after you went home’; 34% were not told ‘who to contact if you are worried’ about treatment or condition after leaving hospital (2009 survey of UK NHS patients attending different hospital outpatient clinics) (CQC 2009).</p> <p>35% of patients said they received copies of letters sent between hospital doctors and their GP in 2009 (CQC 2009).</p> <p>95% of patients at a UK ear, nose and throat surgery unit agreed that they wanted a copy of the letter that the specialist sent to their GP (Pothier <i>et al</i> 2007).</p>
Notification of test results	<p>33% of a sample of US physicians replied they do not notify patients about abnormal test results (Ghandi 2005).</p> <p>8% of UK and 16% of US patients agreed they ‘experienced delays in being notified about abnormal test results in the last two years’ (Schoen <i>et al</i> 2008).</p>
Medications	<p>39% of patients attending one UK hospital reported being informed about medication side effects (CQC 2009). The percentage across hospitals varied from 39% to 81%.</p> <p>48% of US patients reported not getting information about the side effects of drugs (Schoen <i>et al</i> 2005).</p> <p>41% of patients in a US survey, who received regular prescriptions, reported the physician had not reviewed their medications and had not explained side effects (Schoen 2004).</p> <p>One in three doctors failed to discuss side effects of prescribed drugs, and two thirds did not address costs of treatments and tests, according to US patients surveyed (n=39,000 in 2006) (in Adams 2007).</p> <p>In 65% of observed consultations, at least one critical piece of information was not provided to the patient (name of the medication, purpose of the medication, duration of treatment, dosing schedule and expected adverse effects of new medications) (Tarn <i>et al</i> 2006a).</p>
Asking questions, getting answers	<p>60% of UK and 74% of US patients agreed that ‘regular doctor always or often encouraged you to ask questions’ (Schoen <i>et al</i> 2008).</p> <p>24% reported leaving a physician visit without answers to important questions (US patient survey) (Schoen <i>et al</i> 2004).</p> <p>30% of UK outpatients for cardiology, gynaecology and some other services reported that they were not given an opportunity to ask or their doctor did not always give clear answers to questions (CQC 2009).</p>

Table 2: Problems in provider communication to patient

Problem	Evidence
Information from provider – general	<p>69% of UK and 76% of US patients agreed that ‘regular doctor always or often tells you about care, treatment choices and asks opinions’ (Schoen <i>et al</i> 2008).</p> <p>71% of UK and 70% of US patients agreed that ‘doctor always explains things in a way you can understand’ (Schoen <i>et al</i> 2008).</p>
Conflicting information	<p>18% of US patients surveyed reported receiving conflicting information from various doctors (Schoen <i>et al</i> 2004).</p> <p>17% of the US public reported receiving ‘conflicting information from different doctors or healthcare professionals’ (2009 survey; n=1,238) (NPR/KFF/HSPH 2009).</p>
Written information	<p>30% of US and 33% of UK primary care practices surveyed in 2009 replied that they routinely provided written instructions to patients with chronic diseases (Schoen <i>et al</i> 2009).</p> <p>70% of the US public agreed that ‘patients should get a written or online summary after each doctor visit’; 36% of doctors agreed (n=780, physician survey 2010) (Markle 2011).</p>
Physician communication	<p>One study reports a 19% higher risk of patients not adhering to treatments for those whose physician communicates poorly compared with those whose physician communicates well (Haskard, Zolnieriek and DiMatteo 2009).</p>
Patient understanding	<p>94% of doctors said ‘patients sometimes or most times forget potentially important things they are told’ (Markle 2011).</p> <p>26% to 95% of patients were ‘dissatisfied with the information given (in all aspects)’ and wanted more information. Six studies show that patient have better outcomes when the information wanted and given is more closely matched (Kiesler and Auerbach 2006).</p> <p>‘Low readability’ (a reading grade of 9, when grade 6 is recommended) was found when 295 letters copied to patients were analysed. These were copies of the letters sent by ear, nose and throat surgeons to the patients’ GPs (Todhunter <i>et al</i> 2010).</p> <p>Diabetic US patients with low literacy responded incorrectly 47% of the time when asked by their physician to restate the physician’s instructions (Schillinger <i>et al</i> 2003).</p>
Health literacy	<p>US patients with a reading level below grade 4 were associated with mean Medicaid charges of \$10,680; while patients who read above the third-grade level had mean charges of \$2,890 (n=402) (Weiss and Palmer 2004).</p> <p>A US\$993 higher inpatient spending was associated with persons with ‘inadequate health literacy’ as estimated using econometric regression techniques (Howard 2005). Other studies give evidence of limited-literacy individuals making greater use of services designed to treat complications (see IOM 2004) (Baker <i>et al</i> 1998, 2002; Gordon <i>et al</i> 2002; Scott <i>et al</i> 2002).</p>
Electronic health record – access and privacy	<p>66% of the US public and 66% of doctors agreed that ‘patients should be able to view and download their personal health information online’ (Markle 2011).</p> <p>40% of US patients agreed that ‘the patient – not doctors – should hold the complete medical record for patients’; 38% of doctors agreed (Markle 2011).</p> <p>60% of US patients lacked confidence that ‘electronic records would be able to protect the confidentiality of patients’ records’ (Markle 2011).</p> <p>75% of US patients thought it was at least ‘somewhat likely that an unauthorized person would get access to their records if they were placed online’ (41% said ‘very likely’) (±3.5% margin of sampling error) (NPR/KFF/HSPH 2009).</p>

Table 2: Problems in provider communication to patient

Problem	Evidence
Other evidence of communication problems and of optimal communication	<p>One of the top three competencies needed by a physician is communication skills, according to patient ratings in a 1994 US survey. This was above promotion of preventive care, consideration of costs to the patient, correct use of technology and cooperation with other healthcare professionals (McBride <i>et al</i> 1994).</p> <p>Other studies have found that ‘quality communication’ is associated with improved diabetes self-care, and ‘patient-centred care’ with better continuity of care and with more preventive services (Flach 2004).</p> <p>A review of 14 studies found evidence that different verbal behaviours, interaction style and content were associated with positive patient outcomes. These were: empathy, both passive and dominant physician behaviour, tension release, friendliness, courtesy, listening, talking at the patient’s level; as well as giving statements of reassurance, support, encouraging patient questions, providing explanations, and allowing the patient’s point of view to guide the conversation at the conclusion of the visit (Beck 2002).</p>
Specific groups experiencing communication problems	<p>8% to 42% of African-Americans report in different studies that they have personally experienced racial discrimination while seeking healthcare (Blanchard <i>et al</i> 2004; Hausmann <i>et al</i> 2008; Blendon <i>et al</i> 2007). Perceived racism is associated with worse health-related outcomes among racial minorities (Burgess <i>et al</i> 2008; Casagrande <i>et al</i> 2007; Hausmann <i>et al</i> 2008).</p> <p>Black and minority ethnic (BME) users of US mental health services report ‘disproportionately more antagonistic relationships’ with professionals and ‘disengagement from care’. Their perceptions of past racism and ‘classism’ in healthcare settings may ‘negatively impact the affective tone’ of patient–provider communication (Hausmann <i>et al</i> 2010).</p> <p>Older patients may have more difficulty communicating their concerns and understanding providers, especially in understanding information on drug side effects and interactions, and in finding it difficult to disclose medication information to different clinicians (Haverhals <i>et al</i> 2011).</p> <p>Health literacy has emerged in the literature as an organising concept to describe the capabilities needed by patients to seek, understand and use health information. Low health literacy is associated with poorer health status and higher rates of hospital admission; less likelihood of adhering to prescribed treatments and self-care plans; experiencing more drug and treatment errors; and making less use of preventive services (IOM 2004). However, the same report concluded that ‘<i>since the causal relationships between literacy and health-care utilization and cost have not been discovered, it is not possible to establish a valid cost figure for the impact of limited health literacy</i>’.</p>

Problems related to health information-providers

Most of the research listed in the previous table is from studies of patient–physician communication, as this is likely also to be associated with higher costs. Some studies provided evidence of sub-optimal communication of information to patients by providers over the internet through websites.

One study of 29 Swedish-language websites providing medical information about breast cancer found that providing sub-optimal information could be associated with higher costs. The study reported that none of these sites met the European Commission 2002 quality criteria (Nilsson-Ihrfelt *et al* 2004).

No evidence was found from research into the effects of information from peers to peers through patient–peer information (such as sharing sites, for example ‘patients like me’), or the possible cost-consequences of this (Frost and Massagli 2008).

Communication problems causing lower quality and higher costs

The review found some research that gives an indication of different types of communication problems that could be costly, and also identified gaps in the evidence. There are limitations to the small amount of evidence provided by research for assessing quality and cost consequences of sub-optimal communication. Because of the lack of independent research about the extent of communication problems, the review lowered the evidence threshold to include some commercial survey studies. There are many methodological flaws in the design and reporting of these studies that need to be emphasised. Some studies are commissioned or conducted by organisations that are not unbiased. Sometimes they have poorly phrased questions and important unasked questions because the organisation wishes to present findings favourable to its interests. The samples are likely to be different to patients in other countries or services.

As regards independent research, none mapped causal connections between the problems and consequences, or provided empirical evidence of causal links between sub-optimal communication and poor outcomes.

There is not good evidence of the size of the communication problem. There is neither certainty about the quantity of each problem, nor an acceptable degree of certainty about causation; nor whether the problems listed do result in higher cost and/or lower quality. In the absence of such research, we would have to rely on theories of plausible causation, but the studies reviewed presented no such theories.

Summary: problems in communication – cost and quality implications

Although there are limitations to the evidence, it does suggest that the following problems are possibly widespread, result in significantly more resources used and in deficiencies in the quality of care processes and outcomes:

- Individual providers failing to create an environment and relationship that allows effective communication of all types with the patient.
- Sub-optimal skills and consultation contexts (physical and time boundaries) result in less information of the right type being exchanged and a less adequate basis for subsequent patient and provider actions. Treatment effectiveness is likely to be reduced, resulting in more visits, admissions or worse consequences, with higher costs and lower quality outcomes.
- Patients knowingly or unknowingly withholding information from a provider that the provider needs in order to help the patient.
- Providers then give advice or carry out treatments that could be sub-optimal or harmful and waste time and materials.
- Individual providers failing to provide information to the patient in the consultation.

Probably the most serious omission impacting on quality and waste is failing to provide information about medications, which contributes to non-adherence or miss-adherence and may then result in avoidable hospital admission or wasted visits.

- Hospitals and other facilities failing to provide summary information to patients leaving about treatments provided in the facility and necessary after-care.

- Patients assume providers will tell them what they should be doing and assume that, if no information is given, they do not need to act. Important after-care may be missed, resulting in avoidable suffering, visits or admissions.
- Websites or other sources on the internet providing misleading or incorrect information to patients.

Patients may act on this and delay more effective treatment, harm themselves or put demands on clinical providers that increase consultation times. However, skilled providers can use this as an opportunity to improve their relationship with the patient and build on the patient's demonstrated motivation.

Future research that could help inform value-improvement actions would be research to discover:

- if there is any evidence for the above theorised links between problem and consequences,
- whether patient withholding of information necessary to providers is common and a problem,
- email addition to services: prevalence and incidence of use, and outcomes, given the increasing demand for and use of this communication method,
- use of mobile phone text messaging to patients and outcomes of using this communication method.

6.2 Sub-optimal collaboration

Evidence of collaboration problems between providers is provided in Øvretveit 2011a and 2011b. Evidence of sub-optimal patient-provider collaboration found in the search and review are shown in the tables that follow. Only those problems most likely to be associated with lower quality and avoidable waste are included.

Patient involvement in preventing provider error: problems

Table 3: Patient involvement in preventing provider error: problems

Problem	Evidence
Intentions versus actions	<p>72% of US patients in a telephone survey indicated that they would be comfortable helping to mark a surgical site, but only 17% had done so (Waterman <i>et al</i> 2006).</p> <p>84% of US patients said they would be comfortable asking a nurse to confirm their identity, but only 38% had done so (Waterman <i>et al</i> 2006).</p> <p>Other studies also found patients overestimate their ability and willingness to carry out error-preventing or correcting behaviours (review of 12 studies) (Schwappach 2010 and Schwappach and Wernli 2010). Entwistle (2010) found patients' willingness to speak up was influenced by the way that healthcare staff interacted with them, including staff members' instructions to patients and 'expectations of engagement'.</p>

Collaboration in end-of-life and palliative care: problems

Table 4: Collaboration in end-of-life care and in palliative care: problems

Problem	Evidence
Sub-optimal collaboration in end-of-life care and in palliative care	<p>Patients' advanced directives (ADs) may be ignored by care givers. For example, they may be given cardiac resuscitation when their AD said they did not wish this to be done (E4 Compassion and Choice 2011).</p> <p>Patients are often not provided neutral and effective support to choose whether to make an AD and to decide what to include (Meier <i>et al</i> 2010).</p> <p>In the absence of ADs, patients may be subjected to unnecessary suffering from treatments they do not want (Meier <i>et al</i> 2010).</p> <p>Palliative care is an alternative to treatment for prolonging life and can be an intervention providing higher quality care. There is evidence that it is often not offered to patients or available in the US (Goldsmith <i>et al</i> 2008). Palliative care is also an alternative to unwanted treatments at any life stage (CMS 2008).</p> <p>Surveys of the preferences of patients with a terminal illness, and the general public, found that most people would prefer to receive end-of-life care at home if they also had adequate support (E4 Department of Health 2008; Higginson 2000).</p>

A number of problems concerning end-of-life and palliative care are described in the literature, but no evidence is reported about how widespread these might be.

Over-treatment at the end of life can cause unnecessary and unwanted suffering and consume a significant portion of health resources. These resources are not then available for others who could benefit more. It is not always clear when the end-of-life phase starts and providers and family can be reluctant to accept this even if the patient is willing. There is a subjective element to defining 'over-treatment' – the point here is that patients or relatives are often not given choices.

The 'end-of-life problem' can be viewed as the inability of patients and providers to form a relationship for dealing with the one certainty in life. The optimal relationship might be one that respects the patient's wishes and minimises their suffering while respecting the values and vocation of caregivers and the limited healthcare resources available.

Overall, the review search revealed many anecdotal examples and strong opinions but little evidence of patient preferences. It was unable to establish the consequences of providing unwanted care at the end of life, or of failing to provide adequate hospice care or palliative care in hospital or at home.

Non-attendance

One patient-provider relationship problem is patients not attending scheduled appointments – that is, an appointment the patient may or may not know about.

Patient characteristics often associated with non-attendance rates were reported in one review as age, ethnic minorities, gender, health belief factors, insurance scheme, interval between referral and appointment (waiting time), living in deprived areas, socioeconomic status, timing of the appointment, transportation problems, and travel time (E1 Bech 2005).

Consultation time and continuity: problems

Overall, there is evidence that good continuity, sufficient consultation time and optimal doctor-patient communication are cost-effective in the primary care setting – that is, there is evidence that any extra time spent was saved, both for the provider in question and for other providers (Sans-Corrales *et al* 2006). Whether interventions to achieve this are value improvements is another question, and addressed later in chapter 7 'Findings 2 – solutions'.

Table 5: Non-attendance problems

Problem	Evidence
Non-attendance	<p>Rates of 0.1-13% of patients did not attend (DNA) as reported by outpatient clinics, and 2-5% for primary care physicians in a Danish study (Bech 2005).</p> <p>10% of attendees reported missing one or more appointments at an Irish neurology outpatient clinic (Roberts <i>et al</i> 2009).</p> <p>3-14% loss of total family clinic income was reported in one study with a DNA rate of 24% (other walk-in patients were able to use nearly half of this lost time) (Moore 2001).</p> <p>3% of the department's budget was reported as lost from a DNA rate of 4% in one costing study of a UK nuclear medicine department (E3 Clarke 1998).</p>

Table 6: Consultation time and continuity problems

Problem	Evidence
Sub-optimal consultation time and continuity	<p>Short consultation time is associated with lower patient satisfaction and, according to one US study, does 'increase the efficiency' of a family practice (E2 Goedhuys and Rethans 2001).</p> <p>UK general practice doctors with shorter consultation time were found to prescribe more and give fewer evidence-based treatments (Wilson and Childs 2002).</p> <p>Primary care consultations rated by observers as showing less 'patient-centredness' were associated with more referrals to a specialist (Little <i>et al</i> 2001).</p> <p>Frequently changing primary care doctor over a long period of time is associated with higher costs (Cabana and Jee 2004; Hartley 2002).</p> <p>Patients with longer continuity had fewer emergency visits, hospitalisations and days in intensive care, shorter hospital stays, and overall lower resource utilisation and costs (Cabana and Jee 2004; E3 Raddish <i>et al</i> 1999).</p>

Patient non-adherence to prescribed treatment

Many people do not take their medications as prescribed. This results in wasted medications and consultations, and possibly hospital use that could be avoided. Some of the £230m of medications returned to pharmacies each year in the UK could be medications that were prescribed and not taken. Poor or inconsistent adherence can lead to avoidable disease progression, unnecessary hospitalisations and prescriptions, increased adverse events, overdose, antibiotic resistance (Haynes 2008; Tarn *et al* 2006b) and higher costs (Sokol *et al* 2005).

Shared decision making

Patient involvement in treatment decision making is an aspect of the wider subject of patient participation in many aspects of care. Lack of involvement may be related to non-adherence to treatment (Bibowski *et al* 2001). Also, over- or unwanted involvement, for example by older patients, may lead to a failure to seek help, but there is no research into this. There is some evidence that patients' active participation during medical consultation is associated with better health outcomes (Kaplan 1989, 1996).

Table 7: Problems with patients' non-adherence to prescribed treatment

Problem	Evidence
Non-adherence to medications	<p>42% and 35% non-adherence to medications was reported in patients with psychiatric disorders and depression (Cramer and Rosenheck 1998).</p> <p>49% and 45% non-adherence to using electronic measurement devices for patients with chronic obstructive pulmonary diseases (COPD) and asthma were found (Claxton <i>et al</i> 2001). Other studies also provide evidence that adherence among patients with chronic conditions is low and decreases after the first six months of therapy (Osterberg and Blaschke 2005).</p> <p>20% non-adherence for cancer patients and 25% for most other diseases was also reported (Claxton <i>et al</i> 2001).</p> <p>85% of patients were estimated to be 'occasionally non-adherent' (O'Connor 2006).</p>
Non-adherence to medical recommendations, in general	<p>25% of patients do not follow medical recommendations according to one overview of evidence. This overview reported the highest rate of non-adherence was for patients with HIV, arthritis, gastrointestinal disorders and cancer. The lowest was for patients with COPD, diabetes and sleep disorders Adherence is greater to circumscribed regimens (eg medication taking) rather than regimens requiring pervasive behaviour change (DiMatteo 2004).</p>

Table 8: Problems concerning shared decision making

Problem	Evidence
Sub-optimal involvement in decision making	<p>9% of the time patients were judged to have 'participated in medical decisions', from an analysis of 1060 audiotaped outpatient visits with 124 US primary care physicians and surgeons (Braddock <i>et al</i> 1999).</p> <p>A review of studies between 1991 and 2000 on communication about medicines '<i>found scant evidence for the occurrence of shared decision-making... These examples suggest that healthcare professionals may believe they are implementing concordance, while closer examination may reveal this is not the case</i>' (Stevenson <i>et al</i> 2004).</p>

Discussion: collaboration problems and evidence of quality and cost/cost consequences

There is evidence of problems in how providers work with patients, and of inappropriate patient passivity; often influenced by provider's attitudes and actions. The review found research that gives an indication of the different types of problems and identified gaps in evidence. But it found little evidence of how widespread the different collaboration problems are, or certainty about whether the problems listed resulted in higher cost and/or low quality due to a lack of evidence of causality. The following discusses the findings of studies listed.

Patient involvement in preventing provider error

Notwithstanding the evidence given earlier about patients wanting changes in communication and in collaboration, patients' involvement in preventing provider error is one area where there is mixed evidence. Although the 2006 study listed above showed that patients would be 'comfortable helping to mark a surgical site' in order to help reduce the risk of wrong-site surgery, there is little evidence that patients want to be involved in other strategies to reduce common adverse events caused by health providers – such as hospital acquired infections or medication errors (Peat *et al* 2010).

From a patient's view, it is questionable whether their lack of involvement is a problem, or instead a failure of services to use other methods, in particular a failure to use methods which do

not rely on users who are often not capable of protecting themselves from the service in which they have put their trust. However, part of safety collaboration could be providers creating a climate for patients that does not overly increase a patient's anxiety and considers a patient's capabilities. Then patients can be encouraged and supported by providers to carry out specific behaviours, such as confirming identity and medications that could reduce anxiety and increase confidence in the provider.

End-of-life and palliative care

There are many opinion pieces and examples in the literature, but the debate has not been complicated by evidence of how widespread the documented examples are. There does appear to be a problem in how some patients and providers collaborate during end-of-life episodes, and possibly needless suffering and costs. Related to this, there is also some evidence of sub-optimal collaboration in agreeing palliative care plans.

There is certainly evidence of a lack of access to palliative care in many areas (Goldsmith *et al* 2008), and of palliative care reducing costs and improving quality for the most ill and most medically-complex patients (Zhang *et al* 2009; Wright *et al* 2008; Morrison *et al* 2008; Anderson 2007; Brumley *et al* 2007; Penrod *et al* 2006; Hager 2003; Smith *et al* 2003, 2009; Back *et al* 2005; Carlson *et al* 1988; Elsayem *et al* 2004). However, access to palliative care might not be a problem specifically resulting from sub-optimal patient-provider relations.

Non-attendance

After considering the evidence of problems, readers may understand why patients do not attend scheduled appointments. This is a high-cost problem and may be associated with delayed treatment and poor outcomes. Non-attendance results in cost for a healthcare provider if the time cannot be redeployed, and unused or misused personnel time, equipment and service capacity. Providers may lose income if the time cannot be used for another patient or income-generating activity.

This is especially so for specialist appointment-only services (for example, some MRI imaging or specialist hospital treatments) that lack a continuous flow of walk-in patients and short

length of appointments, as there are in many primary care practices. There are possibly also poorer clinical outcomes for the non-attending patient and for other patients who have been denied the service and may have to wait longer. One intervention is to overbook. This shifts the cost to patients and relatives who have to wait longer; however, there are deficiencies with the few costing studies carried out. Non-attendance rates alone are a poor indicator of the cost of this problem to a service. Most costing studies overestimate lost income or costs because they assume that all lost non-attendance income could be replaced by income from full attendance, or that a 'theoretical saving' can be a 'cash saving' (Øvretveit 2009).

Consultation time and continuity

There is some evidence that shorter consultation times in primary care may be associated with lower patient satisfaction, less evidence-based treatments, higher primary care physician income, and higher use of specialists and prescriptions. Income for primary care physicians may be more, but costs in other parts of the system may be higher. Patients often want continuity with these physicians, and lack of continuity may result in more hospital emergency visits, hospitalisations and longer hospital stays. Efficiency for primary care physicians may mean lower quality and disproportionately higher costs and unnecessary use of other services. There is some evidence that any extra time spent is saved over a longer term, both for the provider in question and for other providers (El Sans-Corrales 2006).

Patient non-adherence to treatments

Many people do not take their medicines as prescribed, and many do not follow other recommended treatments. There are different types of non-adherence and also some theories about why. The evidence reviewed showed a significant non-adherence problem and evidence that this is associated with sub-optimal patient-provider relationships. However, there is little good quality empirical evidence of the costs of this problem.

Patient involvement in decision making

There is some evidence that many patients increasingly expect and want providers to involve them in treatment and other decisions, but many different views about types of involvement. Little

research has penetrated to examining which patients want which types of involvement, at which stages of their care and disease, and there is no good evidence of unwanted involvement in certain decisions. There is some evidence of associations between some types of active participation in treatment decisions, and better physiological and functional status outcomes (Kaplan *et al* 1995). There is some evidence that different patients want different types of involvement at different times (Lidz *et al* 1985; Southerland *et al* 1989; Ende *et al* 1989; Strull and Charles 1984; Degner and Sloan 1992; Say *et al* 2006).

One important decision for both older people and their relatives is whether to enter long-term care and, if the person has a choice, which care home to choose. There is evidence that support for making these decisions is often lacking, resulting in an inappropriate or late decision being made. The consequences may be dissatisfaction, or worse, for some or all involved and subsequent higher use of other services or wasted client transfers (Gravolin *et al* 2007).

Summary: problems in collaboration – cost and quality implications

Using available evidence, but also theorising about the likely cost/quality impact of the different problems, the following are problems in sub-optimal patient–provider collaboration possibly causing the most significant avoidable suffering and waste:

- Patient safety problems: Sub-optimal collaboration for improving specific aspects of patient safety may result in avoidable suffering and waste. These include lack of collaboration to confirm identity, confirm site of surgery, reconcile medications at transitions, and not making it easy for patients to ask the provider if they have washed their hands before touching them, where posters, reminders and providers request that the patient asks this.
- Non-attendance: This is a high-cost problem and may be associated with delayed treatment and poor outcomes.
- Consultation time and continuity: Overly-short consultations and frequently changing providers is one type of sub-optimal collaboration associated with lower quality care, outcomes

and waste. The provider with these collaboration problems might not have higher costs, especially if they are paid per visit, but the healthcare system may have higher costs.

- Treatment adherence problems: There is evidence that sub-optimal collaboration in patient and provider consultations is the primary cause of treatment non-adherence, that it is a widespread problem and results in less effective treatments and significant waste.
- Imbalanced decision-making: There is evidence of under-involvement and miss-involvement of patients in treatment and other decisions, and that this is associated with lower treatment adherence, non-attendance, lower quality and higher costs.
- Palliative care problems: Sub-optimal collaboration to agree appropriate pain relief and support, in addition to or instead of other treatments, can lead to lower quality and higher costs.
- End-of-life care problems: Sub-optimal collaboration to manage end-of-life phases can result in needless suffering and waste, especially when providers and patients do not collaborate appropriately to make care plans and draft advance directives.

6.3 Sub-optimal support for self-care

One subject widely covered in research and policy documents is self-care, which is why this is the third sub-heading of the problems and solutions sections of this report. However, little evidence was found of sub-optimal provider support for self-care (or self-management) using the search strategy and evidence criteria for this review. The review did find considerable documentation in qualitative research of patients with different health conditions wanting to do more to care for themselves.

The research describes patients' reports about lack of support or obstacles to self-care, including a lack of usable and authoritative information and contradictory attitudes among different health providers, with some discouraging the patient from playing a greater role. There is also research into lack of support for carers. Some of this may be relevant to patient self-care (Repper *et al* 2008;

Schulz 2001) but research into carer support was not considered in this review.

There is some limited evidence from qualitative studies that US patients with more than one co-existing illness (multiple or co-morbidity) experience a number of obstacles to self-care and to developing coping strategies, and have little support (Jerant *et al* 2005; Bayliss *et al* 2003; Loeb 2006). There is also evidence that patients with multiple morbidities have significantly more complex learning needs to be able to care for themselves, including managing how they relate to different providers (Hitchcock-Noël *et al* 2007).

‘... an elderly person who is depressed with multiple chronic illnesses, in pain, and wants to quit smoking. You get a 15 minute visit and it is difficult for the physician and unsatisfying for the patient’

*US physician (from Terri *et al* 2011)*

6.4 Summary: problems, opportunities and potential savings

Summary of evidence of problems causing avoidable suffering and waste

The search revealed evidence of three types of sub-optimal patient–provider relations and some evidence that these are associated with both suffering and waste.

- Sub-optimal communication issues reported include:
 - individual providers failing to create an environment and relationship that allows effective communication of all types with patients,
 - patients withholding information from a provider,
 - individual providers failing to provide information to the patient, especially about medications and other treatments, in a form they can understand,

- hospitals and other facilities failing to provide summary information to patients who are leaving about the treatments provided in the facility and necessary after-care,
- websites or other online sources providing misleading or incorrect information to patients (weak evidence).
- Sub-optimal collaboration reported:
 - patient safety, for example lack of collaboration to confirm identity, confirm site of surgery or reconcile medications at transitions, where collaboration has been shown to reduce harm to patients,
 - non-attendance for scheduled appointments,
 - overly-short consultations and frequently-changing providers,
 - failure to ensure patient understanding of treatment and to motivate patients that results in treatment non-adherence or miss-adherence,
 - imbalanced decision-making with under-involvement and miss-involvement of patients in treatment and other decisions,
 - in agreeing appropriate pain relief and providing support for palliative care alternatives,
 - in managing end-of-life care – especially when providers and patients do not collaborate appropriately to make care plans and draft advance directives, or these are ignored.
- Sub-optimal support for self-care problems reported:
 - under- or over-emphasis of the patient’s role in managing their illness,
 - lack of understanding and failure to provide the variety of self-care support that different patients need at different times in different situations (flexible matching).

There are other types of sub-optimal patient–provider relationships but no or little research evidence about them or of the suffering and waste they may cause.

Waste and costs of sub-optimal relations

The problems described in this report are only deficiencies if we assume things could be otherwise. By naming them ‘problems’ or ‘sub-optimal’ there is a comparison with an optimal event or relationship. Sub-optimal events are changed by ‘solutions’ or ‘interventions’ to become ‘more optimal’.

There was little research that quantified the waste and suffering that could be reduced. Where studies did, the estimates were not precise. Most of this evidence comes from studies of interventions listed in the findings 2 and 3 (Chapters 7 and 8). The following section outlines the evidence about likely savings, but solutions not yet invented or evaluated may give more savings. Research evidence is typically about solutions that can be easily evaluated and these may not be the most effective.

Figure 4: Practical implications of the evidence of problems

When is a problem a potential saving?

- Problems are invitations for improvement.
- Accept first the ‘invitations’ that look promising for saving both suffering and waste.
- Saving suffering and waste unites clinicians, managers and funders: we need that unity of purpose to create change.
- Good evidence of costs and suffering is persuasive and can direct you to the things to work on first.
- ‘No evidence’ does not mean there is not a problem or a potential improvement. It may mean there is no research, or no clear solution, or that someone is using a solution already and has described it on an internet sharing site (for example, AHRQ 2011, IHI 2011).

Findings 2 – solutions

7.1 How the findings are presented

This section lists interventions that have been found effective for improving quality and reducing waste, or show great potential to reduce waste. It only presents the studies found in the search reporting evidence about both quality and resources, or studies with evidence about quality and with clear resource implications, as judged by this review's author.

These findings are not necessarily evidence that the intervention is a value improvement that will bring savings for a specific health system – that is, that it gives a cost and quality return on investment in three years for an integrated health system. This is because the outcome evidence is usually of intermediate outcomes. The final cost, quality and health outcomes for patients are unknown in many of the studies. Also, the cost of the intervention may be more than the savings, or the costs and savings may be distributed between different parties. Finally, whether the same findings are to be expected elsewhere depends on differences in the context and implementation capability.

It is the later findings in Chapter 8 that draw together the evidence to present possible value improvements estimated to make savings.

7.2 Points to bear in mind

From the earlier evidence of problems presented, three findings are relevant when considering this intervention-solutions part of the report. First, patients and illnesses are different. Particularly for cancer patients, the information provided may be too little for one patient but too much for another. For the same person, the amount and type of information wanted, or that they can use, will vary at different times in their illness episode (Lidz *et al* 1985; Southerland *et al* 1989; Ende *et al* 1989; Strull and Charles 1984; Degner and Sloan 1992). Thus, solutions also need to be optimal for the individual: suited to the person and what they want and need at the time.

Second, improving communication or collaboration will not only require more resources to make and sustain the change, but it may also lead to more use of medications and services for a patient rather than fewer. As regards the resource and cost part of the value improvement equation, we are interested in both the quantity and the quality of resource use – ideally looking at the lowest-cost provider, treatment or diagnostics for the need. The evidence of provider to provider communication value improvements has been given in Øvretveit 2011a and 2011b.

Third, each solution category overlaps. Some communication interventions, such as training, are part of some collaboration interventions and might also be part of interventions to provide support for self-care.

Figure 5: Findings 2 overview

Which interventions have been described for improving communications, collaboration and support for self-care?

- Chapter 7 (Findings 2: solutions) lists evidence of some interventions that are associated with improved quality and lower costs in the following categories:

Communication interventions

- Providing patients with information to prepare for consultation or treatment (especially patients with lower education status), or to choose a provider.
- Interventions to improve provider communication skills.
- Interventions to improve communications between patients and providers using new technology such as email, telemonitoring, telemedicine and texting.

Collaboration interventions

- Providing patients with information to enable them to protect themselves from harm and errors from healthcare.
- Providing patients with help to make an advanced directive and support for end-of-life care decisions.
- Providing palliative care advice and alternatives.
- Interventions to reduce non-attendance and improve visitation.
- Interventions to improve treatment adherence.
- Interventions to support shared decision making.

Self-care support interventions

- Educational programmes led by professionals or lay facilitators, for certain patient groups.
- Some multiple component support programmes for selected patients.

7.3 Communication interventions

Listed below are interventions to change the way patients and providers communicate for which there is evidence of their impact on resources and quality or strong indications of impact on resources.

Table 9: Communication interventions

Intervention	Evidence
Providing written information to patients	<p>Providing information or coaching to patients immediately before consultations can be effective for increasing the patient's knowledge and reducing anxiety, but can also increase consultation time. Other quality and cost outcomes are not known (E1 Kinnersley 2007).</p> <p>Preoperative information improved surgical patients' knowledge and sense of empowerment (E3 Johansson <i>et al</i> 2005). Other quality and cost outcomes are not known.</p> <p>Giving written information to parents about post-discharge care and medications for their children is more effective than only verbal information. This was the conclusion from one Cochrane review, which only found trials of information for parents (E1 Johnson <i>et al</i> 2003). It is not known whether this results in better clinical or resource outcomes.</p> <p>'Leaflets on their own have little effect, but combined oral and written information can improve patients' experience and, in some cases, reduce use of health service resources' (E1 Coulter and Ellins 2007). This is a quote that summarises well the evidence of the effects of providing written information that was also found in the research reviewed for this report four years later in 2011.</p>
Non-adherence to medical recommendations, in general	<p>The evidence is weak, but the potential for cost-effective improvements is great, of an intervention to enable low-income, racial and ethnic minority patients to ask more and better questions of their doctors, and also to recognise the importance of asking questions in decision making (E3 Deen <i>et al</i> 2011). In this study, 250 patients with low patient-activation measure scores achieved significantly higher scores following a patient-activation intervention. It is possible that this change might later result in better clinical and resource outcomes.</p>
Information communicated by new types of testing: DNA testing, and providing images	<p>A DNA test can provide a person with an estimate of a genetic predisposition to some diseases (eg heart disease or lung cancer). A Cochrane review found evidence that two studies communicating genetic test-based risk estimates did change people's dietary behaviour, but reported no change for two other studies assessing physical activity, one study assessing medication or vitamin use, or in five studies assessing smoking cessation (E1 Marteau 2010).</p> <p>For some purposes visual feedback to individuals of their medical imaging results could be a value improvement. One Cochrane review included nine RCTs of giving people their medical images. Of four RCTs using ultraviolet (UV) photography to highlight UV-related skin damage, two found positive effects and two none. Three assessing smoking cessation behaviours found the interventions effective. One trial of patients with heart disease found no effect. The review concluded that 'targeted interventions using medical imaging technologies may be effective in certain contexts, or as applied to certain behaviours' (Hollands <i>et al</i> 2010).</p>
Training providers in communication skills	<p>Patient adherence to treatment is 1.6 times more likely after training physicians in communication skills (E1 Haskard Zolnieriek and DiMatteo 2009). This meta-analysis concluded that 'communication is important and resources devoted to improving it are worth investing in', but like the other studies provided no evidence of downstream effects on health or resource use.</p> <p>Role-play, feedback and small group discussions are effective training strategies if they are learner-centred, practice-oriented and last at least one day (E1 Berkhof <i>et al</i> 2011). Other findings from this recent review of communication skills training for physicians are that there was no evidence for the effectiveness of modelling, written information or oral presentations alone.</p>

Table 9: Communication interventions

Intervention	Evidence
Use of information and communications technology by providers to improve their communication with patients	<p>The need for effective communication might possibly be higher for patients with unexplained medical symptoms and the consequences greater for quality and cost outcomes. GPs trained in standardised communication techniques for delivering psychosocial interventions (three hours) were found to achieve statistically significant improvements in health-related quality of life (SF36) for patients with medically unexplained symptoms, in one RCT (n=150 patients total) (E2 Aiarzaguena <i>et al</i> 2007). No data about resource outcomes were reported but the trial suggested that the improvements may be associated with less health service utilisation. Other trials (E2) found fewer effects for GP communication training of this type (King <i>et al</i> 2002; Rosendal <i>et al</i> 2003; Gask <i>et al</i> 2004; Larisch <i>et al</i> 2004).</p> <p>The ‘growth of e-mail communication in primary care settings may not improve the efficiency of clinical care’ was the conclusion of one RCT. It found that using a triage-based email system did not substitute for phone communication or reduce visit non-attendance in primary care (E3 Katz 2003). Some other studies of similar interventions showed increased patient satisfaction and increased resource use in physician time, with unknown possible reduction in visits (E3 Car and Sheikh 2004; E3 Gagnon <i>et al</i> 2009). Overall there is some weak evidence that adding email to a primary care service may increase short-term costs and improve patient satisfaction. The long-term savings, if any, for any services are unknown. There is, however, the potential to design systems allowing email for certain items, which might reduce visits, hospital attendance and/or medications.</p>
Use of electronic health or medical records (EHR/EMR) or web-based patient portals	<p>‘There is little evidence of clinical benefits from telemedicine’, was the conclusion from one Cochrane review covering studies up to 1999 (Currell <i>et al</i> 2000). It found the studies it reviewed ‘provided variable and inconclusive results for other outcomes such as psychological measures, and no analysable data about the cost-effectiveness of telemedicine systems’. Again, although the Cochrane review finds no good evidence, other studies, often of later types of systems, show some evidence of lower service use and the potential of telemedicine as a value improvement (E1 McLean <i>et al</i> 2010 (asthma); E1 Glueckauf and Ketterson 2004 (chronic illnesses); E4 Botsis 2008; E4 Friedman 1996; E4 Harrison 1999). Hill <i>et al</i> 2010 (E3), in particular, reported evidence from a number of studies in the US Veterans Health Administration system that telemedicine was cost-effective for monitoring patient symptoms in chronic disease care or mental health treatment.</p> <p>There is evidence that mobile phone text messaging has been used to give reminders for attendance at scheduled healthcare appointments (E1 Car 2008), communicate results of medical investigations (E1 Gurol-Urganci 2008), give feedback on treatment success, and to give social support from peers and health professionals. There is weak evidence of effectiveness, but potential for this communication method to serve as a value improvement, especially for patients with chronic illnesses (E4 de Jongh <i>et al</i> 2008).</p> <p>For EHR/EMR, there is weak evidence of time saving and improved data quality, and mixed evidence of improved quality for patients (Black <i>et al</i> 2011). In July 2011, no Cochrane reviews had been made of this intervention and only one review of eHealth has considered the recent EHR/EMR evidence (Black <i>et al</i> 2011).</p> <p>Internet-based patient sites can provide patients with access to personal health information, such as test results, problem summaries and medication lists (E4 Weingart <i>et al</i> 2008). These electronic portals can also assess medication adherence and enable patients to report side effects or adverse events.</p> <p>Electronic personal health record systems (PHR) make medical records and other relevant information accessible to patients and are often linked to EMR. One review reported that there was evidence of patient satisfaction with more access to information through both electronic and manual PHR (E1 Archer <i>et al</i> 2011). A review of patient-held records during pregnancy found these enhance patients’ knowledge and sense of control (E1 Brown <i>et al</i> 2004). Neither review reported evidence of improvements in health outcomes or resource use.</p>

7.4 Collaboration interventions

Listed in table 10 are interventions to change the way patients and providers collaborate for which there is evidence of their potential impact on resources and quality. ‘It is not enough to focus solely on changing practitioner behaviour... interventions also needed to engage patients and provide organizational support to promote shared decision-making’ – this was a conclusion from Graffy *et al* 2009 from their review of personalised care planning for diabetes. Improving collaboration

is often regarded as changing either patient or provider roles, yet interventions to change both may be more effective. However, it is not known whether any greater effectiveness of such multiple interventions is worth their extra cost.

Also not known are the subsequent effects of increasing shared decision making on adherence and on the later ‘downstream’ outcomes of health status or resources. The evidence at present is that many of these interventions may represent promising value improvements.

Table 10: Collaboration interventions

Intervention	Evidence
Matching information and provider style to the patient’s preference	There is some limited evidence to support the effectiveness of matching information to patients’ preferred levels of information, as well as their preferences for ‘decisional control’, and ‘consultative interpersonal behaviour’ (E4 Kiesler <i>et al</i> 2006). Interventions to achieve this matching are described in Kiesler <i>et al</i> 2006, such as using ‘control preference’ scales (Anderson <i>et al</i> 1989). There is no evidence of the impact of these interventions on patient or resource outcomes but it is possible that matching might enable more effective decisions and use of information and that these two downstream outcomes could be influenced by matching strategies. Other less strong evidence is provided in Lidz <i>et al</i> 1985; Southerland <i>et al</i> 1989; Ende <i>et al</i> 1989; Strull and Charles 1984; Degner and Sloan 1992.
Patient self-protection from harm caused by healthcare	<p>There is weak evidence that specific interventions to enable patients to speak up can be effective, notably actions to help reduce patients’ fears about being discourteous to providers such as signs in rooms about how patients can help prevent errors or by providers wearing reminder buttons stating, ‘Ask me if I washed my hands.’ (E4 Waterman <i>et al</i> 2006; E4 Spath <i>et al</i> 2004; E4 Hinkin 2002).</p> <p>Allowing patients or relatives to call a hospital rapid response team in specific situations may be a low-cost intervention to prevent avoidable suffering and waste (E4 De Vita <i>et al</i> 2010; E4 NPSF 2007; Odell <i>et al</i> 2010; Dean <i>et al</i> 2008).</p> <p>Patients collaborating with providers to check the accuracy of their prescribed medications when moving from one provider or unit to another is possibly effective and can reduce waste (E4 Varkey <i>et al</i> 2007).</p> <p>There is some weak evidence that providing poorly selected safety recommendations to patients may reduce quality by raising anxiety and increase waste through the cost of providing them. A study of 160 safety recommendations for patients provided by eight US healthcare organisations found their value was variable. An expert panel judged that few recommendations were based on scientific evidence, were likely to have a significant impact on patient safety or were likely to be used by consumers (E4 Weingart 2009).</p> <p>One review, which selected 14 of the higher quality studies, could not conclude that any interventions to promote patient involvement to enhance safety were effective, but the review is useful for listing possibly cost-effective interventions (E1 Hall <i>et al</i> 2010).</p>
Improving collaboration in end-of-life care	One review of evaluations of end-of life-care pathways found the research was not adequate to draw conclusions about effectiveness (E1 Chan and Webster 2010). It is thought to be possible that these structured multidisciplinary care planning methods could reduce unnecessary suffering and waste (E4 Bookbinder <i>et al</i> 2005).

Table 10: Collaboration interventions

Intervention	Evidence
	<p>Patient/family provider collaboration to give home-based care at the end of life might possibly be lower cost and the same or higher quality. In four trials, no differences between patients receiving home-based end-of-life care, compared with those receiving standard care, which included inpatient care, were found for: functional status, psychological wellbeing or cognitive status (E1 Shepperd <i>et al</i> 2011). The review noted ‘the major gap in the evidence is around cost-effectiveness. The lack of precision around estimates of admission, or transfer, to hospital could have a major bearing on cost’.</p> <p>There is weak evidence that some patients value an advance care planning discussion (ACP, or ‘advanced directive’ (AD) discussion) with an independent mediator. This evidence is from a study of patients attending a UK outpatient oncology clinic and a nearby hospice (E4 Jones 2011). Thirty eight patients (51%) showed preference for the intervention and increased their discussions about end-of-life planning with primary and secondary care professionals and family and friends (the primary study outcome). Satisfaction with services decreased in those receiving the intervention – possibly the ACP discussion raised expectations and made patients more aware of how much communication might be improved.</p> <p>One AD programme in six Canadian nursing homes over four years was associated with nearly half the hospitalisations in the residents who completed ADs (n=527, RCT total n=1,292 residents), less total overall resource use (C\$3,490 vs \$5,230) and less hospitalisation costs (C\$1,415 vs C\$3,625) (E3 Molloy <i>et al</i> 2000).</p>
Collaboration in palliative care	<p>Palliative care aims to give relief from pain and other distressing symptoms, often at the end of life. It is sometimes provided as an alternative to other treatments that may not be wanted by the patient. Palliative care services almost always require close collaboration between the patient and different providers. There is evidence from trials in the USA and Europe of improved quality and significantly lower costs (E3 Morrison <i>et al</i> 2008; E3 Back <i>et al</i> 2005; E3 Brumley <i>et al</i> 2007; E3 Elsayem <i>et al</i> 2008). One review of palliative care for older people’s care homes could not find sufficient evidence to reach conclusions about costs or effectiveness.</p>
Reducing non-attendance (NA) and providing unrestricted visitation	<p>Different interventions for reducing NAs have been evaluated. Only mailed reminders and telephone reminders are likely to be cost-effective in most services, but there is little strong empirical evidence of this. Mailed reminders reduced NAs by 47-68% (E2 Can <i>et al</i> 2003; E1 George and Rubin 2003; E3 Reekie and Devlin 1998; E4 Moser 1994; E3 Quattlebaum <i>et al</i> 1991) and telephone reminders by 27-75% (E2 Bech 2005). A meta-analysis of RCTs found telephone reminders to be slightly more effective than letters (E1 Macheira <i>et al</i> 1992) but mailed reminders are likely to be more cost-effective as their costs are lower.</p>
	<p>There is weak evidence that avoidance of being put at the bottom of a waiting list may be more effective than a small financial incentive for reducing NAs. One before-after study compared offering parents of children with behavioural difficulties a \$10 voucher for attending the paediatric clinic with telling parents that more than three successive missed appointments would move their child to the bottom of the waiting list. The penalty resulted in fewer NAs than the financial incentive (E4 Parrish <i>et al</i> 1987). Another before-after study found a \$3 fee for an appointment at a student health centre resulted in a significant drop in NAs (ie the student lost their \$3 if they did not make use of the appointment) (E4 Wesch <i>et al</i> 1987).</p> <p>Patients having the company of visitors in hospital (where this is wanted) may increase process and outcome quality, and possibly reduce costs, if recovery is faster and fewer medications and nursing time are required. Liberalising visiting hours may increase visits: one study found doing so in an Italian intensive care unit did not increase septic complications, whereas it might reduce cardiovascular complications ‘possibly through reducing anxiety’ (E3 Fumagalli <i>et al</i> 2006).</p>
Personal health budgets	<p>There is still little evidence that personal health budgets improve clinical outcomes, although there is evidence of effectiveness of personal budgets for buying services in other sectors. A case study of Dutch programmes was not able to give evidence for designing a personal health budget system that reduces or stabilises health and social care costs (E4 White 2011).</p>

Table 10: Collaboration interventions

Intervention	Evidence
Improving treatment adherence	<p>Providing information or education alone is probably ineffective for improving medication use. Also, there is no evidence that any one strategy improves medicines use across all diseases, populations or settings, or for all outcomes (E1 Ryan <i>et al</i> 2011).</p> <p>The most effective for improving medication adherence is simplifying dosing regimens (E1 Haynes <i>et al</i> 2005). The low cost makes this a likely cost-effective intervention for improving outcomes. As usual, this theorised downstream link, from increased adherence to health and cost outcomes, is likely but unproven and dependent on the treatment effectiveness.</p> <p>Given the above, one might expect ‘reminder packaging’ to be effective for improving adherence to self-administered long-term medications. But it only slightly increases the proportion of people taking their medications when measured by pill count (E1 Heneghan <i>et al</i> 2006). There was not enough evidence to show if reminder packaging had an effect on improving health outcomes or reducing waste. It is possible that this method combined with others might be more effective.</p> <p>In contrast to the above, a later review found ‘calendar packaging’, especially with education and reminder strategies, can improve medication adherence (E1 Zedler <i>et al</i> 2011). This was a review of 10 trials of simple day-and-date medication pack features (eg blister-calendar pack) designed to improve adherence.</p> <p>For short-term drug treatments, adherence interventions which are also effective are counselling, written information and personal phone calls (E1 Haynes <i>et al</i> 2008). For chronic illnesses, this same review found evidence that only complex interventions led to improvements in health outcomes. These included combinations of more convenient care, information, counselling, reminders, self-monitoring, reinforcement, family therapy, psychological therapy, mailed communications, crisis intervention, manual telephone follow-up, and other forms of additional supervision or attention (E1 Haynes <i>et al</i> 2005). But the improvements in drug use or health were not large, even with the most effective interventions.</p> <p>In addition to the above, the following interventions ‘show promise’ for improving use of medicines: medicines self-monitoring, self-management and direct involvement of pharmacists in medicines management, according to evidence presented by the most recent Cochrane overview of 37 reviews of the subject (E1 Ryan <i>et al</i> 2011). Other strategies for which there is some, but inconsistent, evidence are: reminders; education combined with self-management skills training, counselling or support; financial incentives; and strategies involving lay health workers. One review reports that five interventions targeted at pharmacists showed improved patient satisfaction and adherence (E2 Stevenson <i>et al</i> 2004).</p> <p>A 1997 review of financial incentives was more positive about the effectiveness of this type of intervention for improving adherence for some treatments, notably for tuberculosis among low-income patients (E1 Giuffrida <i>et al</i> 1997). It reported that 10 of the 11 studies selected showed improvements in patient compliance with incentives in the form of money, cash or vouchers redeemable for other goods (food, clothes, gifts, etc).</p> <p>One specific type of intervention with a high potential to achieve value improvement if the medication costs are low enough is ‘patient re-enforcement and reminding’ for adherence to lipid-lowering medications which can reduce risks of heart disease or stroke. One review reported four RCTs which found an absolute increase in adherence of 24%, 9%, 8% and 6%. Simplification of the drug regimen (absolute increase 11%) and patient information and education (absolute increase 13%) also showed some effectiveness (E1 Schedlbauer <i>et al</i> 2010). The review remarked that ‘Increased patient-centredness with emphasis on the patient’s perspective and shared decision making might lead to more conclusive answers when searching for tools to encourage patients to take lipid-lowering medication.’</p>

Table 10: Collaboration interventions

Intervention	Evidence
Contracts for changing treatment adherence and or health behaviour	<p>It is not known whether any of the above interventions ultimately results in less healthcare use/waste/ costs. The evidence and theory suggest some interventions of this type could be value improvements.</p> <p>Some types of contracts between patients and providers can increase adherence to treatment for substance addiction, but there is little evidence that contracts are effective for hypertension treatment adherence, smoking cessation or the other treatments for which this intervention has been assessed (E1 Bosh-Capblanch 2007). Contracts are noted here because the improvements achieved in quality and cost may be positively disproportionate to the intervention costs for addiction treatment.</p>
Patient decision aids – general	<p>For people who are facing health treatment or screening decisions, some decision aids reduce the use of discretionary surgery without adverse effects on health outcomes or satisfaction (E1 O'Connor 2009). Consistent with previous reviews, this review of 55 RCTs of decision aids also found them to be no better than comparisons in affecting satisfaction with decision making, anxiety and health outcomes. The effects of decision aids on other outcomes (patient–practitioner communication, consultation length, continuance, resource use) were inconclusive. Stacey <i>et al</i> updated this review and reported that ‘there appears to be a positive effect on communication with their health practitioner, and a variable effect on the time required for this consultation’ (E1 Stacey <i>et al</i> 2011).</p>
Patient decision aids for specific decisions	<p>Some interventions have been found to be ineffective and would add costs. A patient booklet decision aid for Finnish women considering hysterectomy found no significant difference in costs between this group and usual care group in a RCT (E2 Vuorma <i>et al</i> 2004).</p> <p>One RCT evaluated the cost-effectiveness of patient decision aids for women experiencing heavy uterine bleeding. The women, who had a video of the treatment options and outcomes, a booklet and nurse coaching to help them express their preferences, had a lower hysterectomy rate and greater satisfaction and lower mean overall service costs: \$1,566 (£794; €1,178) in the intervention group compared with \$2,751 in the control group (mean difference \$1,184; 95% confidence interval \$684 to \$2,110) (E2 Kennedy <i>et al</i> 2002).</p> <p>Patients in primary care with benign prostatic hypertrophy and considering hormone replacement therapy were given video-based decision aids in two RCTs. There was no effect on resource use. Thus, this added to healthcare costs when the cost of the intervention was included. A later intervention by the same authors using the internet, which cost less, did not add to costs (E3 Murray <i>et al</i> 2005).</p> <p>One cluster RCT evaluated an intervention aimed at both providers and patients: distance education for primary care practitioners with evidence-based information, assessment of learning needs and education materials for 187 older male patients with lower urinary tract symptoms in primary healthcare. The control group received written guidelines. After three months the costs in the intervention group were lower but the occurrence of symptoms was the same (E2 Wolters <i>et al</i> 2006).</p> <p>An important decision for older people and their relatives is whether to enter long-term care and which care home to choose if the person has a choice. One Cochrane review of interventions to assist decisions about entering long-term care found no evaluations of acceptable quality in 2007 to include in their review (E1 Gravolin <i>et al</i> 2007). The review did list interventions described in the research, including needs assessment, giving adequate information, counselling, providing choices and the facilitation and timing of the decision. If a lower threshold of evidence is used then these decision aids are possible value improvements if they lead to appropriately delaying the move.</p> <p>There is great variation in the quality of the different decision aid interventions and only a few have been well evaluated: the International Patient Decision Aid Standards (IPDAS) (Elwyn <i>et al</i> 2006) may help increase quality. A useful full list of the many interventions of this type is provided by the independent research unit (UOHRI 2011).</p>

Table 10: Collaboration interventions

Intervention	Evidence
Shared decision making	<p data-bbox="408 277 1493 409">Interventions effective for improving patient participation in health consultations are: patient-directed coaching, educational materials and feedback to providers of patient-reported outcome measures, and communication skills training for providers. This was one conclusion from a review of 137 trials of interventions to improve patient participation (E1 Haywood 2006).</p> <p data-bbox="408 439 1485 640">Simple approaches such as providing practitioners with a note from patients about their concerns before the consultation appear effective, according to a review of 35 trials of interventions to alter the interaction between patients and practitioners (E1 Griffin <i>et al</i> 2004). So did some more complex programmes providing specific information about disease and giving attention to emotions. Apparently similar interventions were reported by this review to vary in effectiveness across studies, and ‘some show promise in improving patients’ health’.</p> <p data-bbox="408 669 1461 871">Two trials of interventions to promote shared decision making for people with mental health conditions were included in one Cochrane review (E1 Duncan 2010). One found increased patient satisfaction and one found doctor facilitation of consumer involvement in decision making was increased by the intervention. However, no effects were found on the clinical or health service outcomes in either study. The review stated that ‘no firm conclusions can be drawn from these two studies on any of the outcomes measured and further research is needed’.</p> <p data-bbox="408 900 1490 1032">Training physicians in shared decision making without other changes to the context of their practice is ineffective for improving health outcomes and resource use, but slightly improves process quality indicators of patient satisfaction, according to one unsystematic review of eight peer reviewed studies (E3 Towle and Godolphin 2009). Training alone is thus likely to result in a negative Q+C ROI.</p> <p data-bbox="408 1061 1466 1227">Training providers in being patient-centred may improve communication with patients, enable clarification of patients’ concerns in consultations and improve satisfaction with care. This was the finding from one Cochrane review of 17 trials of different interventions to providers to promote a patient-centred approach in clinical consultations (E1 Lewin 2001). But it could not conclude if the training made a difference to healthcare use or outcomes.</p> <p data-bbox="408 1256 1474 1352">No subsequent reviews with more useful evidence were found for this review. Overall, there is some evidence that multiple interventions, sometimes to both patient and provider, are more effective for achieving shared decision making (E4 Stewart 1995).</p> <p data-bbox="408 1382 1485 1547">One specific intervention was found effective for improving participation in care by urban African-American and low social economic status (SES) patients with uncontrolled hypertension. The intervention was both to improve physicians’ communication skills and to activate patients to participate in their care, and the results also suggested this improved systolic blood pressure (Cooper <i>et al</i> 2011).</p> <p data-bbox="408 1576 1493 1709">As regards one model of patient-centred care, there is some evidence of a shorter length of stay, lower cost per case, and a shift in use from higher-cost nurses to lower-cost ancillary staff in the Planetree model compared with a similar hospital unit, from a five- year comparison study (E4 Stone <i>et al</i> 2008).</p>

7.5 Interventions to enable self-care

Many of the above ‘solutions’ are aimed at enabling providers to improve communication and collaboration with patients. Some of these interventions are aimed at changing providers’ behaviour, so as to enable patients to take more care of their illness. In the section below, interventions mostly aimed only at patients are considered. Listed first are interventions to enable self-care that are led by providers, such as educational programmes given by nurses for asthma patients. Then interventions led by lay people, such as training programmes for patients to help them manage their diabetes. ‘Lay-led’ means a person without a clinical professional qualification: often a patient or past-patient with some training to provide education and support materials for other patients.

‘Provider’ here means:

- an individual clinical professional, such as a primary care physician or nurse who spends time on teaching or coaching self-care skills, sometimes in the patient consultation in addition to their traditional clinical care; or a case manager with ‘self-care support’ added to their patient-coordination tasks
- an individual professional self-care educator or coach
- an organisational provider, which may engage either or both a) and b) to provide support for self-care or provide an internet support website for patients or other support services.

Some of the evidence comes from reviews that considered studies of both provider and lay-led programmes. Those reviews that consider and compare both are noted when listed. Only a few interventions aim to improve patient self-care abilities and the abilities of providers to enable self-care.

Table 11: Summarised findings of systematic reviews on effectiveness strategies to inform, educate and involve patients in their treatment

Topic	Total number of reviews found	Effects on patients’ knowledge	Effects on patients’ experience	Effects on use of health services	Effects on health behaviour and health status
Improving health literacy.	25	Reported in 13 reviews: 10 positive, 2 mixed, 1 negative	Reported in reviews: 10 positive, 5 mixed, 1 negative	Reported in 14 reviews: 9 positive, 3 mixed, 2 negative	Reported in 13 reviews: 4 positive, 6 mixed, 3 negative
Improving clinical decision making.	22	Reported in 10 reviews: 8 positive, 2 mixed	Reported in 19 reviews: 12 positive, 6 mixed, 1 negative	Reported in 10 reviews: 6 positive, 4 mixed	Reported in 8 reviews: 2 positive, 1 mixed, 5 negative
Improving self-care and self-management of chronic disease.	67	Reported in 19 reviews: all positive	Reported in 40 reviews: 24 positive, 11 mixed, 5 negative	Reported in 25 reviews: 14 positive, 9 mixed, 2 negative	Reported in 50 reviews: 39 positive, 15 mixed, 6 negative
Improving patient safety.	18	Reported in 4 reviews: all positive	Reported in 1 review: positive	Reported in 3 reviews: 2 positive, 1 negative	Reported in 17 reviews: 8 positive, 9 mixed

Source: Coulter and Ellins 2007

As before, the only interventions listed are those:
a) for which there is some evidence of effectiveness for improving quality and waste reduction; and b) for which there is weak evidence of effectiveness for quality improvement because of the study design, but great potential for reducing waste based on convincing theory about the cost of the intervention relative to the improvements rather than on strong evidence.

'Pure self-care support' and 'self-care support-plus'

The search focused on pure self-care support interventions – mostly education and coaching. Other self-care support-plus programmes are described in a previous review (Øvretveit 2011a). This found evidence that some were effective, but they also cost more and only a few were saving value improvements. In the listing below, some interventions do include other elements but the selection is confined to those where self-care is the primary element.

Overviews of self-care support evidence

Coulter and Ellins (2006 and 2007) provide a comprehensive summary of interventions for informing, educating and involving patients. These include an assessment of 67 systematic reviews of many types of interventions to promote self-care for people with chronic diseases. Among their findings were:

- Information-only interventions are mostly ineffective. But if they are actively supported by clinicians in different ways, they can improve health outcomes for patients with asthma, diabetes, hypertension, depression and eating disorders. Similarly, decision aids and self-management action plans are more effective when they are used in an interaction between the patient and professional.

- Interactive computer systems improve knowledge and often clinical outcomes as well but it is not clear whether they are more cost-effective than face-to-face delivery.
- Some short-term beneficial effects are provided by short self-management courses for patients run by voluntary groups (often lay-led), in improved knowledge, coping behaviour, adherence, self-efficacy, and in health economic cost-effectiveness. For disadvantaged populations, educational programmes led by professionals are more effective.

The Coulter and Ellins 2006 review also includes in its self-care intervention category patient-held records, telemonitoring and home-based telecare. Some studies they reported and others that are relevant to this review have been listed previously (see 7.3 Communication interventions on page 41).

The most recent review, focusing only on evidence of self-management interventions from 550 studies, is by de Silva (2011). It reports mixed findings about the impact of different self-care interventions on different patients' self efficacy, behaviour, quality of life, clinical outcomes and service use. A key conclusion for the purposes of this value improvement review was that 'the evidence suggests that proactively supporting self-management and focusing on self-efficacy and behaviour change can have an impact on clinical outcomes, crises and unplanned admissions or other costly emergency service use'.

Many studies suggest that self-care support interventions are either cost-saving, or cost-effective in the health economics sense of the term. However, the review for this report questions this general conclusion because of the evidence presented below.

Table 12: Self-care support interventions

Intervention	Evidence
Cost-saving and cost-effectiveness evidence	<p>The methods section explained the difference between a cost-effectiveness study and Q+C ROI estimate. The former precisely values patient outcomes, while the latter only assessed whether quality in some respect was the same or maintained, but also assessed health system budget savings relative to the cost of the intervention. Regarding cost-effectiveness studies that do give evidence of costs, only one review considered all types of self-management training programmes for patients with chronic conditions (E1 Richardson <i>et al</i> 2005). Of 39 health economic research evaluations of self-care support, 29 concluded that the interventions they studied were cost-saving and/or cost-effective; with two UK studies before 2005 showing no savings (E3 Fitzmaurice <i>et al</i> 2002 – anticoagulation treatment; E3 Lord <i>et al</i> 1999 – osteoarthritis). However, Richardson <i>et al</i> pointed to ‘significant flaws’ in the studies, mainly because of a narrow definition of costs and short follow-up periods, and that it could not be concluded that self-care support interventions are cost-effective: ‘Current evidence (to 2005) does not support the hypothesis that these interventions are cost-effective. Cost-effectiveness may vary between condition, setting, and geographical location and results may lack generalisability’.</p>
Provider-led interventions – reviews	<p>Evidence of improved outcomes from self-management education programs for some conditions was also found in one meta-analysis of 71 trials (E1 Warsi <i>et al</i> 2003). This considered such programmes for patients with asthma, arthritis, diabetes mellitus, hypertension and some other conditions. However, it could not identify differences in the effectiveness of the programmes because of their different intervention characteristics, such as the number of sessions in which patients participated, programme duration, the type of programme facilitator and whether or not they used a formal syllabus. No cost evidence was reported.</p> <p>Osteoarthritis self-management programmes do not appear to have clinically beneficial effects on pain or function, according to a meta-analysis of 53 evaluations of self-management programmes for hypertension, osteoarthritis, and diabetes mellitus (E1 Chodosh <i>et al</i> 2005). However, self-management programmes for older people with diabetes mellitus and hypertension ‘probably produce clinically important benefits’. No cost-effectiveness assessment was made and more details of specific interventions and their results are needed to assess Q+C ROI.</p>
Provider-led interventions – specific patient groups	
COPD	<p>One review of self-management education interventions for people with COPD included nine trials. It found evidence from these of less ‘rescue medication’, but no effect on days lost from work, lung function, emergency department visits or hospital admissions, and an increased use of courses of oral steroids and antibiotics for respiratory symptoms (E1 Monninkhof 2003). The evidence from this review of these nine interventions suggests a negative Q+C ROI and that these interventions were not a value improvement.</p>
COPD	<p>An update of the above COPD review (E1 Effing <i>et al</i> 2007) again found no effect of self-management education on hospital admissions, emergency room visits, days lost from work and lung function, and the same results for lower rescue medication, but increased use of oral steroids and antibiotics for respiratory symptoms.</p>
COPD	<p>Contrary results to those described above were reported for a self-management programme for COPD patients assessed by an RCT and involving seven Canadian hospitals (E3 Bourbeau 2003). Self-management education was associated with 40% fewer hospital visits, 57% fewer hospital admissions for other problems, 41% reduction in emergency department visits and 60% fewer unscheduled physician visits. The intervention was weekly visits by health professionals over two months and monthly telephone follow-up. The costs are likely to be less than the costs of the visits avoided, and this, together with the apparently higher quality, suggested this intervention provides a positive Q+C ROI and is possible value improvement.</p>

Table 12: Self-care support interventions

Intervention	Evidence
COPD	After an educational intervention and with supervision and support, patients experienced a significant reduction in hospitalisations and emergency visits after two-years (E3 Gadoury <i>et al</i> 2005). This was the finding of one RCT of this intervention (n=191 from seven hospitals). Most patients were elderly, not highly educated, had advanced COPD and had been hospitalised in the past year. There are not enough details to assess costs and savings, but this intervention could possibly have achieved a value improvement.
Depression and post-traumatic stress disorder (PTSD)	Curious evidence of outcomes is provided by one RCT of self-management and psycho-educational group therapies for patients with both depression and chronic PTSD. No significant change in self-management behaviours was observed but it did find lower use of healthcare resources (E3 Dunn <i>et al</i> 2007).
Asthma	Similar findings were reported in an evaluation of self-management programme for asthma patients: lower use of healthcare but no changes in self-management behaviours (E3 Downs <i>et al</i> 2006). Effing <i>et al</i> 2007 report that many asthma self-management programmes have been found to be effective for certain purposes.
Asthma	An RCT with children with asthma examined self-management education using interactive multimedia tools (E3 Krishna 2003). This intervention was associated with increased asthma knowledge among children and caregivers, decreased asthma symptom days, fewer emergency department visits, and lower average daily doses of inhaled corticosteroids. Increased asthma self-management knowledge and behaviours were associated with fewer urgent physician visits and less frequent use of quick relief medicines. No costs were reported but given the low cost of the interactive multimedia tools relative to the reduced visits and medications, this represents a possible value improvement.
Asthma	One of the few RCT costed studies (n=78) found two educational sessions and two follow-up sessions for self- management of asthma, led by nurses or physiotherapists, were associated with reduced visits to GPs, reduced overall costs and improved quality of life after 12 months (E2 Gallefoss 2002). The control and intervention groups had mean total costs of NOK16,000 and 10,500 per patient respectively (1NOK = approx £0.9). Taking the possible costs of the intervention into account this probably represents a value improvement and a small positive Q+C ROI.
Diabetes	Some people with type 2 diabetes mellitus experienced improved knowledge of diabetes, better clinical outcomes and reduced medication use after group-based educational programmes (for at least one hour with at least six participants in each group). This was the finding of one meta-analysis of 11 RCTs (E1 Deakin <i>et al</i> 2005). It reported the probability that one person in every five trained would reduce their diabetes medication and consequently lower costs, but the exact amount was not estimated.
Diabetes	In one RCT study, a six-hour structured group educational programme was given by two professional healthcare educators in community settings for people with type 2 diabetes. The costs of the programme were £206 per patient (£76 per patient estimated for a real world 'hypothetical primary care trust') and the positive clinical outcomes result in an estimated cost per QALY gained of £2,092 (Gillett <i>et al</i> 2010). If a treatment up to £30,000 is cost-effective, then if this intervention costs £76 it is cost-effective. However, whether it provides a Q+C ROI for a health system is a different question.

Table 12: Self-care support interventions

Intervention	Evidence
Heart failure	<p>Post-hospital discharge self-care support programmes, especially for older people with congestive heart failure, is one type of intervention with evidence of a positive Q+C ROI. Programmes that involve the patient and family in hospital care planning, self-care education, and then provide follow-up visits and advice were found to be effective in one meta-analysis of 18 studies from eight countries (E1 Phillips <i>et al</i> 2004). This meta-analysis did not find any incremental efficacy with more intensive post-discharge interventions. Comparable benefits resulted from a home visit; home visits and/or frequent telephone follow-up; and extended home care services. This is one of the few 'self-care support-plus' interventions noted in this review, but it is noted because of some degree of certainty from the research of both quality improvement and reduced waste from avoidable admissions, and the savings being likely to be more than the costs of the programmes.</p>
Ulcerative colitis	<p>Self-management training and follow-up on request for patients with ulcerative colitis was associated with reduced hospital visits (0.9 versus 2.9 per patient per year), and fewer GP visits (0.3 versus 0.9 per patient per year) in a UK RCT (n=203) (E3 Rogers <i>et al</i> (no year given)).</p>
Inflammatory bowel disease	<p>Patients with inflammatory bowel disease experienced fewer hospital visits and felt more able to cope with their condition, after a self-care RCT of an intervention carried out across 19 UK hospitals (E3 Kennedy <i>et al</i> 2003). The intervention used patient guidebooks developed with service users. All patients prepared a written self-management plan and hospital specialists were trained to provide a patient-centred approach to care.</p>
Rehabilitation interventions	<p>Professionally-led self-management or rehabilitation interventions in the UK show better outcomes than lay-led interventions, according to some evidence presented by Griffiths <i>et al</i>'s 2007 overview; there is some evidence for this, as a general statement, from the studies considered in this review. The paper speculates this may be because professionally-led programmes 'are well targeted to patients most likely to benefit and provide interventions which lay-led programmes do not: correcting health beliefs and teaching specific, clinical, disease management skills, or including exercise programmes' (E3 Griffiths <i>et al</i> 2007).</p>
Lay-led self-care programmes	<p>The above Coulter and Ellins (2006) overview also drew attention to conflicting findings from studies of lay-led programmes and to the lack of evidence of change in resource use reported in four UK evaluations, in contrast with the findings of some US studies (E4 Griffiths <i>et al</i> 2007). It noted that the UK studies found small changes in self-efficacy, and three found no changes in self-rated health status.</p> <p>Evidence was found in one review of similar types of lay-led self-management education programmes being associated with short-term improvements in patients' confidence to manage their condition, in their perceptions of their own health and in how often people took aerobic exercise (17 trials assessed by E1 Foster <i>et al</i> 2007). It reported small improvements in pain, disability, fatigue and depression, from different trials with different patient groups, but no evidence of fewer visits to doctors or of less time spent in hospital.</p> <p>One US RCT reported reduced emergency department and outpatient visits, improved health behaviours, reduced symptoms and improved health status. This was from an RCT evaluating seven two-and-a-half-hour weekly sessions of peer-facilitated self-management education, in community settings, with groups of 15 to 20 participants (n=1,140 randomised, for first phase of the study; E4 Lorig <i>et al</i> 1999). The patients were those with heart disease, lung disease, stroke or arthritis. The second uncontrolled phase of the study (n=831) reported reduced service use and less emotional distress two years after the programme (E4 Lorig 2001). This 'Stanford model' intervention was the model for the extensive UK lay-led Expert Patients Programme (Department of Health 2001).</p>

Table 12: Self-care support interventions

Intervention	Evidence
Lay-led self-care programmes: specific patient groups and interventions	<p>Improved self-efficacy and energy levels in people with long-term health conditions compared to those randomised to wait for the course (n=629) was found in one early RCT of the UK Expert Patients Programme. There was no effect on routine health service use (GPs, practice nurse and outpatient visits) but some evidence of lower costs associated with overnight hospital and day case use: 'Overall, the costs in both groups were similar, because the costs of sending people on the course were recouped from savings elsewhere in the system. (E3 Kennedy <i>et al</i> 2007). As regards health economic cost-effectiveness, assessed through cost per QALY, the programme was judged to be cost-effective. An exact assessment cannot be made from the data provided in the Kennedy <i>et al</i> 2007 study of the Q+C ROI because it does not consider provider or health system budget impacts at one, three, and five years, but the evidence suggests the programme assessed is a possible value improvement.</p> <p>A high-quality cost-effectiveness RCT of the UK Expert Patient Programme found the intervention 'is very likely to provide a cost effective alternative to usual care in people with long-term conditions' (E3 Richardson <i>et al</i> 2008). The programme evaluated was a lay-led self-care group of six weekly sessions to teach self-care support skills, with 248 patients remaining in the intervention arm of the six-month follow-up. The study found better patient outcomes, with a slightly lower cost of about £27 per patient. However, it did note 'considerable potential for more research to consider whether other self-care programmes represent better value for money and improve patients' outcomes still further'.</p>
Arthritis	<p>Higher health and social care costs were found for the UK participants of a six-session arthritis self-management programme who were also given an education booklet (E3 Patel <i>et al</i> 2009). The control group were only given the education booklet (n=812). At 12 months the health and social care costs in the intervention group were £101 higher (95% confidence interval £3 to £176) than those in the control group.</p>
Osteoarthritis	<p>Evidence of the highest positive Q+C ROI, possibly because of the low cost of the intervention, is provided by one study of a programme using group discussions and education (E4 Groess 2000). The aim was to promote empathy, cohesiveness, and sharing of information and coping techniques between group members with osteoarthritis who volunteered (n=363 mean age). The study reports a three-year cost:benefit ratio of 1:11 (for every \$1 spent, \$11 were saved) at the first year, and between 1:22 for social support alone to 1:34 for social support and education. However, one significant flaw of the study was that no details of any kind were give about how savings were estimated. We do not know if the number of visits were costed and compared between different groups or whether these and other measures were used to estimate costs.</p>

Discussion: self-care support programmes

There are a number of limitations to the available evidence for making decisions about investing in any of these programmes.

- The evidence is limited about effects on healthcare resources. Few studies measure this and many are unable to show with any degree of certainty that changes in resource use can be attributed to the programmes. Resource use may shift, for example from specialist outpatient to primary care, or may increase overall.
- There is no systematic assessment of whether the same intervention has different effects for patients with different diseases or with co-morbidities. Studies combining patients with different diseases often do not analyse whether there are significantly different outcomes for patients with asthma to those with heart disease or diabetes in the same study.
- There is no systematic comparison of the effectiveness of simple interventions (for example, one training session and a manual) to multiple component interventions (for example, training providers as well as training patients), especially those multi-interventions that also aim to develop social support. Only a few interventions aim to improve both patient self-care abilities and the abilities of providers to enable self-care. Theory suggests that the latter may be more effective, if more costly, but there is no evidence from comparative studies.

It is possible for decision-makers to read one review of self-management training and conclude that the effects are minimal, and uncertain concerning downstream clinical and cost outcome. Yet many interventions are being used, for many patient groups, with many differences between the patients in their capacity to benefit and motivate, and many different processes and long-term outcomes are being measured. The research does not sufficiently differentiate which interventions are most effective for which patients.

Theory and some research into disease management (E1 Krause 2005) suggests that careful selection of the patients most likely to benefit is the key to achieving higher effectiveness for both health outcomes and lower costs. This is also likely to apply to self-care programmes, yet little research has been undertaken into specially-designed, targeted self-care support. For example, there are few studies of self-care interventions for older people with hypertension from low-income ethnic minority groups.

Overall, although there are different findings from different studies, the weight of the evidence points in the direction of lay-led self-management training being a value improvement, with the usual qualification about targeting those patients most likely to benefit and effective implementation. However, one overview of the evidence and of the potential of programmes for cancer patients did note that ‘the difficulties in evidencing the empirical effectiveness of complex programs may contribute to the lack of value and engagement placed on such models by clinicians’ (Wilson 2008).

Chapter 8

Findings 3 – value improvements that save

8.1 Solutions – evidence of value improvements giving savings

The problems listed in this report are only deficiencies if we assume that things could be otherwise. ‘Sub-optimal’ events can be changed to ‘more optimal’ by using ‘solutions’ or ‘interventions.’

Chapter 7 of this report (Findings 2 – solutions) lists the evidence of interventions that have been found to be effective for improving quality and reducing waste, or show great potential to reduce waste. This chapter uses this evidence to make estimates about whether the cost of the intervention may be paid for by any cumulative savings over a three-year period for an integrated health system (a three-year Q+C ROI).

‘Likely’ and ‘possible’ saving value improvements are listed for communication, collaboration and support for self-care interventions, as well as some ‘likely to cost more than they save.’ The likely saving value improvements are those interventions where there is adequate evidence of both improved quality and lower costs, and the costs of implementing the intervention (the investment) are likely to be paid for by lower costs within three years.

The second group, ‘possible saving value improvements’, is where the certainty of both higher quality and lower costs from the research is less strong. However, either the intervention is low cost, and thus savings are possible, or there is high plausibility from the available evidence of higher quality and savings. Some of the interventions in

this possible group have a high evidence rating (for example, E1). This may only refer to strength of evidence about improved quality; the evidence of cost-savings may be weaker.

The warning has been made before in this report: these are indications, and local estimates will need to be made because results depend on local implementation and context factors such as financing arrangements. Also, no evidence may mean there is no research or the research is poor. In some reviews it can also mean that research found no effects or no savings.

Communications value improvements

These are changes which give more appropriate information or increase understanding, and which may save resources three years or less after the start of the investment:

None are ‘likely’, but some are ‘possible’ value improvements

No ‘likely’ value improvements were found: this means that this review did not find research into communications interventions which reported strong evidence of both improved quality and less use of resources.

However, there was some evidence of improved quality and/or less use of resources that may cover the cost of the intervention for the following:

- Providing information: appropriate written and oral information prior to consultation, or prior to treatment, or post-treatment, if the information is matched to the patient's needs and abilities (E1 Griffin *et al* 2004; E3 Johansson *et al* 2005; E1 Coulter and Ellins 2007; E1 Johnson *et al* 2003).
- Patient writes concerns before consultation: an intervention to enable patients to write a note of their concerns before a clinical consultation (E1 Griffin *et al* 2004).
- Mobile phone text messaging: to give patients reminders about a scheduled healthcare appointment (to reduce non-attendance; E1 Car 2008), to communicate results of medical investigations (E1 Gurol-Urganici *et al* 2008), and feedback on treatment success, especially for patients with chronic illnesses (E4 de Jongh *et al* 2008).
- Mailed reminders and telephone reminders: to reduce non-attendance, or move non-attenders to the bottom of the waiting list (E2 Can *et al* 2003; E1 George and Rubin 2003; E3 Reekie and Devlin 1998; E4 Moser 1994; E3 Quattlebaum *et al* 1991; E2 Bech 2005).
- Enable question asking: specific appropriate interventions to enable patients from low-income, ethnic minority groups to ask their doctors more and better questions and to recognise the importance of asking questions in decision making (E3 Deen *et al* 2011).
- Training doctors: a specific intervention using role playing, feedback and small group discussions to improve patient communication skills (E1 Haskard Zolnieriek and DiMatteo 2009).
- Visual feedback: to patients of their medical imaging results for those who smoke or are at risk of UV-related skin cancer (E1 Hollands *et al* 2010).
- Offering patient email access: to physicians or specialist nurses for specific patients for specific purposes (E3 Car and Sheikh 2004; E3 Gagnon *et al* 2009).
- Patient internet sites: specific systems established by the patient's provider or their health system, with patient access and the ability to comment on personal health information – test results, problem summaries, medication lists and side effects (E4 Weingart *et al* 2008).
- Patient directed record tools: interventions to enable selected patients to use internet-based personal health record systems (PHRs) to create their own medical record and health diaries (E4 Archer *et al* 2011).

Likely to cost more than they save (communication interventions)

- Training without practice and feedback: educational interventions to providers in patient communication or collaboration skills that use only oral presentations without skill practice and feedback (E1 Berkhof *et al* 2011).
- Email access for all: offering all patients email communication direct to their physicians (E3 Katz 2003, but recent unpublished Kaiser Permanente (USA) data questions this for email to primary care doctors).

Collaboration value improvements

These are changes that enable patients and providers to work better together to improve a patient's health, and can save resources. Again, only specific interventions evaluated in a study are likely or possible to have these results. These results should not be expected from a whole category of interventions, such as all patient decision aids. The estimates are that they can save resources within three years or less after the start of the investment:

Medication-related – 'likely' value improvements

- Simplifying dosing: increases medication adherence and is a low-cost intervention (E1 Haynes *et al* 2005). Further downstream impact from increased adherence also affecting health and cost outcomes is likely, but unproven, and dependent on the effectiveness of the treatment for which adherence has increased.
- 'Calendar packaging': ideally with education and reminder strategies, to improve medication adherence (E1 Zedler *et al* 2011).

Medication-related – ‘possible’ value improvements

- Medication reconciliation: certain interventions to enable patients and providers to check the accuracy of their prescribed medications together when moving from one provider or unit to another (E3 Varkey *et al* 2007). Evidence is weak but assumptions about the costs of the intervention suggest that the potential Q+C ROI is high.
- Incentives for treatment compliance: for low-income patients with tuberculosis (E1 Giuffrida *et al* 1997).
- Patient reinforcement and reminding: for increasing adherence to lipid-lowering medications (which can reduce risks of heart disease or stroke), or simplification of the drug regimen or patient information and education for this purpose (E1 Schedlbauer *et al* 2010).

Patient role and participation – ‘likely’ value improvements

- Decision aids: some decision aids that can help patients choose between treatments or decline to use a treatment (E2 Kennedy *et al* 2002).

Patient role and participation – ‘possible’ value improvements

- Patient activation for safety: low-cost specific interventions to enable patients to speak up about known safety risks – for example, signs in rooms and staff wearing reminder buttons (E4 Waterman *et al* 2006; E4 Spath *et al* 2004; E4 Hinkin 2002).
- Combined intervention for physicians and specific patient groups: an intervention to improve physicians’ communication skills and activate patients to participate in their care, for patients from low-income, ethnic minority groups (E3 Cooper *et al* 2011).
- Specific interventions to improve patient participation in health consultations: these use patient-directed coaching, educational materials and feedback to providers of patient reported outcome measures, or specific communication skills training (E1 Haywood 2006).

- Access to rapid response team: allowing patients or relatives to call a hospital rapid response team in specific situations (E4 De Vita *et al* 2010; E4 NPSF 2007; E4 Odell *et al* 2010; E4 Dean *et al* 2008).
- Palliative care alternatives: patient/family-provider collaboration to provide palliative care as an alternative to other treatments which may not be wanted by the patient (E3 Morrison *et al* 2008; E3 Back *et al* 2005; E3 Brumley *et al* 2007; E3 Elsayem *et al* 2008).
- End-of-life home-based care: interventions to enable patient/family and provider collaboration to give home-based care to those patients at the end of life (E1 Shepperd *et al* 2011).
- Advanced directives or advanced care planning support programme: with independent regulated experts facilitating patients to prepare advanced directives (E3 Molloy *et al* 2000).

‘Likely’ to cost more than they save (collaboration interventions)

- Some safety recommendations: providing poorly selected safety recommendations to patients may reduce quality by raising anxiety, increase waste through the cost of preparing and providing the information, and through triggering patient concerns that unnecessarily interrupt healthcare routines (E4 Weingart 2009).
- Training without workplace change to allow training to be practised: training physicians in shared decision making, without other changes to the context of their practice (E3 Towle and Godolphin 2009).

Support for self-care

These are changes to enable patients to better care for themselves by providing information, education, access to experts by telephone or internet and other supports. This may then mean that a patient makes less, or more appropriate, use of a provider’s services or other resources such as medications.

Research evidence and reasoning from intermediate outcomes suggests that the following are likely to both improve quality and save resources three years or less after the start of the investment:

- Self-care for chronic illness: most types of self-care programmes for patients with chronic illnesses, but only if patients selected are those with the highest risk of avoidable admission and with the desire and capacity for self-care (E4 Lorig 2001). The selection and matching to the type of programme appears to be more important than the particular programme used.
- Versions of lay-led self-care teaching: some applications of the UK Expert Patients Programme of lay-led self-care teaching, with selected patients being those with the highest risk of avoidable admission (E3 Richardson *et al* 2008). Peer-facilitated self-management education for patients with heart disease, lung disease, stroke, or arthritis (E4 Lorig 1999). This intervention was the model for the UK lay-led Expert Patients Programme.

Some self-management programmes for patients with specific diseases

- Asthma: some interventions for asthma patients' self-management (E3 Downs *et al* 2006; E3 Krishna 2003).
- Type 2 diabetes: a group-based educational programme for people with type 2 diabetes mellitus (E1 Deakin *et al* 2005).
- Congestive heart failure: post-hospital discharge self-care support programmes for older people with congestive heart failure (E1 Phillips *et al* 2004).
- Ulcerative colitis: self-management training and follow-up on request for patients with ulcerative colitis (E3 Rogers *et al* (no year given)).
- Osteoarthritis: group discussions and education for patients with osteoarthritis (E4 Groess 2000).

'Possible' value improvements

- Inflammatory bowel disease: a 'possible' value improvement to be considered is a multiple component intervention for people with inflammatory bowel disease, including training for hospital specialists to provide a patient-centred approach to care (E3 Kennedy *et al* 2003).

'Likely' to cost more than they save

- Osteoarthritis: one type of osteoarthritis self-management programme (E1 Chodosh *et al* 2005).

Part 3: Practical implications

Chapter 9

Discussion

9.1 Limitations of the review

The review's limitations need to be emphasised (summarised in Figure 6 on page 61). The findings are not definitive statements of the only changes that will both improve quality and save money. Rather, they are indications of which changes decision makers could consider first and they show a way of thinking about how to improve quality when there is extreme pressure on time and resources.

The management review reported in this study departed from the traditional systematic review method for medical treatments. It did so by focusing on evidence about specific quality and cost outcomes of interventions; in grading evidence; including primary studies that did not meet the most rigorous criteria for research design but were relevant to the questions; and in making estimations about final outcomes, often from evidence of intermediate outcomes or process indicators.

The first limitation concerns the evidence from the research to answer the review questions. These are further described later, but are noted here. There is a growing body of research into patient-provider relations. For example, the Picker website lists '124 systematic and high quality narrative reviews that evaluated various initiatives designed to educate and support people with long-term conditions' (Picker 2011). However, the certainty and generalisability of the evidence of whether these initiatives save resources as well as improve quality is limited.

Evidence from these intervention studies is often about intermediate outcomes and not about downstream patient and cost outcomes resulting from the interventions – possible longer-term outcomes are important for assessing a return on investment that can take at least three years to pay back.

Second, the search and selection of studies was not comprehensive and some studies could have been missed. Much of the literature had already been reviewed, and the search was primarily to supplement these reviews by examining the reviews and primary studies for evidence of costs of the interventions and resource savings.

Third, the economic perspective taken is that of a healthcare provider system over three years. It does not consider wider social costs and savings made by patients and their informal carers or other stakeholders. Also, more interventions might be included if the return on investment can be longer than three years.

Fourth, generalisability of the findings from this review is limited. Most of the evidence is of a specific intervention or change carried out in one setting and often for one type of patient group. Whether the same intervention would produce the same outcomes elsewhere or for other patients is unknown, especially in another country. Reviews and multi-centre studies may give more generalisable findings, if the same intervention has been studied in different settings for different patients. But the results to expect in our own service with our patients are uncertain.

This is not least because we may not be able to implement the change in the same way as in the research and because our health system may be different.

Thus, research and the evidence can help practical improvements but can be misleading if local decision makers do not recognise the limitations and make their own assessments. The limitations are in one sense good news for researchers, as actionable evidence of the type considered here is much needed. But they also present a challenge for researchers to be more innovative in their research methods and in their collaborative research practices, and communicate in more usable formats to provide the information that decision makers need.

9.2 Limitations of the research reviewed

Reviews like this show what research has studied, rather than showing which problems and interventions exist, or which interventions might be effective. Research tends to be carried out into problems and interventions that yield to established research methods, and into issues of concern to industry such as adherence to medications.

‘No evidence’ often means no research, rather than meaning not proven or even disproven. Also, research may find an intervention ineffective for certain types of patient or patient conditions, or in certain settings, but it may be effective for others.

The lack of evidence of savings and improved quality from changing patient–provider relations may say more about research than it does about the innovations being carried out at present. There is no lack of descriptive evidence about interventions and changes that providers and patients are already making to improve patient–provider relations. For these changes, there is also some evidence of results (for example, from quality improvement research without control groups) but not evidence considered sufficiently strong for most systematic reviews of research.

Figure 6: Summary of limitations of the review

The limitations of this review need to be taken into account when using the information given here to decide actions:

- a. Some relevant primary research may have been missed.
- b. The search terms might not have identified some relevant studies.
- c. The exclusion criteria and thresholds for strength of evidence may have excluded some studies that provide useful evidence.
- d. The value improvement estimations give little certainty about likely local results of repeating an intervention. This is primarily because:
 - These estimates often use evidence of the intermediate effects of an intervention (for example, after an intervention giving a patient information about self-care, their improved understanding or fewer visits to a physician may be an intermediate effect).
 - The evidence of these intermediate effects is used to theorise about what may happen later, the downstream effects (for example, patient behaviour change, saved physician time), and, later still, end outcomes for health and resource use (for example, better health status or lower costs than would otherwise have happened without the intervention). The assumptions linking intermediate to end outcomes might be incorrect.
 - The estimates often make assumptions about the resources needed to implement the intervention, which may be incorrect. The resources needed will vary according to the capabilities of providers and health systems to make changes.

Limitations of systematic reviews and medical trial designs

As regards the problems and type of interventions considered in this review, there are limitations to some traditional medical research methods and systematic review methods for establishing the effects of complex social interventions (Kessler and Glasgow 2011; Craig *et al* 2008).

Most systematic reviews report insufficient evidence from uncontrolled designs or exclude such studies at an early stage even though they may be appropriate designs for certain questions. Research designs and review methods are likely to exclude many possibly effective interventions because they are difficult to assess using controlled trials, especially the more complex multi-component interventions that may be the more effective ones for supporting self-care.

Where controlled trial designs can be applied their external validity (generalisation) is questionable. For example, one study tested a telephone-counselling system previously shown to change patient behaviour in efficacy studies. However, the study found it was ineffective in primary care settings because patients failed to telephone the counsellors (Cohen *et al* 2008). In the original controlled trial, research assistants had made home visits to help participants initiate contact with the telephone system. This support provided by the research team during the efficacy trials appeared to be an essential part of the intervention to encourage and enable patients to initiate use of the telephone-counselling system.

Little research considers costs

Even when using criteria that accepted less strong evidence than traditional systematic reviews (graded E3, E4), this review found the research gave little acceptable costing information, or any other evidence about resource aspects of problems and interventions.

Some studies giving evidence of sub-optimal relations speculated about the possible impact of this on the use of healthcare resources, but no valid costing evidence was found in any reviews or primary studies. Regarding intervention studies, this review author's estimate is that about 1% of studies gave quantitative evidence of the cost of the intervention and about 2% provided quantitative evidence of

the impact on healthcare resources and/or costs, but the latter studies rarely costed implementation. None provided adequate evidence of cash-in-budget savings for providers or any other stakeholders.

As regards the systematic reviews considered in this review, most did not comment on the lack of evidence about resource use in the studies they reviewed or on whether research should provide such evidence to help practical decision making. The following was one conclusion from one review which did comment on the absence of costing data, with respect to home-based end-of-life care:

'the major gap in the evidence is around cost-effectiveness. The lack of precision around estimates of admission, or transfer, to hospital could have a major bearing on cost. This needs to be addressed, given the high costs of care at the end of life in developed countries'

(Shepperd *et al* 2011).

Figure 7: Acting on the evidence

The following are some issues to bear in mind when considering the research selected and presented in this review report:

- other types of sub-optimal patient-provider relations and support for self-care have been noted, but not studied in research or quantified,
- some problems do not have solutions invented yet; we do not know how easily some may be solved,
- some problems have theoretical solutions, but no one has tested them,
- some solutions have been tried, but not adequately evaluated; we have reports of the change, but limited or no evidence of effectiveness,
- some solutions have been evaluated and proved to be ineffective, or high cost relative to the savings,
- some solutions are effective and low cost, but may be difficult to implement or high cost in some services – for example, some services may need a computer upgrade to implement IT-supported communications with patients.

Chapter 10

Practical implications: What can I do with this?

The limitations mean that the review is primarily a guide for making a first assessment about which interventions to consider further and which research to consider first. To help this assessment, this section gives a simple method for assessing whether the primary research can be used locally to estimate likely problems or the impact of an intervention described in the research. It also discusses other practical implications.

10.1 Actions for operational managers of health systems or provider services

Managers and implementers can use this review to help answer three questions:

- Do any of the problems listed exist in our services? If so, how significant are they and what are the consequences of not taking action about them?
- Could we improve quality and reduce costs in our service by implementing any of the solutions?
- If we were to implement any of these solutions, where would the investment money and time come from and what would we not do, or do less of, to resource this investment?

Others are making changes to improve quality and lower costs. Some of these changes have been evaluated. Some of the evaluations give more certain findings than others and have been published. This review selected and lists the best evidence about costs and savings from this

research. A premise of this review is that managers can benefit from others' testing of these changes and from the research that has found what works and saves money.

However, this does not mean that copying another's changes guarantees local improvement. The evidence has to be assessed for its relevance to the manager's local setting and current service issues.

Even if there is strong evidence that one of the listed interventions resulted in improved quality and lower costs at the test site where the research was carried out, a manager still needs to make an assessment about whether it could be implemented locally and whether the costs and savings would be more or less than those reported at the test site. Even stronger evidence from a systematic review of improved results at many sites, or from many studies, also has to be assessed for its local relevance.

The research evidence shows what to expect from an intervention but each service will be different. The impact could be plus or minus 50% of that shown in the research, or more, which may mean that interventions making small cost-savings elsewhere actually result in losses if implemented locally. Research has identified the types of quality problems to look for that could be reduced at a cost less than the cost of the problem. Providers will need to use data from their service about the size of each problem, the wasted time and the financial cost of the problem to the service, given the current financing system.

Understand the current financing system and adapt the intervention if necessary

The service might be financed differently to the one in the study. It might not have to bear the cost of the problem, or it may even receive extra income as a result of the problem. For example, poor communication about medications at discharge may result in an adverse drug event causing re-admission. This re-admission may give the provider extra income in some financing systems. For this reason, it is important that providers are aware of how they are rewarded or penalised for different quality problems, and that they need to work with purchasers to make changes towards value-based financing that rewards rather than punishes them for doing the right thing.

Calculating one's own estimates is especially important for assessing the likely spend-cost of the solution. The result is likely to be different from that of the service cited in the study. Each service will need a slightly different solution; it will need to be implemented in a slightly different way and will use more or less resources than those at the study site.

Research shows that for some solutions to be effective, they need to be adapted to the service in question. Research also shows why this is so and how to carry out the adaptation (Øvretveit 2011b).

The causes of a problem in patient-provider relations in one service will be different in their specifics from those in another, even though they may be generally similar. Research can propose likely causes and can help providers start an analysis of causes, but problems are never due to just one cause and a solution has to involve multiple changes to address the different causes. The research does not give a detailed road map; only by knowing the specific causes in a service can the provider then design the combination of solutions for the causes.

The checklist shown in Figure 8 gives guidance for answering the second question:

‘Could we improve quality and reduce costs in our service by implementing any of the solutions?’

More detailed guidance is provided in an appendix to the Report to Congressional Requesters (GAO 2011).

Figure 8: Checklist for assessing whether to act on an evaluation

Assessing the research

- **Intervention and context description:** Were enough specific details given of the intervention to be reasonably able to replicate it locally and of the context to assess if any special conditions are needed to implement it?
- **Sample:** Which people or organisations were measured to get data about outcomes? Was the sample large enough and appropriate for the research objectives? If there was a comparison sample, was it a fair comparison?
- **Outcome measures:** Are the measures direct indications of the most important impacts of the intervention, or of intermediate or final outcomes? Are they measures of the costs of the changed service relative to the unchanged service or a comparison service? Or are they measures of visits or length of stay, where we have to guess the money value of any savings?
- **Attribution certainty:** Which other influences might explain any changes in the observed outcomes? Are these considered or controlled for by comparisons or randomisation? How likely is it that the intervention or something else caused the ‘outcomes’ reported in the study?

Assessing the local relevance

- **Different likely outcome:** How similar and different are your people or organisations from those in the study for whom outcomes were measured? Will the outcomes be greater or lesser for your people or organisations?
- **Resources:** Considering the resources they had to implement the intervention in the study, do you need more or fewer resources to implement something similar?
- **Context:** How is your context similar and different in ways that may affect ease and cost of implementation, future running costs and savings? Context includes features of the local facility, health system, funding and regulation that will affect implementation, availability of investment resources and operational funding payments.

Figure 9: Questions of costs and savings

When reports claim, ‘waste costs of ...’ or ‘potential savings from ...’, then be sceptical and ask:

- ‘where is the evidence and how strong is this evidence?’
- ‘has a solution been developed?’
- ‘how effective is the solution and how much does it cost?’
- ‘what would be different in my service for my patients and providers?’

10.2 Actions for researchers

The findings of this review have implications for researchers. The limitations of the research for informing practical action have been described. Possibly the most important implication for researchers is to provide more evidence about the cost consequences of problems, about the spending costs of interventions, and about savings or increased costs for different stakeholders.

A second subject for attention is to go beyond reports of associations between variables and address causality. This can be done using a logic model or theory of how interventions or problems link to later downstream events, or by identifying underlying principles that are common across studies and explain findings, be they effective or ineffective. If a logic model includes features of context critical to implementation, then the external validity or generalisability of the research will be greater.

Priorities for future research

The following subjects and interventions are proposed as priorities for future research. The two criteria for choosing the items on this list are: a) it is likely the research will more than pay for itself if it provides an actionable answer to these questions, and b) because the interventions already show promise for significantly reducing avoidable suffering and healthcare resource use.

Most prevention and health promotion interventions

- Little good evidence exists about both the costs and the health improvements that are thought to follow from many primary, secondary and tertiary prevention interventions, and from workplace or community health promotion programmes for different citizen or patient groups. There is little evidence to guide investment decisions about such interventions and programmes, and about whether, or for whom, any may be value improvements over different time periods.

Matching information and provider decision-support style to patient preferences and needs

- In which ways do patients vary in their preferences and needs for treatment information and decision involvement, and what are the quality and cost consequences of not matching?

Communication interventions – research priorities

- In which situations, for which patients, do different types of telemedicine improve quality and reduce costs? (There are conflicting findings from E1 Currell *et al* 2000, compared to E1 McLean *et al* 2010 (asthma); E1 Glueckauf and Ketterson 2004 (chronic illnesses); E4 Botsis 2008; E4 Friedman 1996; E4 Harrison 1999 and E3 Hill *et al* 2010).
- For which patients at which times could their ability to email or telephone their physician or specialist nurse result in improved quality and reduced costs?
- Which ‘smart home technologies’ improve quality and reduce costs? For example, social alarms, electronic assistive devices, telecare social alert platforms, environmental control systems, automated home environments and ‘ubiquitous homes’. In 2009, ‘there were no studies testing their effectiveness’ (E1 Martin *et al* 2009).

Collaboration interventions – research priorities

- Which methods are most effective for matching information and provider style to the patient’s preference and capabilities for action?
- Which interventions to promote patient actions to reduce risks of harm from healthcare are effective for improving quality and saving resources?
- Which types of ACP or AD programmes for people, and in which situations, improve quality of life and quality of death (EIU 2010) and reduce costs, and which type of regulations are required to avoid the abuse of these programmes?
- Do end-of-life, structured, multidisciplinary care planning methods (clinical pathways) reduce unnecessary suffering and waste, and what are their costs?

- For which patients in which situations can patient–provider contracts or patient incentives improve quality and reduce costs?
- Which interventions to assist decisions about entering long-term care result in improved quality and reduced costs?

Support for self-care interventions – research priorities

- Do self-management education interventions for people with COPD or arthritis cost more than they save and are there any significant improvements in quality of life that may justify any extra cost? (Contradictory costing findings for COPD are to be found in E1 Monninkhof 2003; E1 Effing *et al* 2007; E3 Bourbeau 2003; E3 Gadoury *et al* 2005; and significantly higher costs for arthritis self-management programmes reported by E3 Patel *et al* 2009.)
- Why do some specific interventions to improve self-management in some patients not change self-management behaviours, but do reduce use of healthcare? (As reported by Downs *et al* 2006 for asthma patients and Dunn *et al* 2007 for patients with depression and PTSD.)

10.3 Actions for research funders

The priorities for future research will not be addressed unless potential funders are willing to invest in research, and in research that is likely to produce a return on investment in terms of yielding actionable knowledge. In this respect, the return on investment of many traditional research designs and review methods is questionable.

The gaps in the research were described earlier in terms of conceptualising and measuring patient and provider relations and different patient-centred and patient-activation approaches. Limitations have been noted in:

- the empirical data about the size and consequences of different types of sub-optimal relations,
- the data about effectiveness and costs of interventions, and savings or losses,
- theory about the links between changes to patient–provider relations and intermediate and final outcomes,

- descriptions and evaluations of programmes to spread effective approaches to improving communication, collaboration and self-care.

These gaps are attractive opportunities for research funders and researchers to be in the forefront of a new field. Some gaps in knowledge can be reduced through better RCTs. Many will require new research methods more suited to understanding relationships between people and behaviour in social systems, and for quantifying resource use, waste and savings. Innovation in research and in research funding is required to provide practical answers. This is to both stimulate action and help practitioners, who are already making changes, to make better informed decisions.

10.4 Actions for regulators

The evidence is that sub-optimal communication, coordination and self-care is costly in terms of unnecessary suffering and wasted resources. It is part of a regulator’s mission to act on this evidence in order to protect patients and to help reduce costs for purchasers and providers. Regulators have a powerful influence and a key leadership role in stimulating improvements.

The research suggests specific actions that regulators can take, which includes:

- developing measurable process-of-care standards for key aspects of patient–provider communication and collaboration known to be essential,
- setting safety and quality goals that target communication and collaboration problems shown in the research,
- developing and using appropriate indicators to highlight performance in key aspects of communication, collaboration and providing self-care support,
- creating and assessing standards for ACP and AD that prevent abuse and ensure compliance with ethical and clinical best practice.

Regulators’ influence on providers can have both good and unanticipated negative consequences. Regulators sometimes underestimate the costs of compliance. For this reason, collaboration with providers and other stakeholders is necessary to develop standards, methods and indicators, and for pilot testing.

10.5 Actions for purchasers

When purchasers pay for the consequences of problems caused by sub-optimal communications, collaboration or self-care they are wasting money that could be used for other patients. The challenge is knowing which problems cause the most suffering and waste and which are resolvable at a cost proportionate to the likely savings.

This review offers some indications, but the practical challenge is to gather details of the specific services and patients covered then set local purchaser strategies to address these.

This will include:

- identifying those patients most likely to benefit from improvements in the areas where the cost savings are also high,
- selecting provider performance indicators that can be used to track the indicators and outcomes most influenced by the improvements needed,
- revising payment systems to avoid penalties and give incentives for effective actions, especially for providing self-care support, so as to pay for investments in changes and for sustaining them in a changed service,
- sharing costs and savings – either through a purchaser venture capital fund, or by outsourcing to a cost and savings sharing agent the tasks of agreeing a project, monitoring expenditure and savings, and sharing the resulting savings or costs.

Chapter 11

Conclusions

This review presents evidence of suffering and costs associated with sub-optimal communication and collaboration between health professionals and patients, and with sub-optimal support for self-care. Research shows the consequences for patients of health professionals not taking patients' preferences and lifestyles sufficiently into account and of not agreeing assessment and treatment plans in a more collaborative way.

There is also research that shows many patients and their carers feel unsupported in their efforts to take care of their health conditions and there is a high cost to the health system of failure to provide adequate support for self-care. Research also shows that services and factors outside of the health system affect people's ability to care for their health conditions.

In addition to this evidence of the problems, the research reviewed provides some evidence of solutions. There are interventions and changes to promote patient–professional communication and collaboration to bring about a more active role for patients, to change provider behaviour, and to support self-care. There is little high-quality evidence of the effectiveness of different interventions, and even less evidence of the costs and possible savings to different parties. This does not mean that some interventions might not improve quality and save money, just that it remains unproven for most if traditional systematic review standards of evidence of effectiveness are used to judge strength of evidence.

The value improvement estimates, and the method for making these assessments from the available evidence, provide a way of going beyond the evidence to give useful guidance for managers and researchers. If the limitations of the estimates are recognised and if managers use the guidance to make their local assessments, then the research reviewed can be helpful. It can provide a basis for changes that improve the quality of health services and provide a return on the investment.

Improvement will not come just because we know that there is a problem, or even that there is an effective solution. Improvement is more likely if the professionals and managers who give their time to make the change can expect that it will make a positive difference for patients, and give a time and resource return on their investment. In a resource-constrained health service, changes that can both save money and improve patient experience and outcomes are more likely to gain the widespread support needed to carry them through. These are the types of 'value improvement' that this report has considered.

Bibliography

- Adams D. Unmet expectations: Doctors, patients give each other mixed reviews. *American Medical News* 29 Jan 2007. <http://www.amaassn.org/amednews/2007/01/29/pr120129.htm> (accessed 29 July 2011).
- AHRQ. *US Department of Health and Human Services. AHRQ Healthcare Innovations Exchange. Rockville, Maryland: Agency for Healthcare Research and Quality.* <http://www.innovations.ahrq.gov/index.aspx> (accessed 15 September 2011).
- Aiarzaguena JM, Grandes G, Gaminde I et al. A randomized controlled clinical trial of a psychosocial and communication intervention carried out by GPs for patients with medically unexplained symptoms. *Psychological Medicine* 2007;37:283-294.
- Anderson G. *Chronic Conditions: Making the Case for Ongoing Care.* Baltimore: Johns Hopkins Bloomberg School of Public Health; 2007.
- Anderson LA, DeVellis R, Feussner JR. Patients' perceptions of their clinical interactions: development of the multidimensional desire for control scales. *Health Educ Res* 1989;4:383-97.
- Archer N, Fevrier-Thomas U, Lokker C, McKibbin K, Straus S. Personal health records: a scoping review. *J Am Med Inform Assoc* 2011;18:515-522.
- Auslander WF, Sterzing PR, Zayas LE, White NH. Psychosocial resources and barriers to self-management in African American adolescents with type 2 diabetes: a qualitative analysis. *Diabetes Educ* 2010;36(4):613-22.
- Back AL, Li YF, Sales AE. Impact of palliative care case management on resource use by patients dying of cancer at a Veterans Affairs medical center. *Journal of Palliative Medicine* 2005;8(1):26-35.
- Bailey JV, Murray E, Rait G, Mercer CH, Morris RW, Peacock R et al. Interactive computer-based interventions for sexual health promotion. *Cochrane Database of Systematic Reviews* 2010; Issue 9. Art. No.: CD006483. doi:10.1002/14651858.CD006483.pub2.
- Baker DW, Parker RM, Williams MV, Clark WS. Health literacy and the risk of hospital admission. *Journal of General Internal Medicine* 1998;13(12):791-798.
- Bayliss EA, Steiner JF, Fernald DH, Crane LA, Main DS. Descriptions of barriers to self-care by persons with comorbid chronic diseases. *Ann Fam Med* 2003;1:15-21.
- Bech M. The economics of non-attendance and the expected effect of charging a fine on non-attendees. *Health Policy* 2005;74:181-191.
- Beck RS, Daughtridge R, Sloane PD. Physician-patient communication in the primary care office: a systematic review. *J Am Board Fam Pract* 2002;15:25-38.
- Berkhof M, van Rijssen HJ, Schellart AJ, Anema JR, van der Beek AJ. Effective training strategies for teaching communication skills to physicians: an overview of systematic reviews. *Patient Educ Couns* 2011;84(2):152-62. Epub 29 Jul 2010.
- Bibowski RM, Ripsin CM, Lorraine VL. Physician-patient congruence regarding medication regimens. *Journal of the American Geriatric Society* 2001;49:1353-7.
- Black AD, Car J, Pagliari C et al. The impact of eHealth on the quality and safety of health care: a systematic overview. *PLoS Med* 2011;8:e1000387-e1000387.
- Blakeman T, Bower P, Reeves D, Chew-Graham C. Bringing self-management into clinical view: a qualitative study of long-term condition management in primary care consultations. *Chronic Illn* 2010;6(2):136-50.
- Blanchard J, Lurie N. R-E-S-P-E-C-T: patient reports of disrespect in the health care setting and its impact on care. *J Fam Pract* 2004;53:721-730.
- Blendon RJ, Buhr T, Cassidy EF, Perez DJ, Hunt KA, Fleischfresser C et al. Disparities in health: perspectives of a multi-ethnic, multi-racial America. *Health Aff (Millwood)* 2007;26:1437-1447.
- Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient Self-management of Chronic Disease in Primary Care. *JAMA* 2002;288(19):2469-2475.
- Bookbinder M, Blank A, Arney E, Wollner D, Lesage P, McHugh M et al. Improving end-of-life care: development and pilot-test of a clinical pathway. *Journal of Pain and Symptom Management* 2005;29(6):529-43.
- Bosch-Capblanch X, Abba K, Pricor M, Garner P. Contracts between patients and healthcare practitioners for improving patients' adherence to treatment, prevention and health promotion activities. *Cochrane Database of Systematic Reviews* 2007; Issue 2. Art. No.: CD004808. doi:10.1002/14651858.CD004808.pub3.
- Botsis T, Demiris, G, Pedersen S, Hartvigsen G. Home telecare technologies for the elderly. *J Telemed Telecare* 2008;14(7):333-337.
- Bourbeau J, Julien M, Maltais F, Rouleau M, Beaupré A, Bégin R et al. Reduction of Hospital Utilization in Patients With Chronic Obstructive Pulmonary Disease. *Arch Intern Med* 2003;163(5):585-591.
- Braddock CH, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: time to get back to basics. *JAMA* 1999; 282:2313-20.
- Brown HC, Smith HJ. Giving women their own case notes to carry during pregnancy. *Cochrane Database of Systematic Reviews* 2004;(2):CD002856.
- Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S et al. Increased satisfaction with care and lower costs: Results of a randomized trial of in-home palliative care. *Journal of the American Geriatric Society* 2007;55(7):993-1000.
- Burgess DJ, Ding Y, Hargreaves M et al. The association between perceived discrimination and underutilization of needed medical and mental health care in a multi-ethnic community sample. *J Health Care Poor Underserved* 2008;19:894-911.
- Cabana MD, Jee SH. Does continuity of care improve patient outcomes? *The Journal of Family Practice* 2004;53(12):974-80.
- Can S, Macfarlane T, O'Brien KD. The use of postal reminders to reduce non-attendance at an orthodontic clinic: a randomised controlled trial. *British Dental Journal* 2003;195(4):199-201.
- Car J, Gurol-Urganci I, de Jongh T, Vodopivec-Jamsek V, Atun R. Mobile phone messaging reminders for attendance at scheduled healthcare appointments. *Cochrane Database of Systematic Reviews* 2008; Issue 4.
- Car J, Sheikh A. Email consultations in health care: 1-scope and effectiveness. *BMJ* 2004;329(7463):435-8. See also, Car J, Sheikh A. Email consultations in health care: 2-acceptability and safe application. *BMJ* 2004;329(7463):439-42.
- Carlson R, Devich WL, Frank RR. Development of a comprehensive supportive care team for the hopelessly ill on a university hospital medical service. *Journal of the American Medical Association* 1988;259(3):378-383.
- Casagrande SS, Gary TL, Laveist TA et al. Perceived discrimination and adherence to medical care in a racially integrated community. *J Gen Intern Med* 2007;22:389-395.
- Challis D, Hughes J, Reilly S, Abell J, Stewart K. *Self-care and Case Management in Long-term Conditions: The Effective Management of Critical Interfaces.* Southampton: National Institute for Health Research Service Delivery and Organisation programme; 2010.
- Chan R, Webster J. End-of-life care pathways for improving outcomes in caring for the dying. *Cochrane Database of Systematic Reviews* 2010; Issue 1. Art. No.: CD008006. doi:10.1002/14651858.CD008006.pub2.
- Chodosh J, Morton SC, Mojica W et al. Meta-analysis: chronic disease self-management programs for older adults. *Ann Intern Med* 2005;143(6):427-38.

- Christensen C, Grossman J, Hwang J. *The Innovator's Prescription: A Disruptive Solution for Health Care*. Cambridge: Harvard Business School Press; 2008.
- CHSRF. *Evidence Boost: Self-management education to optimize health and reduce hospital admissions for chronically ill patients*. www.chsrf.ca/research_themes/safety_e.php (accessed 8 June 2011).
- Clarke EA, Notghi A, Harding LK. Counting the cost of patients who do not attend nuclear medicine departments. *Nuclear Medicine Communications* 1998;19(3):193-7.
- Claxton AJ, Cramer J, Pierce C. A systematic review of the associations between dose regimens and medication compliance. *Clin Ther* 2001;23:1296-1310.
- CMS. Medicare Hospice Conditions of Participation – Final Rule. 73 FR 32204, 5 June 2008.
- Cohen D, Crabtree B, Etz R, Balasubramanian B, Donahue K, Leviton L et al. Fidelity Versus Flexibility: Translating Evidence-Based Research into Practice. *Am J Prev Med* 2008;35(5S):S381-S389.
- Cooper L, Roter D, Carson C, Bone L, Larson S, Miller E et al. A Randomized Trial to Improve Patient-Centered Care and Hypertension Control in Underserved Primary Care Patients. *JGIM* 2011;26(11):1297-1304. doi:10.1007/s11606-011-1794-6 (accessed 21 July 2011).
- Coulter A, Ellins J. (Picker Institute Europe). *Patient-focused interventions: A review of the evidence*. London: The Health Foundation; 2006. www.health.org.uk/QQUIP.
- CQC. *Outpatient survey – National briefing*. London: UK NHS Care Quality Commission; 2009. www.esds.ac.uk/findingData/snDescription.asp?sn=6576 (accessed 15 Sept 2011).
- Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. *Developing and evaluating complex interventions: new guidance*. London: Medical Research Council; 2008. www.mrc.ac.uk/complexinterventionsguidance (accessed 15 Sept 2011).
- Cramer JA, Rosenheck R. Compliance with medication regimens for mental and physical disorders. *Psychiatr Serv* 1998; 49:196-201.
- Crowe M, Whitehead L, Jo Gagan M, Baxter D, Panckhurst A. Self-management and chronic low back pain: a qualitative study. *J Adv Nurs* 2010; 66(7):1478-86.
- Currell R, Urquhart C, Wainwright P, Lewis R. Telemedicine versus face to face patient care: effects on professional practice and health care outcomes. *Cochrane Database of Systematic Reviews* 2000; Issue 2. Art. No.: CD002098. doi:10.1002/14651858.CD002098.
- de Jongh T, Gurol-Urganci I, Vodopivec-Jamsek V, Car J, Atun R. Mobile phone messaging telemedicine for facilitating self management of long-term illnesses (protocol). *Cochrane Database of Systematic Reviews* 2008; Issue 4. Art. No.: CD007459. doi:10.1002/14651858.CD007459.
- de Silva D. *Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management*. London: The Health Foundation; 2011.
- De Vita M, Smith G, Adam S. Identifying the hospitalised patient in crisis - A consensus conference on the afferent limb of Rapid Response Systems. *Resuscitation* 2010;81(4):375-382.
- Deakin T, McShane CE, Cade JE, Williams RD. Group based training for self management strategies in people with type 2 diabetes mellitus. *Cochrane Database of Systematic Reviews* 2005;(2):CD003417.
- Dean BS, Decker MJ, Hupp D, Urbach AH, Lewis E, Benes-Stickle J. Condition HELP: a pediatric rapid response team triggered by patients and parents. *J Healthc Qual* 2008;30(3):28-31.
- Deen D, Lu WH, Rothstein D, Santana L, Gold MR. Asking questions: The effect of a brief intervention in community health centers on patient activation. *Patient Education and Counseling* 2011;84(2):257-260.
- Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? *J Clin Epidemiol* 1992;45:941-950.
- Devlin, N Parkin, D. Does NICE have a cost-effectiveness threshold and what other factors influence its decisions? A binary choice analysis. *Health Economics* 2004;13(5):437-452.
- DiMatteo MR. Variations in patients' adherence to medical recommendations: a quantitative review of 50 years of research. *Med Care* 2004; 42:200-209.
- DoH. *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*. London: Department of Health, The Stationery Office; 2008. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277 (accessed 27 November 2009).
- DoH. *Research evidence on the effectiveness of self-care support*. London: UK NHS Department of Health; 2007.
- DoH. *The Expert Patient: A new approach to chronic disease management in the 21st Century*. UK Department of Health, The Stationery Office; 2001.
- Downs JA, Roberts CM, Blackmore AM, Le Souëf PN, Jenkins SC. Benefits of an education programme on the self-management of aerosol and airway clearance treatments for children with cystic fibrosis. *Chron Respir Dis* 2006;3(1):19-27.
- Dugdale D, Epstein R, Pantilat S. Time and the Patient-Physician Relationship. *Journal of General Internal Medicine* 1999;14(S1):34-40.
- Duncan E, Best C, Hagen S. Shared decision making interventions for people with mental health conditions. *Cochrane Database of Systematic Reviews* 2010; Issue 1. Art. No.: CD007297. doi:10.1002/14651858.CD007297.pub2.
- Dunn NJ, Rehm LP, Schillaci J, Soucek J, Mehta P, Ashton CM et al. A randomized trial of self management and psychoeducational group therapies for comorbid chronic posttraumatic stress disorder and depressive disorder. *J Trauma Stress* 2007;20(3): 221-37.
- Effing T, Monninkhof EM, van der Valk PD, van der Palen J, van Herwaarden CL, Partidge MR et al. Self-management education for patients with chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews* 2007;(4):CD002990.
- EIU. *The quality of death: Ranking end-of-life care across the world*. London: Economist Intelligence Unit; 2010. http://www.eiu.com/sponsor/lienfoundation/qualityofdeath (accessed 11 August 2011).
- Elsayem AK, Swint MJ, Fisch JL, Palmer S, Reddy P, Walker D et al. Palliative care inpatient service in a comprehensive cancer center: Clinical and financial outcomes. *Journal of Clinical Oncology* 2004;22(10):2008-2014.
- Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ* 2006;333:417-21.
- Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *J Gen Intern Med* 1989;4:23-30.
- Entwistle VA et al: Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Qual Saf Health Care* 2010;19:e33.
- Fitzmaurice DA, Murray ET, Gee KM, Allan TF, Hobbs FD. A randomised controlled trial of patient self-management of oral anticoagulation treatment compared with primary care management. *J Clin Pathol* 2002;55(11):845-9.
- Flach S, McCoy K, Vaughn T, Ward M, BootsMiller B, Doebbeling B. Does Patient-centered Care Improve Provision of Preventive Services? *Journal of General Internal Medicine* 2004;19(10):1019-1026.

- Foot C and Maybin Jo. *How to deliver high-quality, patient-centred, cost-effective care: Consensus solutions from the voluntary sector*. London: The King's Fund; 2010.
- Foster G, Taylor SJ, Eldridge SE, Ramsay J, Griffiths CJ. Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database of Systematic Reviews* 2007;(4):CD005108.
- Friedman R, Kazis L, Jette A, Smith M, Stollerman J, Torgerson J et al. A telecommunications system for monitoring and counseling patients with hypertension. Impact on medication adherence and blood pressure control. *American Journal of Hypertension* 1996;9(4 Part 1):285-292.
- Frost J and Massagli M. Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data. *J Med Internet Res* 2008;10(3):e15.
- Fumagalli S, Boncinelli L, Lo Nostro A, Valoti P, Baldereschi G, Di Bari M et al. Reduced cardiocirculatory complications with unrestricted visiting policy in an intensive care unit: results from a pilot, randomized trial. *Circulation* 2006;113(7):946-52.
- Gadoury M-A, Schwartzman K, Rouleau M, Maltais F, Julien M, Beaupre A et al. Self-management reduces both short- and long-term hospitalisation in COPD. *Eur Respir J* 2005;26:853-857.
- Gagnon M-P, Légaré F, Labrecque M, Frémont P, Pluye P, Gagnon J et al. Interventions for promoting information and communication technologies adoption in healthcare professionals. *Cochrane Database of Systematic Reviews* 2009; Issue 1. Art. No. : CD006093. doi:10.1002/14651858. CD006093.pub2.
- Gallefoss F, Bakke P. Cost-benefit and cost-effectiveness analysis of self-management in patients with COPD: A 1-year follow-up randomized, controlled trial. *Respir Med* 2002;96:424-431.
- Gandhi T. Fumbled handoffs: one dropped ball after another. *Ann Intern Med* 2005;142(5):352-58.
- GAO. *Value in health care, Report to Congressional Requesters, report GAO-11-445*. <http://www.gao.gov> (accessed 28 July 2011).
- Gask, L, Dowrick C, Dixon C, Sutton C, Perry R, Torgerson D, Usherwood, T. A pragmatic cluster randomized controlled trial of an educational intervention for GPs in the assessment and management of depression. *Psychological Medicine* 2004;34: 63-72.
- George A, Rubin G. Non-attendance in general practice: a systematic review and its implications for access to primary health care. *Family Practice* 2003;20(2):178-84.
- Gillett M, Dallosso H, Dixon S, Brennan A, Carey M, Campbell M et al. Delivering the diabetes education and self-management for ongoing and newly diagnosed (DESMOND) programme for people with newly diagnosed type 2 diabetes: cost-effectiveness analysis. *BMJ* 2010;341:c4093 doi:10.1136/bmj.c4093.
- Giuffrida A, Torgerson D. Should we pay the patient? Review of financial incentives to enhance patient compliance. *BMJ* 1997; 315:703-7.
- Glueckauf RL, and Ketterson TU. Telehealth interventions for individuals with chronic illness: Research review and implications for practice. *Professional Psychology: Research and Practice* 2004;35:615-627.
- Goedhuys J, Rethans J-J. On the relationship between the efficiency and the quality of the consultation. A validity study. *Fam Pract* 2001;18:592-596.
- Goldsmith B, Dietrich J, Du Q, Morrison R. Variability in access to hospital palliative care in the United States. *Journal of Palliative Medicine* 2008;11(8):1094-1102.
- Goodrich J and Cornwell J. *Seeing the person in the patient: The Point of Care review paper*. London: The King's Fund; 2008.
- Gordon MM, Hampson R, Capell HA, Madhok R. Illiteracy in rheumatoid arthritis patients as determined by the Rapid Estimate of Adult Literacy (REALM) score. *Rheumatology* 2002;41(7):750-754.
- Graffy J, Eaton S, Sturt J, Chadwick P. Personalized care planning for diabetes: policy lessons from systematic reviews of consultation and self-management interventions. *Primary Health Care Research and Development* 2009;10:210-222. doi:10.1017/S1463423609001157.
- Gravolin M, Rowell K, de Groot J. Interventions to support the decision-making process for older people facing the possibility of long-term residential care. *Cochrane Database of Systematic Reviews* 2007; Issue 3. Art. No.: CD005213. doi:10.1002/14651858. CD005213.pub2.
- Greenhalgh T, Peacock R. Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. *BMJ* 2005. doi:10.1136/bmj.38636.593461.68.
- Greenhalgh T, Robert G, Bate P, Kyriakidou O, Macfarlane F, Peacock R. *A systematic review of the literature on diffusion, dissemination and sustainability of innovations in health service delivery and organisation*. London: NHSSDO Programme; 2004. www.sdo.lshtm.ac.uk .
- Griffin SJ, Kinmonth, AL, Veltman, MW, Gillard, S, Grant J, Stewart M. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. *Annals of Family Medicine* 2004;2:595-608.
- Griffiths C, Foster G, Ramsay J, Eldridge S, Taylor S. How effective are expert patient (lay led) education programmes for chronic disease? *BMJ* 2007;334:254-1256.
- Groess EJ and Cronan TA. A cost analysis of self management programs for people with chronic illness. *Am J Comm Psy* 2000;28(4):455-80.
- Gurol-Urganci I, de Jongh T, Vodopivec-Jamsek V, Car J, Atun R. Mobile phone messaging for communicating results of medical investigations. *Cochrane Database of Systematic Reviews* 2008; Issue 4.
- Guyatt GH, Oxman AD, Vist GE, Kunz R, Falck-Ytter Y, Alonso-Coello P et al. GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. *BMJ* 2008;336:924-6.
- Hager P. A high-volume specialist palliative care unit and team may reduce in-hospital end-of-life care costs. *Journal of Palliative Medicine* 2003;6(5):699-705.
- Hall J et al Effectiveness of interventions designed to promote patient involvement to enhance safety: a systematic review. *Qual Saf Health Care* .2010;19:e10.
- Harris Interactive. *Few patients use or have access to online services for communicating with their doctors, but most would like to*. London: Harris Interactive; 2006. www.harrisinteractive.com/news/allnewsbydate.asp?NewsID=1096.
- Harrison R, Clayton W, Wallace P. Virtual outreach: a telemedicine pilot study using a cluster-randomized controlled design. *Journal of Telemedicine and Telecare*1999;5(2):126-130.
- Hartley LA. Examination of primary care characteristics in a community-based clinic. *J Nurs Scholarsh* 2002;34:377-382.
- Haskard Zolnieriek K, DiMatteo MR. Physician Communication and Patient Adherence to Treatment: A Meta-analysis. *Med Care* 2009;47(8):826-834. doi: 10.1097/MLR.0b013e31819a5acc.
- Hausmann LR, Jeong K, Bost JE, Ibrahim SA. Perceived discrimination in health care and health status in a racially diverse sample. *Med Care* 2008;46:905-914.
- Hausmann LRM, Kressin NR, Hanusa BH et al. Perceived racial discrimination in health care and its association with patients' healthcare experiences: does the measure matter? *Ethn Dis* 2010;20:40-47.

- Haverhals LM, Lee CA, Siek KA, Darr CA, Linnebur SA, Ruscini JM et al. Older adults with multi-morbidity: medication management processes and design implications for personal health applications. *J. Med. Internet Res* 2011; 13(2): e44. doi:10.2196/jmir.1813
- Haynes R, Yao X, Degani A, Kripalani S, Garg A, McDonald H et al. Interventions to enhance medication adherence. *Cochrane Database of Systematic Reviews* 2005;(4):CD000011.
- Haynes RB, Ackloo E, Sahota N, McDonald HP, Yao X. Interventions for enhancing medication adherence. *Cochrane Database of Systematic Reviews*. 2008; Issue 2. doi:10.1002/14651858.CD000011.pub3.
- Haywood K, Marshall S, Fitzpatrick R. Patient participation in the consultation process: A structured review of intervention strategies. *Patient Education and Counseling* 2006;63(1):12-23.
- Henderson C, Laugharne R. User-held personalised information for routine care of people with severe mental illness. *Cochrane Database of Systematic Reviews* 1999; Issue 3. Art. No.: CD001711. doi: 10.1002/14651858.CD001711.
- Heneghan CJ, Glasziou PP, Perera R. Reminder packaging for improving adherence to self-administered long-term medications. *Cochrane Database of Systematic Reviews* 2006; Issue 1. Art. No.: CD005025. doi:10.1002/14651858.CD005025.pub2.
- Hibbard JH, Collins PA, Mahoney E, Baker LH. The development and testing of a measure assessing clinician beliefs about patient self-management. *Health Expect* 2010;13(1):65-72.
- Higginson IJ, Sen-Gupta GJA. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 2000;3:287-300.
- Hill RD, Luptak MK, Rupper RW, Bair B, Peterson C, Dailey N, Hicken BL. Review of Veterans Health Administration telemedicine interventions. *Am J Manag Care* 2010;16(12 Suppl HIT):e302-10.
- Hinkin J. Hand decontamination: what interventions improve compliance? *EDTNA /ERCA J* 2002;28:134-7.
- Hitchcock-Noël P, Parchman M, Williams J et al. The Challenges of Multimorbidity from the Patient Perspective. *J Gen Intern Med* 2007 22(Suppl 3):419-24.
- Hollands GJ, Hankins M, Marteau TM. Visual feedback of individuals' medical imaging results for changing health behaviour. *Cochrane Database of Systematic Reviews* 2010; Issue 1. Art. No.: CD007434. doi:10.1002/14651858.CD007434.pub2 .
- Howard DH, Gazmararian J, Parker RM. The impact of low health literacy on the medical costs of Medicare managed care enrollees. *The American Journal of Medicine* 2005;118, 371-377.
- IHI. *Quality improvement case studies and improvement stories*. <http://www.ihl.org/IHI/Topics/Improvement/ImprovementMethods/ImprovementStories/imindexpage.htm?Page1/410andcbUser1/41andcbIHI1/41> (accessed 7 May 2010).
- Illich I. *Medical Nemesis: The Expropriation of Health*. New York: Random House; 1976.
- IOM. *Health literacy: a prescription to end confusion*. Washington, DC: National Academies Press; 2004. <http://www.nap.edu> (accessed 15 Sept 2011).
- Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. *Patient Educ Couns* 2005;57:300-7.
- Johansson K, Nuutila L, Virtanen H, Katajisto J, Salanterae S. Preoperative education for orthopaedic patients: systematic review. *J Adv Nurs* 2005;50:212-23.
- Johnson A, Sandford J, Tyndall J. Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *Cochrane Database of Systematic Reviews* 2003; Issue 4: CD003716.
- Jones L, Harrington J, Barlow C, Tookman A, Drake R, Barnes K, King M. Advance care planning in advanced cancer: Can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. *Palliative and Supportive Care* 2011;9:3-13.
- Kaplan SH, Gandek B, Greenfield S, Rogers W, Ware JE. Patient and visit characteristics related to physicians' participatory decision-making style. Results from the Medical Outcomes Study. *Medical Care* 1995;33(12):1176-87.
- Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware JE Jr. Characteristics of physicians with participatory decision-making styles. *Annals of Internal Medicine* 1996;124:497-504.
- Kaplan SH, Greenfield S, Ware JE Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medical Care* 1989;27:S110-S123.
- Katz SJ, Moyer CA, Cox DT, Stern DT. Effect of a triage-based e-mail system on clinic resource use and patient and physician satisfaction in primary care: A randomized controlled trial. *Journal of General Internal Medicine* 2003;18(9):736-44.
- Kennedy AD, Sculpher MJ, Coulter A, Dwyer N, Rees M, Abrams KR et al. Effects of decision aids for menorrhagia on treatment choices outcomes and costs: A randomized controlled trial. *JAMA* 2002;288:2701-2708.
- Kennedy A, Nelson E, Reeves D et al. A randomised controlled trial to assess the impact of a package comprising a patient-orientated, evidence-based self-help guidebook and patient-centred consultations on disease management and satisfaction in inflammatory bowel disease. *Health Technol Assess* 2003;7(28):1-113.
- Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Richardson G et al. The effectiveness and cost effectiveness of a national lay-led self-care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *J Epidemiol Community Health* 2007; 61(3):254-61.
- Kessler R and Glasgow R. A Proposal to Speed Translation of Healthcare Research Into Practice: Dramatic Change Is Needed. *Am J Prev Med* 2011;40(6):637-644.
- Kiesler D, Auerbach S. Optimal matches of patient preferences for information, decision-making and interpersonal behavior: Evidence, models and interventions. *Patient Education and Counseling* 2006; 61(3):319-341.
- King M, Davidson O, Taylor F, Haines A., Sharp D, Turner R. Effectiveness of teaching general practitioners skills in brief cognitive behaviour therapy to treat patients with depression: randomised controlled trial. *British Medical Journal* 2002;324:947-953.
- Kinnersley P, Edwards A, Hood K, Cadbury N, Ryan R, Prout H et al. Interventions before consultations for helping patients address their information needs. *Cochrane Database of Systematic Reviews* 2007; Jul 18; (3):CD004565. Epub 2007 Jul 18.
- Krause DS. Economic effectiveness of disease management programs: a meta-analysis. *Dis Manag* 2005;8(2):114-34.
- Krishna S, Francisco BD, Balas EA, König P, Graff GR, Madsen RW. Internet-enabled interactive multimedia asthma education program: a randomized trial. *Pediatrics* 2003;111(3): 503-10.
- Larisch A, Schweickhardt A, Wirsching M et al. Psychosocial interventions for somatising patients by the general practitioner: a randomized controlled trial. *Journal of Psychosomatic Research* 2004;57:507-514.
- Lewin SA, Skea ZC, Entwistle V, Zwarenstein M, Dick J. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews* 2005;1.
- Lidz CW, Meisel A, Munetz M. Chronic disease: the sick role and informed consent. *Cult Med Psychiatry* 1985;9:241-255.

- Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, Ferrier K. Observational study of patient-centredness and 'positive' approach on outcomes of general practice consultations. *BMJ* 2001;323:908.
- Loeb SJ. African American older adults coping with chronic health conditions. *J Transcult Nurs* 2006;17:139-47.
- Lord J, Victor C, Littlejohns P, Ross FM, Axford JS. Economic evaluation of a primary care-based education programme for patients with osteoarthritis of the knee. *Health Technol Assess* 1999;3(23):1-55..
- Lorig K, Ritter P, Stewart A, Sobel D, Brown BW Jr, Bandura A et al. Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Med Care* 2001;39:1217-1223.
- Lorig KR, Sobel DS, Stewart AL, Brown BW Jr, Bandura A, Ritter P et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care* 1999;37(1):5-14.
- Macheira WM, Leon G, Rowe BH, Stephenson BJ, Haynes RB. An overview of interventions to improve compliance with appointment keeping for medical services. *JAMA* 1992;267(13):1813-7.
- Markle. *Health in a Networked Life*. <http://www.markle.org/health/public-opinion-surveys/latest-surveys> (accessed 7 Feb 2011).
- Marteau TM, French DP, Griffin SJ, Prevost AT, Sutton S, Watkinson C et al. Effects of communicating DNA-based disease risk estimates on risk-reducing behaviours. *Cochrane Database of Systematic Reviews* 2010; Issue 10. Art. No.: CD007275. doi:10.1002/14651858.CD007275.pub2.
- Martin S, Kelly G, Kernohan WG, McCreight B, Nugent C. Smart home technologies for health and social care support. *Cochrane Database of Systematic Reviews* 2008; Issue 4. Art. No.: CD006412. doi:10.1002/14651858.CD006412.pub2.
- McBride CA, Shugars DA, DiMatteo MR, Lepper HS, O'Neil EH, Damush TM. The physician's role. Views of the public and the profession on seven aspects of patient care. *Arch Fam Med* 1994;3:948-53.
- McLean S, Chandler D, Nurmatov U, Liu J, Pagliari C, Car J, Sheikh A. Telehealthcare for asthma. *Cochrane Database Syst Rev* 2010;10:10.1002/14651858.CD007717.pub2.
- Meier D, Dietrich J, Morrison S, Spragens L. *Palliative Care, Quality and Costs, in IOM (Institute of Medicine). The Healthcare Imperative: Lowering Costs and Improving Outcomes: Workshop Series Summary*. Washington, DC: The National Academies Press; 2010.
- Merelle SY, Sorbi MJ, Duivenvoorden HJ, Passchier J. Qualities and health of lay trainers with migraine for behavioral attack prevention. *Headache* 2010;50(4):613-25.
- Meyer J, Smith B. *Chronic Disease Management: evidence of predictable savings*. Washington DC: Health Management Associates; 2008.
- Molloy DW, Guyatt GH, Russo R, Goeree R, O'Brien BJ, Bédard M et al. Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. *JAMA* 2000;283(11):1437-44.
- Monninkhof E, van der Valk P, van der Palen J et al. Self-management education for patients with chronic obstructive pulmonary disease: a systematic review. *Thorax* 2003;58(5):394-8.
- Moore CG, Wilson-Witherspoon P, Probst JC. Time and money: effects of no-shows at a family practice residency clinic. *Family Medicine* 2001;33(7):522-7.
- Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, Meier DE. Cost savings associated with US hospital palliative care consultation programs. *Archives of Internal Medicine* 2008;168(16):1783-1790.
- Moser SE. Effectiveness of post card appointment reminders. *Family Practice Research Journal* 1994;14(3):281-8.
- Murray E, Burns J, See Tai S, Lai R, Nazareth I. Interactive Health Communication Applications for people with chronic disease. *Cochrane Database of Systematic Reviews* 2005; Issue 4. Art. No.: CD004274. doi:10.1002/14651858.CD004274.pub4.
- Nicolson D, Knapp P, Raynor DK (Theo), Spoor P. Written information about individual medicines for consumers. *Cochrane Database of Systematic Reviews*. 2009; Issue 2. Art. No.: CD002104. doi:10.1002/14651858.CD002104.pub3.
- Nilsson-Ihrfelte E, Ilskog M, Blomqvist C, Ahlgren J, Edlund P, Hansen J et al. Breast cancer on the Internet: the quality of Swedish breast cancer websites. *The Breast* 2004;13:376-382.
- NPR/Kaiser Family Foundation/Harvard School of Public Health. *The public and the health care delivery system*. NPR/Kaiser Family Foundation/Harvard School of Public Health; 2009. <http://www.kff.org> (accessed 15 Sept 2011).
- NPSF. *National Patient Safety Foundation presents annual Socius Award to North Carolina Children's Hospital at NPSF annual Congress May 2-4, 2007 in Washington DC, USA*. http://www.npsf.org/pr/pressrel/2007-05-4_2.php (accessed 19 July 2011).
- O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2009; Issue 3. Art. No.: CD001431. doi:10.1002/14651858.CD001431.pub2.
- O'Connor PJ. Improving medication adherence: challenges for physicians, payers and policy makers. *Archives of Internal Medicine* 2006;166:1802-4.
- Odell M, Gerber K, Gager M. Call 4 Concern: patient and relative activated critical care outreach. *Br J Nurs* 2010;19(22):1390-5.
- Osterberg L, Blaschke T. Adherence to medication. *N Engl J Med* 2005;353:487-497.
- Øvretveit J (2003). *What is the best strategy for improving quality and safety of hospitals – a review and synthesis of the evidence*. Copenhagen: WHO; 2003. Also from WHO web page (<http://www.euro.who.int/hen>); <http://www.euro.who.int/en/what-we-do/data-and-evidence/health-evidence-network-hen/publications/pre2009/what-are-the-best-strategies-for-ensuring-quality-in-hospitals>.
- Øvretveit J (2005a). *What are the advantages and disadvantages of different quality tools – a review and synthesis of the evidence*. Copenhagen: WHO; 2005. <http://www.euro.who.int/hen>.
- Øvretveit J (2005b). Leading Improvement. *Journal of Health Organization and Management* 2005;19(6):413-430.
- Øvretveit J (2009). *Does improving quality save money? A review of evidence of which improvements to quality reduce costs for health service providers*. London: The Health Foundation; 2009. www.health.org.uk or in public folder in <https://www.dropbox.com/home> (User = jovreta@aol.com Pass = aaaaaa).
- Øvretveit J (2011a). *Does clinical coordination improve quality and save money? A review of the evidence of costs and savings of improvements to patient care coordination*. London: The Health Foundation; 2011. www.health.org.uk or in public folder in <https://www.dropbox.com/home> (User = jovreta@aol.com Pass = aaaaaa).
- Øvretveit J (2011b). Understanding the conditions for improvement: research to discover which context influences affect improvement success. *BMJ Qual Saf* 2011;20(Suppl_1):i18-i23.
- Øvretveit J (2012a). *Summary of 'Do changes to patient-provider relationships improve quality and save money?'*. London: The Health Foundation; 2012. www.health.org.uk or in public folder in <https://www.dropbox.com/home> (User = jovreta@aol.com Pass = aaaaaa).

- Parrish JM, Charlop MH, Fenton LR. Use of a stated waiting list contingency and reward opportunity to increase appointment keeping in an outpatient pediatric. *Journal of Pediatric Psychology* 1986;11:81-9.
- Patel A, Buszewicz M, Beecham J, Griffin M, Rait G, Nazareth I et al. Economic evaluation of arthritis self-management in primary care. *BMJ* 2009;339:b3532.
- Pearson ML, Mattke S, Shaw R, Ridgely MS, Wiseman SH. *Patient Self-Management Support Programs: An Evaluation*. Final Contract Report (Prepared by RAND Health under Contract No. 282-00-0005). Rockville, MD: Agency for Healthcare Research and Quality; 2007. AHRQ Publication No. 08-0011.
- Peat M, Entwistle V, Hall J, Birks Y, Golder S. Scoping review and approach to appraisal of interventions intended to involve patients in patient safety. *J Health Serv Res Policy* 2010;15:17-25.
- Penrod JD, Deb P, Luhrs C, Dellenbaugh C, Zhu CW, Hochman T et al. Cost and utilization outcomes of patients receiving hospital-based palliative care consultation. *Journal of Palliative Medicine* 2006;9(4):855-860.
- Phillips CO, Wright SM, Kern DE, Singa RM, Shepperd S, Rubin HR. Comprehensive discharge planning with post-discharge support for older patients with congestive heart failure: a meta-analysis. *JAMA* 2004;291:1358-67.
- Picker Institute. *Invest in Engagement*. <http://www.investinengagement.info/SiteGuidetop> (accessed 21 Nov 2011).
- Piette J, Schillinger D, Potter M, Heisler M. Dimensions of Patient-provider Communication and Diabetes Self-care in an Ethnically Diverse Population. *Journal of General Internal Medicine* 2003;18(8):624-633.
- Pitkethly M, MacGillivray S, Ryan R. Recordings or summaries of consultations for people with cancer. *Cochrane Database of Systematic Reviews* 2008; Issue 3. Art. No.: CD001539. doi:10.1002/14651858.CD001539.pub2.
- Pothier DD, Nankivel P, Hall CEJ. What do patients think about being copied into their GP letters? *Ann R Coll Surg Engl* 2007;89:718-2.
- Quattlebaum TG, Darden PM, Sperry JB. Effectiveness of computer-generated appointment reminders. *Pediatrics* 1991;88(4):801-5.
- Raddish M, Horn SD, Sharkey PD. Continuity of care: Is it cost effective? *American Journal of Managed Care* 1999; 5(6):727-734.
- Ranmal R, Prictor M, Scott JT. Interventions for improving communication with children and adolescents about their cancer. *Cochrane Database of Systematic Reviews* 2008; Issue 4. Art. No.: CD002969. doi:10.1002/14651858.CD002969.pub2.
- Reekie D, Devlin H. Preventing failed appointments in general dental practice: a comparison of reminder methods. *British Dental Journal* 1998;185(6):472-4.
- Repper J, Nolan M, Grant G, Curran M, Enderby P, Goward P. *Family Carers on the Margins: Experiences of Assessment in Mental Health*. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation. Nottingham University, Sheffield University and Sheffield Hallam University; 2008.
- Richardson G, Gravelle H, Weatherly H, Ritchie G. Cost-effectiveness of interventions to support self-care: A systematic review. *International Journal of Health Services* 2005;21(4): 423-432.
- Richardson G, Kennedy A, Reeves D, Bower P, Lee V, Middleton E et al. Cost effectiveness of the Expert Patients Programme (EPP) for patients with chronic conditions. *J Epidemiol Community Health* 2008; 62(4):361-7.
- Roberts K, Callanan I, Tubridy N. Failure to attend out-patient clinics: is it in our DNA? *Int J Health Care Qual Assur* 2011;24(5):406-12.
- Rogers A, Robinson A, Thompson D. Randomised controlled trial of guided self management for patients with ulcerative colitis. *The National Primary Care Research and Development Centre* (no year given). www.npcrdc.man.ac.uk/research.cfm. See also: Robinson A, Thompson DG, Wilkin D, Roberts C et al. Guided self management and patient-directed follow up of ulcerative colitis: a randomised trial. *Lancet* 2001;358(9286):976-81.
- Rosendal M, Bro F, Fink P, Christensen KS, Olesen F. Diagnosis of somatisation: effect of an educational intervention in a cluster randomised controlled trial. *British Journal of General Practice* 2003;53:917-922.
- RWJ. *Return on Investments in Public Health: A Summary of Groundbreaking Research Studies*. Policy Highlights Brief. Princeton, NJ: Robert Wood Johnson Foundation; 2011. www.rwjf.org
- Ryan R, Santesso N, Hill S, Lowe D, Kaufman C, Grimshaw J. Consumer-oriented interventions for evidence-based prescribing and medicines use: an overview of systematic reviews. *Cochrane Database of Systematic Reviews* 2011; Issue 5. Art. No.: CD007768. doi:10.1002/14651858.CD007768.pub2.
- Sans-Corrales M, Pujol-Ribera E, Gené-Badia J, Pasarín-Ruad M, Iglesias-Pérez B, Casajuana-Bruneta J. Family medicine attributes related to satisfaction, health and costs. *Family Practice* 2006;23(3):308-316.
- Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: A narrative review. *Patient Education and Counseling* 2006;60:102-14.
- SBU. *Patient Education in Managing Diabetes: A Systematic Review*. Stockholm: Swedish Council on Health Technology Assessment; 2009.
- Schedlbauer A, Davies P, Fahey T. Interventions to improve adherence to lipid lowering medication. *Cochrane Database of Systematic Reviews* 2010; Mar 17;(3):CD004371.UK.
- Schillinger D, Piette J, Grumbach K, Wang F, Wilson C, Daher C et al. Closing the loop: Physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine* 2003;163(1):83-90.
- Schlender M. *Health Technology Assessments by the National Institute for Health and Clinical Excellence*. New York: Springer Science+Business Media; 2007.
- Schoen C et al. Primary care and health system performance: adults' experiences in five countries. *Health Affairs* 2004. doi: 10.1377/hlthaff.w4.487.
- Schoen C, Osborn R, Doty M, Squires D, Peugh J, Applebaum S. A Survey Of Primary Care Physicians In Eleven Countries, 2009: Perspectives On Care, Costs, And Experiences. *Health Affairs* 2009. Published online before print November 2009, doi:10.1377/hlthaff.28.6.w1171.
- Schoen C, Osborn R, How S, Doty M, Peugh J. In Chronic Condition: Experiences of Patients with Complex Health Care Needs, in Eight Countries. Published online before print November 2008, doi:10.1377/hlthaff.28.1.w1.
- Schoen C, Osborn R, Huynh PT, Doty M, Zapert K, Peugh J, Davis K. Taking the pulse of health care systems: experiences of patients with health problems in six countries. *Health Affairs* 2005; Jul-Dec: Suppl Web Exclusives:W5-509-25.
- Schulz R. Some critical issues in caregiver intervention research. *Aging Ment Health* 2001;5:S112-S115.
- Schwappach DL and Wernli M. Predictors of chemotherapy patients' intentions to engage in medical error prevention. *Oncologist* 2010;15:903-12.
- Schwappach DL. Review: engaging patients as vigilant partners in safety: a systematic review. *Med Care Res Rev* 2010;67(2):119-48. Epub 2009 Aug 11.

- Scott TL, Gazmararian JA, Williams MV, Baker DW. Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Medical Care* 2002;40(5):395-404.
- Shepperd S, Wee B, Straus SE. Hospital at home: home-based end of life care. *Cochrane Database of Systematic Reviews* 2011; Issue 7. Art. No.: CD009231. doi:10.1002/14651858. CD009231.
- Smith TJ and Cassel JB. Cost and non-clinical outcomes of palliative care. *Journal of Pain Symptom Management* 2009;38(1):32-44.
- Smith TJ, Coyne P, Cassel B, Penberthy L, Hopson A, Hager MA. A high-volume specialist palliative care unit and team may reduce in-hospital end-of-life care costs. *Journal of Palliative Medicine* 2003;6(5):699-705.
- Sokol MC, McGuigan KA, Verbrugge RR, Epstein RS. Impact of Medication Adherence on Hospitalization Risk and Healthcare Cost. *Med Care* 2005;43(6):521-30.
- Spath P (ed.) *Partnering with Patients to Reduce Medical Errors*. Chicago: Health Forum Inc; 2004.
- Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2011; Issue 10. Art. No.: CD001431. doi:10.1002/14651858. CD001431.pub3.
- Stevenson F, Cox K, Britten N, Dundar Y. A systematic review of the research on communication between patients and health care professionals about medicines: the consequences for concordance. *Health Expectations* 2004;7:235-245.
- Stewart MA. Effective physician-patient communication and health outcomes: a review. *Canadian Medical Association Journal* 1995;152: 1423-33.
- Stone S. A Retrospective Evaluation of the Planetree Patient-Centred Model of Care on Inpatient Quality Outcomes. *Health Environments Research and Design Journal* 2008;1(4):55-69.
- Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *JAMA* 1984;252:2990-2994.
- Sutherland HJ, Llewellyn-Thomas HA, Lockwood GA, Tritchler DL, Till JE. Cancer patients: their desire for information and participation in treatment decisions. *J R Soc Med* 1989;82:260-263.
- Tarn DM, Heritage J, Paterniti DA, Hays RD, Kravitz RL, Wenger NS. Physician communication when prescribing new medications. *Arch Intern Med* 2006a;166:1855-1862.
- Tarn DM, Paterniti DA, Heritage J, Hays RD, Kravitz RL, Wenger NS. Physician communication about the cost and acquisition of newly prescribed medications. *American Journal of Managed Care* 2006b;12(11):657-64.
- Terri R, Fried T, Tinetti M, Iannone L. Primary Care Clinicians' Experiences With Treatment Decision Making for Older Persons With Multiple Conditions. *Arch Intern Med* 2011;171(1):75-80.
- Todhunter P, Clamp P, Gillett S, Pothier D. Readability of outpatient letters copied to patients: can patients understand what is written about them? *The Journal of Laryngology and Otology* 2010;24:324-327.
- Towle A, Godolphin W. Education and training of health care professionals, Ch53 381-88, in Edwards A and Elwyn G (eds.) *Shared decision-making in health care: Achieving evidence-based patient choice*. Oxford: Oxford University Press; 2009.
- University of Ottawa Health Research Institute (UOHRI). *An inventory of patient decision aids*. <http://decisionaid.ohri.ca/cochinvent.php> (accessed 20 July 2011).
- Varkey P, Cunningham J, Bisping S. Improving Medication Reconciliation in the Outpatient Setting. *The Joint Commission Journal on Quality and Patient Safety* 2007;33(5):286-294.
- Vuorma S, Teperi J, Aalto A et al. A randomised controlled trial among women with heavy menstruation – impact of a decision aid on treatment outcomes and costs. *Health Expectations* 2004;7:327-337.
- Wallerstein N. *What is the evidence on effectiveness of empowerment to improve health?* In Minkler M and Wallerstein N (eds.) *Community-based participatory research for health*. San Francisco, CA: Jossey Bass; 2003.
- Warsi A, LaValley MP, Wang PS, Avorn J, Solomon DH et al. Arthritis self-management education programs: a meta-analysis of the effect on pain and disability. *Arthritis and Rheumatism* 2003;48(8):2207-2213.
- Waterman A, Gallagher T, Garbutt J, Waterman B, Fraser V, Burroughs T. Hospitalized Patients' Attitudes About and Participation in Error Prevention. *J Gen Intern Med* 2006;21(4):367-370.
- Weingart SN, Hamrick HE, Tutkus S, Carbo A, Sands DZ, Tess A et al. Medication safety messages for patients via the Web portal: the MedCheck intervention. *Int J Med Inform* 2008;77(3):161-8.
- Weingart SN, Simchowit B, Kahlert-Eng T, Morway L, Spencer J, Zhu J, et al. The 'You CAN' campaign: teamwork training for patients and families in ambulatory oncology. *Jt Comm J Qual Safe* 2009;35:63-71.
- Weiss BD and Palmer R. Relationship between health care costs and very low literacy skills in a medically needy and indigent Medicaid population. *Journal of the American Board of Family Practice* 2004;17(1):44-47.
- Wesch D, Lutzker JR, Frisch L, Dillon MM. Evaluating the impact of a service fee on patient compliance. *Journal of Behavioral Medicine* 1987;10(1):91-100.
- White C. Improvement in Practice: *The personal touch. The Dutch experience of personal health budgets*. London: The Health Foundation; 2011.
- Wilson A, Childs S. The relationship between consultation length, process and outcomes in general practice: a systematic review. *Br J Gen Pract* 2002;52:1012-1020.
- Wilson P. The UK Expert Patients Program: Lessons learned and implications for cancer survivors' self-care support programs. *J Cancer Surviv* 2008;2:45-52.
- Wolters R, Grol R, Schermer T, Akkermans R, Hermens R, Wensing M. Improving initial management of lower urinary tract symptoms in primary care: costs and patient outcomes. *Scand J Urol Nephrol* 2006;40(4):300-306.
- Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Journal of the American Medical Association* 2008;300(14):1665-1673.
- Zedler BK, Kakad P, Colilla S, Murrelle L, Shah NR. Does packaging with a calendar feature improve adherence to self-administered medication for long-term use? A systematic review. *Clin Ther* 2011;33(1):62-73.
- Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC et al. Health care costs in the last week of life: Associations with end-of-life conversations. *Archives of Internal Medicine* 2009;169(5):480-488.

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The Health Foundation is an independent charity working to continuously improve the quality of healthcare in the UK.

We want the UK to have a healthcare system of the highest possible quality – safe, effective, person centred, timely, efficient and equitable.

We believe that in order to achieve this, health services need to continually improve the way they work. We are here to inspire and create the space for people to make lasting improvements to health services.

Working at every level of the system, we aim to develop the technical skills, leadership, capacity and knowledge, and build the will for change, to secure lasting improvements to healthcare.

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