

Research paper

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Managing people with long-term conditions



An Inquiry into the Quality of General Practice in England

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This paper was commissioned by The King's Fund to inform the Inquiry panel.

The views expressed are those of the authors and not of the panel.

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Executive summary

Better management of people with long-term conditions has been a key priority of the NHS since the early 1990s. At that time it was recognised that if people with long-term conditions were managed effectively in the community, they should remain relatively stable and enjoy a quality of life free from frequent crises or observed increases in hospital visits. However, relatively little information exists on what constitutes best practice in terms of the role that general practice should play in this care alongside other primary, community and social care providers.

This report forms part of the inquiry into the quality of general practice in England commissioned by The King's Fund. Its core aims are to:

- establish what constitutes best practice in the management of long-term conditions (LTC management)
- describe the role that GPs and the wider general practice team should play in delivering high-quality care to those people with long-term chronic illnesses
- make an assessment of current care quality
- establish whether measures of quality in LTC management could be developed to support quality improvements in general practice, and what these might be.

The research undertook a literature review of the evidence and best-practice guidance supplemented with face-to-face interviews with selected expert informants. The research focused on six key areas:

- arthritis
- dementia
- depression
- diabetes
- people with multiple long-term conditions
- managing long-term conditions across a population.

Arthritis

The current state of care quality to people with both osteoarthritis and rheumatoid arthritis is difficult to determine given the lack of objective quality measures. However, the evidence suggests that care quality is currently highly variable and sub-optimal and could be significantly improved.

A better understanding of the condition among primary care professionals is required, and a more proactive approach to care management is needed. General practice has a core role to play, but delivering high-quality care to people with arthritis should be shared across care settings and multi-professional teams.

Dementia

Research suggests that early diagnosis and intervention is important in increasing the quality of life and life expectancy of people with dementia, and that general practice plays a pivotal role in this. However, while the vast majority of first diagnoses for suspected dementia occur in general practice, this often occurs late in the illness or at a time of crisis, when the opportunities for the management of the condition to maximise quality of life have passed.

There is evidence to suggest that many GPs are either unable or unwilling to recognise dementia symptoms, for a range of reasons, including:

- an inability to differentiate symptoms that may be attributed to the natural signs of ageing and/or could be confused with other disorders
- the lack of specialist services to which patients may be referred
- the lack of training and/or time to make an adequate diagnosis
- the judgement that such individuals might cope better and feel less distressed if a formal diagnosis were avoided.

There was also evidence of a lack of ownership of dementia care responsibility within general practice, and a lack of necessary partnership working and/or care continuity. However, examples do exist of high-quality care – for example, where general practice has developed ‘in-reach’ services into care homes, or has used multi-disciplinary care and assessment processes.

Currently, there is no widespread use of approaches to measure the quality of dementia care in general practice, although audit criteria that support high-quality care have been developed.

Depression

For people who experience depression over extended periods of time, high-quality care involves being supported by a planned system of collaborative care that involves case management, systematic follow-up and improved integration of primary and secondary care. High-quality care also requires sensitivity towards a patient’s perception of the cause and nature of the problem. The evidence suggests the need for a strengths-based approach that provides treatment while also seeking to aid recovery.

There is a lack of clarity among GPs about what their role should be in the care for people with depression. Our research suggests that GPs possess many of the right skills, but some lack the confidence, support or time to use them. Overall, there is considerable potential to improve the quality of care to people with mild-to-moderate depression in general practice, but there is a need for increased clinical education and training, alongside work to build collaborative care models with specialists and to tackle social attitudes and stigma.

Diabetes

General practice plays a pivotal role in the management of diabetes, and has made a significant contribution to its effective management. Many aspects of diabetes management have improved markedly in recent years, through

better recording and ongoing management (incentivised through the Quality and Outcomes Framework). However, the evidence suggests that there still remains a high degree of variability in performance. For example, only 51 per cent of people with type 2 diabetes, and 32 per cent of people with type 1 diabetes, currently receive all the care processes set out in best-practice guidance from the National Institute for Health and Clinical Excellence (NICE). Key areas for improvement include the initiation and implementation of care planning and the need to share information with patients and among care providers.

People with multiple long-term conditions

The impact of multi-morbidity is profound. People with several long-term conditions have markedly poorer quality of life, poorer clinical outcomes and longer hospital stays, and are the most costly group of patients that the NHS has to look after. There is little evidence suggesting what high-quality care looks like for people with multiple long-term conditions (and hence few quality measures that could be applied). However, what evidence does exist suggests that people with multiple long-term conditions tend to get poorer treatment than others.

The challenges posed by multi-morbidity underline the importance of general practice, but also the need for it to work more collaboratively with other care providers – and vice versa. Problems in the care of people with multiple needs appear to be system-wide rather than specific to general practice. This suggests a need for a collaborative care model comprising multi-disciplinary case management, systematic follow-up, and working that is better integrated – for example between mental and physical health professionals. While GPs or other professionals in general practice might not necessarily take the lead role, they need to work closely with whoever does provide the case management, as well as maintaining clinical responsibility and remaining a locus of care continuity for the patient.

Population management

'Population management' refers to the strategic activity of proactively identifying individuals who are at risk of deterioration, with the intention of then developing interventions to help slow that deterioration and avoid the need for institutional care. The use of such approaches to manage long-term conditions across a population has advanced in recent years, with mixed results. General practice appears to have taken a peripheral, rather than central, role.

Where interventions are appropriately targeted, there is great potential in population management for improving care quality for patients with long-term care needs. The involvement of general practice is important to the development of the service – particularly in terms of sharing the data and information they have on patients. The high-quality general practice of the future will need to embrace this contribution to managing populations and so seek to provide more proactive and cost-effective care.

Conclusions

There is a significant amount of guidance and expert agreement on what constitutes high-quality care for people with long-term conditions, but relatively little agreement on the role that general practice should play in partnership with other care providers to deliver it.

Apart from certain indicators developed through the Quality and Outcomes Framework, there is otherwise little data and information to judge current care quality. What evidence does exist suggests that significant improvements have been made in some areas – particularly for diseases such as diabetes, heart failure and chronic obstructive pulmonary disease – but less progress has been made for depression, dementia and arthritis, and these require a more collaborative care model for a higher quality of care to be achieved.

In the future, general practice should play a pivotal role in the delivery of high-quality care to people with long-term conditions as part of a shared care model in which responsibility is distributed across different teams and settings. Currently, quality of care remains variable. This might be significantly improved if a more proactive approach to multi-disciplinary care management were adopted. Measures of quality linked to incentives should be developed to help support general practice to play its part in improving the quality and cost-effectiveness of care to people living with long-term conditions.

1 Introduction

As part of the inquiry into the quality of general practice in England commissioned by The King's Fund, this research report examines the quality of the management of people with long-term conditions (LTCs) and long-term mental health problems.

The core aims of this report are:

- to establish what constitutes best practice in the management of long-term conditions
- to describe the potential roles that GPs and the wider general practice team should play in the delivery of high-quality management of long-term conditions
- to establish whether and what measures of quality in the management of long-term conditions have and could be developed to support quality improvement in general practice.

This report provides a current assessment of what is known about the current quality of long-term conditions management in general practice, including how quality varies from practice to practice. It also reviews the measures (if any) that are used to assess or hold GP practices to account for such quality, provides one or two practical examples of best practice (where these exist), and provides a commentary on the challenges faced by general practice in meeting the quality agenda for long-term conditions management. Finally, the report makes some recommendations on the potential impact for stimulating significant quality improvements in general practice in the management of people with LTCs.

Given that high-quality approaches to LTC management are likely to vary from condition to condition, the research has sought to focus on five key areas:

- arthritis
- dementia
- depression
- diabetes
- people with multiple co-morbidity.

In addition, the research considers the role of general practice in the management of long-term conditions within local populations, since proactive case finding appears important in identifying such individuals who are at risk of hospitalisation and/or home care support.

The choice of the four specific conditions was influenced by the fact that each has been subject to major guidance related to the quality of care in recent years. Taken together, the report attempts to make some generic comments on the quality of management of long-term conditions in general practice, and on how this may be measured and improved in the future.

Report structure

Following a short description of the methodology employed in this research (Section 2), the report begins with a brief overview of recent government policy to show how the proactive management of people with long-term conditions has become central to the reform agenda (Section 3). It then examines in detail each of the four condition-specific areas (sections 4–7) as well as co-morbidity (Section 8), using a common template as follows:

- Background
- What does high-quality care look like?
- What is the role of general practice?
- The current quality of care in general practice
- Measuring quality
- The potential impact of quality improvement.

Section 9 examines the role that general practice should play in the management of LTCs across a population.

Section 10 is a unifying chapter that provides a summary of the key findings and develops an understanding of the generic roles that general practice should play in the management of people with long-term conditions. It also seeks to judge the importance of improving quality, and identifies key measures that may be used for this purpose. The section concludes with a commentary on the specific challenges faced by general practice in delivering high-quality care for people with LTCs.

Methods

The research was undertaken from April to December 2009, and consisted of two key phases of work as follows:

Phase 1: Literature review

The literature review phase of the work included a systematic review of all English policy documentation and published guidance related to the management of people with long-term conditions, with a specific focus on the tracer conditions. In addition, we undertook a non-systematic review of the national and international literature on models of LTC and disease management, to examine the evidence for best practice and the suggested roles that general practice should play.

The research team used PubMed, ASSIA and HMIC bibliographic databases to search for articles on the management of long-term conditions in primary care. The number of articles resulting was further refined for relevance, to choose those that looked specifically at the role of GPs and general practice in LTC management for the conditions selected in the research. An example of the study terms is provided in Appendix 1.

Phase 2: Qualitative research

To supplement the findings from the literature, we carried out face-to-face and/or telephone interviews with a range of key informants, using a

purposeful selection of between 8 and 12 individuals per LTC. We piloted the interview protocol with half a dozen respondents before refining it and creating a general interview template. We then adapted the template for use by LTC and by type of respondent. (For an example of the interview protocol used, see Appendix 2).

Each interview also contained generic questions about the management of people with co-morbidity. Expert informants typically included policy-makers, GPs with a special interest (GPSIs), community nurses, secondary care clinicians, commissioners, lead academics, and representatives from patient groups and/or the third sector. For a list of the numbers and types of expert informants interviewed in the research, see Appendix 3.

The sub-study examining the management of LTC populations took a slightly different methodology, by undertaking a number of field visits to specific case-study sites that had been proactive in risk stratification and case finding. The methodology for this part of the study is explained in Section 9.

2 Policy review

In England, integrating care for the management of people with a long-term condition (LTC), including the ability to promote and support self-care, has become a core strategy for its National Health Service (NHS). For example, the previous government set a central commitment to provide the opportunity for all 15.4 million people in England who have a LTC to receive an integrated and personalised care plan by 2010 (Department of Health 2006b).

Within this main policy lie a number of sub-policies, including:

- the active promotion of self-care strategies to enable people with LTCs to live independently in the home environment (the *Your Health, Your Way* initiative – Department of Health 2009a)
- the piloting of personal health budgets to enable LTC patients and carers to tailor their care packages (Department of Health 2009b)
- investment in population-oriented health management through the use of predictive modelling techniques that enable at-risk individuals and populations to be targeted with appropriate interventions (Department of Health 2007a)
- a movement towards new integrated care organisations, which potentially provide an in-house set of comprehensive health and social care services to registered patients, as well as an advocacy role in brokering the provision of care outwith these organisations (Department of Health 2009c).

The focus on LTC management derives from a policy environment in the 1990s that revealed that a growing proportion of inpatient activity was being fuelled by people with long-term conditions such as asthma, diabetes, and sickle cell anaemia (Department of Health 2004a). It was shown that, if managed effectively (for example, through proactive case finding), activity could be relatively stable and should not result in frequent crisis and observed increases in inpatient stays (Billings *et al* 1993, 2006).

As a result of these observations, it became apparent that a fundamental shift was required in the way care needed to be delivered – from the episodic treatment of illness in institutions to the proactive management of patients in the community. This finding was in line with international evidence showing how the long-term economic burden in health and social care was directly related to people living longer with increasingly complex conditions (see Comas-Herrera and Wittenberg 2003).

LTC management emerged as a key strand of health policy in the late 1990s, with the publication of a number of National Service Frameworks (NSFs) for mental health, cancer, coronary heart disease (CHD) and diabetes. Other NSFs subsequently emerged, including a specific NSF for long-term conditions that was published in 2005 and one for COPD in 2008. These NSFs set out to establish national standards and to identify key interventions for particular care groups or diseases, with the NSF for long-term conditions being the exception to such single-disease specific frameworks.

To facilitate the implementation of standards of LTC management in general practice, the Quality and Outcomes Framework (QOF) (which was adopted from 2004 onwards) placed a particular focus on paying general practice for the achievement of evidence-based performance targets in the identification and management of people with LTCs registered in general practice. Practices are awarded points according to the number of indicators they meet, and they receive funding accordingly.

The QOF was designed to make the monitoring of patients with long-term conditions more proactive. The 18 clinical areas incentivised through QOF include aspects of care to people with dementia, depression, and diabetes that will be reviewed in this study – but not for arthritis or directly for people with multiple co-morbidities. The overall impact of the QOF is contested, but by its very presence shows the importance attached to the role of general practice in managing people with long-term chronic care needs.

In recent years, the application of LTC management into practice has been further prioritised by a number of key policies. In 2004, the government published the *NHS Improvement Plan*, which promised higher-quality care for people with long-term conditions. The document established a new role – the community matron – and pledged to roll out the Expert Patients Programme, in which patients receive intensive education to become experts in their own condition (Department of Health 2004a).

More recent policies have reiterated the importance of LTC management – for example, as set out in the White Paper *Our Health, Our Care, Our Say* (Department of Health 2006a), the *NHS Next Stage Review* (Darzi 2008) and world class commissioning – an approach to systematically improving and making more influential the planning, procurement and performance management of the NHS as a key lever in promoting system redesign and improving health and well-being (Department of Health 2007b). An implicit agenda in these policies has been to better co-ordinate care planning and delivery between health and social care, as well as to focus on upstream interventions that promote health and well-being and minimise illness.

The election of the coalition government in 2010 has since led to a major reform programme of the NHS, though the focus on LTC management looks set to remain a key focus of activity given the need to reduce unscheduled hospital admissions (Department of Health 2010). In particular, the policy has highlighted:

- the need to better involve patients in decisions about their own health to facilitate self-care
- the importance of personalised care planning
- the need to reduce emergency re-admissions to hospitals for those people that could be managed in the community.

Delivering higher-quality care for people with long-term conditions

At present, it is widely recognised that the delivery of high-quality LTC management is not widespread and requires standardisation across the country. Key issues include:

- removing barriers to accessing LTC management

- developing the levers and incentives to enable professionals to deliver it
- supporting the workforce to adjust to a new way of working, including a focus on governance, professional practice and cultural relationships.

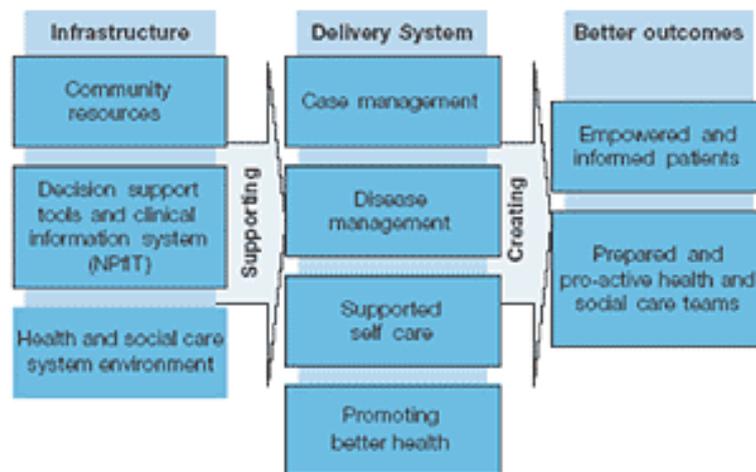
Moreover, while LTC management has become a key priority, relatively little information exists on what constitutes best practice – specifically on the roles that general practice and other primary, community and social care agencies should play within this.

In 2004, at the same time that the QOF was being introduced, an English ‘model’ of LTC management was set out (Department of Health 2004b). Derived from a number of similar models developed in the United States (such as Wagner’s Chronic Care Model and Kaiser Permanente’s Population Risk Pyramid), the model was based on three key approaches:

- supported self-care for the majority of those living with – or at high risk of – long-term conditions
- disease management for people with a complex single or multiple conditions who would need to be managed proactively by responsive specialist services
- case management for the small minority of patients with highly complex and multiple conditions requiring high-intensity professional support.

The model is illustrated in Figure 1.

Figure 1 The NHS and social care long-term conditions model



Source: Department of Health (2005a, p 9)

Soon after the publication of the LTC model of care, an NSF for LTCs emerged (Department of Health 2005b). This NSF set out 11 quality requirements for LTC care that should be applied to everyone with one or more LTCs (see Box on p 15). At the heart of the NSF was the need to integrate services to promote independence and empowerment, including working across professional boundaries:

These QRs [quality requirements] are designed to put the individual at the heart of care and to provide a service that is efficient, supportive and appropriate at every stage from diagnosis to end of life. The emphasis throughout this NSF is on supporting people to live with long-term conditions, improving their quality of life and providing services to support independent living... implementing this NSF by 2015 will improve services significantly.

(Department of Health 2005b, p 5)

The 11 quality requirements of the Department of Health's long-term conditions model

1. A person-centred service
2. Early recognition, prompt diagnosis and treatment
3. Emergency and acute management
4. Early and specialist rehabilitation
5. Community rehabilitation and support
6. Vocational rehabilitation
7. Providing equipment and accommodation
8. Providing personal care and support
9. Palliative care
10. Supporting family and carers
11. Caring for people with neurological conditions during admission to hospital or other health and social care settings

Source: Department of Health (2005, pp 4–5)

To support the intensive case management for high-risk individuals with multiple LTCs, the Department of Health invested from 2004 onwards in the creation of a new nurse profession – the community matron (Department of Health 2004a). Community matrons seek to identify patients who meet criteria denoting that they are, or will be, high-intensity users of health care, and provide them with high-intensity help, to ensure that their multiple health and social care needs are met and so enable them to remain at home. The case-management work of community matrons has been central to the government's approach for the management of people with long-term conditions, although the evidence suggests that the cost-effectiveness of the interventions they provide is currently variable, as is their level of engagement with general practice (see Section 9).

The need to better manage patients with long-term conditions outside hospital is now widely accepted, and is embedded in recent policy documents. However, the management of people with long-term conditions is set to remain one of the most pressing challenges to the NHS – not least because of the cold financial climate at the time this report was written. This paper seeks to establish the role that general practice should take to meet this challenge, in order to ensure that patients with LTCs receive high-quality and cost-effective care.

3 Arthritis

Arthritis is the umbrella term used to describe the condition resulting from the inflammation of the joints and bones. There are numerous types of arthritis. These can be categorised as either inflammatory arthritis (IA), non-inflammatory arthritis, or connective tissue disease. It is estimated that one in five people in the United Kingdom is affected by arthritis (Arthritis Care 2007). This section focuses on the two main types of arthritis: osteoarthritis (OA) and rheumatoid arthritis (RA).

Osteoarthritis

OA is the most common form of arthritis. It is characterised by the damage or failure of joints when the connective tissue or cartilage degenerates. This can cause the bones to rub painfully against each other, the growth of new bones in affected joints, or the joints to become misaligned. This process results in stiffness and chronic pain, and thus OA is associated with limitations in carrying out daily activities than other diseases among older people (Jagger *et al* 2006).

OA can have a considerable physical, social, psychological and economic impact on people's quality of life (Breedveld 2004; Gupta *et al* 2005), although research indicates some reluctance among people to report the full extent of the pain they experience and therefore a delay in diagnosis (McHugh *et al* 2007).

The Arthritis Research Campaign (ARC) has estimated that 4.4 million people in the United Kingdom have x-ray evidence of moderate-to-severe OA of the hands, 550,000 of the knees, and 210,000 of the hips (ARC 2002). More than 1 million adults with OA consult their GP at least once a year in the United Kingdom (Arthritis Research UK 2008). Women over 50 years of age are also more likely than men to have OA in their hands, feet and knees (Jagger *et al* 2006). Although some types of OA are hereditary, there are four main risk factors for developing the condition:

- congenital abnormalities
- injury or surgery
- being overweight or obese
- occupation.

Rheumatoid arthritis

Rheumatoid arthritis (RA) affects the body's immune system by attacking the joints and causes them to become inflamed (Arthritis Research UK 2008). RA can limit motion and lead to the degeneration of bone and cartilage. It is unclear what causes the body's immune system to attack joints. However, it has been found that RA can cluster in families (ARC 2002) and could therefore be genetic. Other risk factors are potentially involved too, such as the environment, infection or trauma (ARC 2002; ARMA 2004a).

As the Arthritis and Musculoskeletal Alliance (ARMA) has highlighted, some people may experience a remission in RA (ARMA 2004b). However, for

others the condition can damage joints and cause disabling pain, 'flare-ups', stiffness and reduced function in joints. All of these contribute to a substantial impact on people's quality of life. However, evidence suggests people with RA can be reluctant to seek help from their GP, as they attribute pain to other causes or feel pessimistic about receiving help from health care professionals (Sheppard *et al* 2008). Initial reluctance to consult GPs was found to be the principal reason for the delay between onset of RA symptoms and rheumatologist assessment (Kumar *et al* 2007).

The National Audit Office (NAO) estimated that 580,000 adults in England have RA, and an estimated 26,000 new cases are diagnosed annually. Forty-five per cent of people with RA are of working age, and over 60 per cent have lived with the condition for more than 20 years (NAO 2009). Women are almost three times more likely than men to be affected by RA (arc 2002). RA is more prevalent among people aged over 65 years of age, but it is most likely to develop between the ages of 30 and 50.

Those who are affected by RA at working age can experience difficulty in staying in employment. In a longitudinal study of 353 people, after five years approximately 22 per cent had stopped work due to RA (Young *et al* 2002). In 2007/8 the estimated cost of incapacity benefit for RA was £122 million, and the estimated annual cost of RA to the NHS in England is £557 million, of which £171 million can be attributed to GP activity, such as blood tests and visits (NAO 2009).

Musculoskeletal conditions in general are the most common reason for recurring GP visits, and make up 30 per cent of primary care consultations (Department of Health 2006c). OA and RA are chronic and debilitating conditions, but in both cases early identification and intervention and ongoing monitoring and support can minimise the damage.

What does high-quality care look like?

The *Musculoskeletal Services Framework* (Department of Health 2006c) outlines how GPs and others are responsible for the 'active management' of arthritis through:

- facilitating self-management
- giving the patient information
- interfacing with other primary care services.

It also suggests that general practice and others should support people to return to work. Other key guidelines on the management and standards of care for OA and RA that illustrate what high-quality care should look like are outlined below.

High-quality care for OA

There are two main guidelines for the management of OA, from the National Institute for Health and Clinical Excellence (NICE) and the Arthritis and Musculoskeletal Alliance (ARMA):

- *The Care and Management of Osteoarthritis in Adults: Clinical guideline 59* (NICE 2008b)
- *Standards of Care: Osteoarthritis* (ARMA 2004b).

The NICE (2008a) guidelines establish a number of key priorities for the management of OA, and set out the need for:

- an holistic assessment of the person (focusing on function, quality of life, occupation, mood, relationships and leisure activities)
- provision of education and advice – for example, to encourage patients to self-manage by strengthening muscle and fitness through exercise
- provision of analgesia
- timely referral for joint-replacement surgery where applicable.

Information and advice on self-management also feature in the ARMA (2004b) guidelines, which recommend ensuring prompt access to services to enable early diagnosis and treatment, as well as ongoing support.

The experts interviewed as part of this study commonly reported that the NICE and ARMA guidance was representative of best practice. However, they felt that a broader awareness of arthritis would underpin a GP's willingness to accept patients' musculoskeletal complaints as more than 'just aches and pains' and their readiness to help. They commonly reported that diagnosis needed to be followed up by a patient-centred care plan that emphasised weight loss and physical exercise. The care plan should enable the patient to be referred to professionals within a multi-disciplinary team, such as physiotherapists, occupational therapists or specialists if necessary.

High-quality care for RA

A number of guidelines applicable to RA have been produced, including:

- *The Management of Rheumatoid Arthritis in Adults. Clinical guideline 79* (NICE 2009c)
- *Standards of Care. Inflammatory Arthritis* (ARMA 2004a)
- *18 week Commissioning Pathway Inflammatory Arthritis (Joint Pain)* (Rheumatology Futures Group 2009).

In order to prevent the progression of RA and so reduce the likelihood of developing severe disability, all the guidance recommends aggressive treatment (involving disease-modifying anti-rheumatic drugs), commencing ideally within three months of symptom onset (Emery *et al* 2002; Nell *et al* 2004; Luqmani *et al* 2006). This, of course, depends on early and appropriate diagnosis and referral from general practice. According to the NICE guidance (2009 RA), referral for specialist opinion should be made for any person with suspected persistent synovitis of undetermined cause. This should be done urgently if:

- the small joints in the hands and feet are affected
- more than one joint is affected
- there has been a delay of more than three months between onset of symptoms and seeking help.

In addition to the RA guidance, experts interviewed suggested that referral to specialists should be made if any of the three symptoms proposed by Emery *et al* (2002) are present:

- three or more swollen joints

- experiencing pain on squeezing the metatarsophalangeal or metacarpophalangeal joints
- experiencing 30 minutes or more of morning stiffness.

There was unanimous agreement among the experts interviewed that high-quality care for RA requires the early recognition of symptoms and a prompt referral to a specialist for diagnosis. Those we interviewed accepted as important the current recommendation in NICE guidance for treatment to commence promptly following diagnosis.

For example, NICE (2009c) recommends that a combination of disease-modifying anti-rheumatic drugs (DMARDs) be offered as soon as possible for newly diagnosed RA. Treatment should be monitored rigorously and regularly in outpatient appointments, reflecting the 'tight control' model used for diabetes management (Emery 2006). Once RA control is achieved, DMARD doses should be reduced cautiously (NICE 2009d). This requires regular check-ups to monitor the effects of medication on RA as well as any side-effects. Analgesics, NSAIDs and biological drugs can be prescribed in certain circumstances (NICE 2009d).

According to the majority of expert informants that we interviewed, high-quality care in general practice would also involve awareness of the potential for patients to have or develop other long-term conditions, such as cardiovascular disease or depression. Annual, or more frequent, check-ups in primary or secondary care should consider the possibility of the patient having co-morbidities, and should include checks on blood pressure and weight (for example). NICE guidelines for RA also recommend access to a named member of the multidisciplinary team who is responsible for co-ordinating care provided by other health care professionals, such as physiotherapists, occupational therapists and psychologists.

People with RA can experience very painful flare-ups, and the experts we interviewed were in agreement that, in such an event, it was important to have access to the most appropriate type of treatment – ideally within 24 hours. This could be achieved, for example, by speaking to a specialist nurse via a telephone helpline. The specialist nurse could then facilitate an appointment for a joint injection. Prompt access should also be accessible out of hours.

The expert informants also described aspects of high-quality care that applied to arthritis in general, such as the importance of the patient being informed and thus empowered to carry out self-management of their condition – particularly through physical exercise and weight loss. This would be achieved through the provision of well-designed and appropriate information that gives a realistic but positive outline of:

- what the condition is
- what might happen in the future
- what to do when pain is experienced
- services to contact for help and advice.

The experts felt that health care professionals needed to support patients to manage their pain by recognising the psychosocial impact of the condition and discussing their concerns and/or referring them to organisations such as Arthritis Care or NRAS, which provide information and peer support. Patients

have concerns about either remaining in or returning to employment. High-quality care would involve health care professionals discussing such concerns with patients and making referrals to other professionals where possible or signposting to patient groups.

The theme of patient-centred care emerged strongly from interviews with experts. One respondent highlighted that the location of care needed to be physically accessible to people with mobility problems, while another suggested the importance that care professionals were prepared to discuss a patient's general well-being: how they are coping and what their concerns are. This, in turn, would enable the patient to take better control of their condition:

I think at the end of the day it is all around providing holistic care, which puts the patient at the centre of the journey. With arthritis – be it osteo- or rheumatoid or whatever – these are usually long-term, lifelong conditions, and patients have to learn to live with and live around this difficulties and overcome the problems... So you actually plan the care around what the patients perceive to be important and actually allow patients more control over their journey – again, obviously, advised where there is clinical need as to what is safe and appropriate.

GPSI in rheumatoid arthritis

What is the role of general practice?

The majority of people with arthritis symptoms will seek their help in the first instance from a GP (NAO 2009). The literature and the expert interviews showed that the course of treatment very much depends on what GPs do at this initial stage:

General practice is crucial because it's got to recognise what needs referring and what doesn't, at the earliest stage. If you just wait and watch, then that's the worst option – because you've actually allowed chronicity to occur.

Professor in rheumatology

This study – encompassing, as it does, a review of the literature, best-practice guidance and the views of expert informants – suggests that high-quality care in general practice in the management of people with arthritis would need to fulfil the following core aspects of care and management.

- **Early recognition of symptoms and prompt diagnosis** Professionals in the general practice setting (and GPs in particular) must be aware of arthritis and be able to recognise its symptoms. Awareness is particularly important given that some patients do not present musculoskeletal pain as their primary complaint. In cases of RA, prompt and accurate diagnosis – perhaps with support of a specialist or GPSI – is important.
- **Prompt and appropriate referral** In cases of RA, the GP should use the guidelines to make a prompt referral to a specialist, ideally within the first or second consultation. Prompt referral would be enabled by establishing a referral protocol with the local specialist team. This would require both parties to be willing and able to communicate with each other. The expert informants felt that the subsequent diagnosis of RA should be made by a rheumatologist or a GP with special interest,

as they would have the appropriate level of expertise to interpret diagnostic tests. Specialists would also have the expertise to prescribe the course of medication needed to stabilise the patient's RA.

In contrast, in cases of OA GPs are able to make a diagnosis in the majority of cases.

- **In emergency flare-up situations, GPs should facilitate rapid access to treatment** This should take place ideally within 24 hours – for example, by contacting the nurse specialist or rheumatologist.
- **Patient information and supported self-care** Following diagnosis, GPs or practice nurses should provide patients with either verbal or written information about their arthritis. GPs or practice nurses should signpost patients to patient groups and ensure they can access a support network.
- **Patient-centred care plan** Diagnosis should be followed with a care plan, developed in partnership with the patient, to enable them to understand the health-promoting activities they should seek to follow (for example, weight loss or physical exercise). These should enable the patient to understand the next steps in their treatment.
- **Proactive case management** The general practice team should undertake long-term monitoring of patients with arthritis. They should monitor how medication is affecting the condition and the person, whether any co-morbidities are present, and the patient's general well-being. This requires the professional to be empathetic, and to give serious consideration to patients' concerns about employment, child care and relationships.

Some experts felt that GPs had limited time to do this and that the practice nurse might therefore be better placed to assess the psychosocial aspects of care, as well as to provide the motivation and support to make lifestyle changes. If the patient's psychosocial needs cannot be met within the general practice, the nurse or GP should signpost them to other services:

There are core issues for all long-term condition patients that they need right from the beginning. They need proactive, positive support, good messages right at the beginning of their journey. They need the information that's going to empower them. They need reassurance, and they need rapid access when they can't cope. And nurses are brilliant at putting the context of that in a patient-centred approach that looks at the social and psychological needs of that patient.

Rheumatology nurse consultant

- **Ongoing care** GPs can provide ongoing prescriptions for medication if appropriate. In the case of RA, prescriptions should be consistent with what the specialist has prescribed, based on regular monitoring.
- **Multi-disciplinary team-working** GPs or practice nurses should make referrals to a multidisciplinary team (such as physiotherapists, occupational therapists or surgeons) as needed. Within this process, they should discuss choices and support patients in making them.

The current quality of care in general practice

When it comes to the quality of arthritis management, the published evidence suggests that performance within general practice is not always consistent with guidelines – a view generally backed up by the experts we interviewed during the study.

For example, a recent NAO (2009) report found that less than 50 per cent of people with RA are referred by their GP to a specialist within three months, while people with RA visit their GP an average of four times before being referred (Steward and Land 2009). One reason proposed for the delay in diagnosis of long-term musculoskeletal conditions is a lack of knowledge and awareness about these conditions among GPs. This could be exacerbated by the fact that less than half (43 per cent) of PCTs provide education to GPs about inflammatory arthritis (ARMA 2009).

In addition to this apparent lack of knowledge, some experts also suggested there was a lack of interest among GPs in treating arthritis, as it is not currently a long-term condition that attracts incentive payments through the QOF:

In their years of training to be a doctor, GPs get two hours' [training]¹ on musculoskeletal (conditions)... You've got people in society who think arthritis isn't something you should bother about, so they don't go and present... And nothing in the QOF to incentivise them to anything anyway. All these pressures to do nothing. So people get worse, they deteriorate, they give up their job, they get depressed, they become expensive users of health and social care systems – when they could, if caught early, be kept mobile, be kept independent, pay tax through having jobs, not claim disability benefits. So much to be gained from it, and yet there's so little being done about it.

Chief executive, arthritis support organisation

These impressions are supported by a recent study by the think tank RAND (Steel *et al* 2008) that revealed how only 29 per cent of eligible patients for OA treatment by a specialist had been provided with the care they should have received – the lowest figure in comparison to nine other conditions they examined. Research by Broadbent *et al* (2008) that assessed the self-reported quality of care for 320 patients at various general practices showed a low level of satisfaction with the level of information they were provided about their condition (17–30 per cent) and a wide-ranging set of views in terms of quality of treatment (5–90 per cent).

Regarding treatment provision for OA, research carried out before NICE guidelines were introduced shows variation in general practice according to the type of OA treated and the type of treatment. For example, OA in the knee is more common than OA in the hips. However, data suggests that following referrals, hip replacement surgery is more likely to occur than knee replacement surgery (Linsell *et al* 2005). The data also suggests that pharmacological interventions are favoured compared to exercise, weight loss and physiotherapy (Jordan *et al* 2004; Porcheret *et al* 2007).

1 This refers to the NAO (2009) report, which showed 70 per cent of trainee GPs had tutorials on musculoskeletal conditions, receiving an average of two hours teaching on back pain, joint injections and OA.

Regarding information provision for OA, research indicates that GPs are not always providing this adequately, and/or that patients do not recall receiving it (Victor *et al* 2004; McHugh *et al* 2007). Interviews with our expert informants also raised a common concern that patients do not feel they are given enough information about how to manage their condition.

The NAO (2009) study of services for RA looked at care provided to 1,200 individuals. It concluded that the likelihood of RA being diagnosed and treated within the 'window of opportunity' had not increased since 2003, despite the introduction of the 18-week target from referral to treatment. The study also showed that half of those who had experienced a delay in diagnosis attributed this to their GP. Respondents said their GPs had been unable to make a diagnosis based on test results, had made a misdiagnosis, or had taken a long time to make a specialist referral. Specialists would usually repeat the tests, thus leading to more delay and cost.

Interestingly, the majority of GPs in the NAO study said they had either 'very good' or 'some' knowledge of RA (96 per cent), but 74 per cent were 'somewhat confident' in making a diagnosis, compared to 18 per cent who were 'very confident'. This dissonance between GPs' knowledge of RA and their ability to diagnose reflects the literature and expert interview data, which suggests that GPs are not confident that they can manage RA as well as specialists can (see, for example, Memel and Somerset 2003).

Measuring quality

At present, no robust or routinely collected measures are currently in use in general practice to monitor the quality of care for people with arthritis. Arthritis is not a clinical area prioritised through the QOF. However, there have been some quality indicators developed by RAND, NICE and the National Primary Research and Development Centre (NPRDC) regarding OA treatment in primary care (Broadbent *et al* 2008 – see Table 1).

RAND has also developed a set of 27 validated quality measures for treatment of RA that spans physician and rheumatologist care (MacLean *et al* 2004). However, there is no evidence to suggest that such indicators are being collected or used with general practice or any other care provider in the United Kingdom. None of the experts interviewed believed they were aware of any measures currently used to assess the quality of care in general practice for OA or RA.

Two expert informants felt that, despite the availability of best-practice guidelines, without the existence and use of quality measures there was little current incentive to improve quality:

That is the trouble with guidelines. You can have as many guidelines as you like, but... unless practices are measured by the Care Quality Commission, or whoever it is actually going to be measuring that, and equally measuring patient satisfaction, I don't think it is going to make any difference.

Director, musculoskeletal conditions group

I think getting some musculoskeletal measures on QOF would be the single biggest step to improving quality of care. Unfortunately, money talks – and with only a limited amount of time in the day, if it is not part of QOF it is put on the 'to do' list sometime, and never gets done. So certainly

the biggest thing that could help arthritis care is to get musculoskeletal measures on QOF.

GPSI in rheumatoid arthritis

Table 1: Quality indicators for osteoarthritis treatment in primary care

	Quality indicator	Source
Information provision indicators	The percentage of patients with symptomatic OA whose notes contain a record that they have been offered education regarding the natural history, treatment, and self-management of the disease at least once	RAND
	The percentage of patients with OA treated with an NSAID whose notes contain a record that they have been advised of the gastro-intestinal and renal risks associated with this drug	RAND
Regular assessment indicators	The percentage of patients treated for symptomatic OA whose notes contain a record that they have been assessed for functional status in the last year	RAND
	The percentage of patients treated for symptomatic OA whose notes contain a record that they have been assessed for degree of pain in the last year	RAND
	The percentage of patients with OA regularly treated with NSAID whose notes contain a record that they have been asked about gastro-intestinal symptoms within the previous 12 months	RAND
Treatment provision indicators	The percentage of patients in whom oral pharmacological therapy was initiated to treat OA and whose notes contain a record that they were offered paracetamol first (unless contra-indicated)	RAND NPRDC
	The percentage of patients with OA treated with an NSAID whose notes contain a record that ibuprofen (or a cox-2 inhibitor) has been considered for first-line treatment (unless contra-indicated or intolerant)	NICE NPRDC
	The percentage of patients with severe symptomatic OA of the knee or hip that has failed to respond to non-pharmacological and pharmacological therapy and whose notes contain a record that they were offered referral to an orthopaedic surgeon to be evaluated for total joint replacement within 6 months unless surgery is contra-indicated	RAND
	The percentage of patients in whom oral pharmacological therapy was changed from paracetamol to a different oral agent and whose notes contain a record that they were offered a trial of maximum-dose paracetamol	RAND

Source: Adapted from Broadbent *et al* (2008)

The potential impact of quality improvements

The NICE costing report that accompanied the publication of OA treatment guidelines in 2008 showed that full implementation of the guideline was estimated to lead to annual savings of nearly £7.3 million, through reduced GP consultations and hospital admissions (NICE 2008a). Further, evidence suggests that physical exercise and physiotherapy can be cost-effective for knee pain (Segal *et al* 2004; Jessep *et al* 2009). In terms of RA, improved treatment of recent-onset RA should avoid or delay the onset of disability (NICE 2009c). Reduced costs to the NHS can be inferred from the reduced

likelihood of severe disability. It was not possible for NICE to quantify the NHS savings arising from prompt access to specialist care.

According to the NAO (2009), if services to people with arthritis were reconfigured to ensure quicker diagnosis and earlier treatment, the short-term costs to the NHS would increase but there could be productivity gains and better quality of life for patients in the long term. Increasing the number of patients seen within three months of symptom onset to 20 per cent (from the current figure of 10 per cent) could initially increase the cost to the NHS by £11 million over a five-year period, due to expenditure on drugs and the associated monitoring of patients. This could become cost-neutral after approximately nine years, and then there could be productivity gains of around £31 million for the economy due to reduced levels of sick leave and lost employment. Further, quality of life could increase by 4 per cent over the first five years in terms of quality-adjusted life years (QALYs) gained (NAO 2009).

Clearly, the current state of quality of care for people with OA and RA in general practice is problematic to determine, due to the lack of objective measures and indicators available. However, the evidence examined here would suggest that it is currently sub-optimal and highly variable, and could be significantly improved through a better understanding of the condition among primary care professionals and a more proactive approach to care management (which might also prove cost-effective to implement). What is clear is that responsibility for delivering high-quality care to patients with arthritis should be shared across care settings and multi-professional teams, and that general practice has a core role to play as part of that continuum of care.

4 Dementia

Dementia can be described as 'a syndrome which may be caused by a number of illnesses in which there is a progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities' (Department of Health 2009d, p 15).

There are estimated to be approximately 750,000 people living with dementia in the United Kingdom at present, though the number is set to increase to more than 1 million people by 2025 (Alzheimer's Society 2007, 2010). While dementia is predominantly a disorder that affects people in later life (its incidence and prevalence rise exponentially with age), it also affects about 12,000 people under the age of 65 (NAO 2007a). Late-onset dementia – especially Alzheimer's disease – is also more prevalent among women.

It is estimated that 11,000 members of black and minority ethnic background have dementia, with members of BME communities comprising 1.7 per cent of the total population with dementia (Alzheimer's Society 2007). There is a greater likelihood of dementia prevalence in areas where larger proportions of older people live. Overall in the United Kingdom, 10 per cent of deaths among men over 65 years, and 15 per cent of deaths among women in the same age group, are linked to dementia. The majority of dementia-related deaths occur between the ages of 80 and 95 years (Alzheimer's Society 2007).

Dementia is characterised by a decline in a person's memory, reasoning and communication skills and their ability to carry out daily activities. Simultaneously, a person with dementia may also develop behavioural and psychological symptoms, such as depression, psychosis, aggression and 'wandering' (Department of Health 2009d). Dementia is largely an irreversible condition (NICE/SCIE 2006a). There are numerous forms of dementia including:

- Alzheimer's disease caused by clumps of protein (or 'plaques') developing around brain cells (NHS Choices 2010). This accounts for 62 per cent of dementias in England (NAO 2007a)
- vascular dementia caused by restricted blood circulation to part of the brain (NHS Choices website)
- dementia with Lewy bodies caused by protein developing inside nerve cells (NAO 2007a)
- fronto-temporal dementia caused by the shrinking of the frontal and temporal parts of the brain. This occurs mostly among people under 65 years of age, and is much rarer than other types of dementia, affecting 2 per cent of people with dementia in England (NAO 2007a).

The causes of dementia-related illnesses are not well understood, but all result in changes from structural and chemical changes in the brain leading to the death of brain tissue. The progression of the various types of dementia varies. However, in general terms, there are three phases: early, middle and late stage:

- Early-stage dementia can often be misinterpreted as symptomatic of other problems, such as stress or ageing, because it can be indicated by short-term loss, confusion and anxiety.

- In the middle stage, people require more support as they become increasingly forgetful, and they can become distressed or angry.
- In the late stage, symptoms can include:
 - being unable to easily recognise familiar objects, surroundings or people
 - becoming increasingly frail
 - developing a progressive slow or unsteady gait
 - difficulty eating
 - incontinence
 - gradual loss of speech (NAO 2007a).

Understandably, the onset of such symptoms can have a profound impact on the quality of life both for the person with dementia and their relatives and friends, who can also be their caregivers (Alzheimer's Society 2007). People with dementia typically live for between seven and 12 years after diagnosis (Department of Health 2009d p 17).

What does high-quality care look like?

A number of documents have been published recently outlining what high-quality care for people with dementia should include. Examples include:

- guidance published by NICE/SCIE (2006a) emphasising the need for integrated health and social care
- the national dementia strategy (Department of Health 2009d)
- the NICE technology appraisal for various drug therapies for Alzheimer's disease (NICE 2007).

Generally, the experts interviewed as part of this study agreed with the published guidance, and provided more detail on how it should be implemented in the context of general practice.

The national dementia strategy argues that high-quality care can be achieved for dementia sufferers and their carers only if a shift is achieved in the way that society – including health and social care professionals – perceive dementia (Department of Health 2009d). Positive changes in attitudes and beliefs about the disease, and about the needs of people living with it, could encourage people with symptoms to seek help, and could encourage health care professionals to offer help by referring for a diagnosis. Similarly, the NICE/SCIE guidance (2006a) sets out that when a health care professional is approached by an individual (or their carer) with potential symptoms of dementia, he or she should be willing to take appropriate action:

The professional should not dismiss the signs of dementia and should seek to obtain a diagnosis as soon as possible so that treatment can begin. Health care staff should consider referring patients showing signs of mild cognitive impairment for assessment because over 50% of people with such symptoms then go on to develop dementia.

(NICE/SCIE 2006a, p 22)

According to the NICE/SCIE (2006a) guidance, a number of tests or assessment should be carried out to obtain an accurate diagnosis of dementia, including:

- a full medical history
- a medication review
- a clinical cognitive assessment using a standardised instrument such as the Mini Mental State Examination (MMSE) (though this has subsequently been found to be ineffective for diagnosis in certain groups)
- blood tests (to rule out other conditions)
- structural imaging tests.

The guidance argues that there should ideally be a rapid referral to a specialist (such as a geriatrician, neurologist or psychiatrist working in a memory clinic) to carry out these tests and assessments and/or interpret the results to make an informed diagnosis. An early diagnosis can enable health and social care teams, the individual and their carers to maintain the independence of people with dementia for as long as possible (NICE/SCIE 2006a). An accurate diagnosis may require the individual to make a number of visits to the specialist team. Ideally, the diagnosis of dementia should be conveyed to the patient by a specialist (or GPSI) and then communicated to the patient's GP.

When it comes to conveying the diagnosis of dementia to the patient, the evidence shows that some GPs and other health care professionals are reluctant to break this type of 'bad news' to patients. This may be because they are under the impression there is no point in making a diagnosis if there are no treatment options or support services available for the person. Alternatively, it may be because the professional does not wish to distress the patient or the carer by telling them they have a terminal condition. However, the guidance and the data from the expert interviews shows that it is important for the professional to be forthcoming with the diagnosis, and to handle this with due sensitivity. Nonetheless, for certain types of dementia, it is recognised that drug treatments can help slow the progress of the disease (and potentially reduce anxiety) if caught early enough.

Providing that a diagnosis is made and given to the patient early on during their illness, plans can be made for the ongoing care of the individual. The individual should undergo an holistic assessment that considers their medical, psychological and social care needs. The earlier these discussions occur, the earlier the various aspects of care can be arranged and therefore the individual stands a better chance of having a better quality of life:

One of the cornerstones [of dementia care]... is that if you tell people earlier, they can do stuff about it... They need to know what's going on, because one of the things that gets lost in dementia as you become more severely ill is your insight into having dementia. Then, if you want to accurately forward plan, if you want to carry out advanced planning, if you want to say what sort of risk you're willing to put up with before going into a care home, if you want to have those discussions with your family, then if you don't have them when you're first diagnosed, [within] the first couple of years, then you may never be able to have them...

So there's a whole sense of planning for the future... but also there's good definitive evidence to suggest that if you gear up carers and people with dementia at the beginning of their journey, they'll have a better journey with their dementia – so that instead of having a dementia that is blighted by crises... you have one whereby you know where you can go for help.

Professor of mental health and ageing

There are some psychological treatments that can help people to cope with the symptoms of dementia – for example, cognitive stimulation, behavioural therapy, reality orientation therapy and multisensory orientation. Physical exercise can also be beneficial to mood and mental function. Where appropriate, the specialist team should begin pharmacological treatment. Continuing prescription can be provided in primary care as long as there are good lines of communication between the health care teams.

Based on the holistic assessment of needs mentioned above, the individual and a health care professional should make a care plan and appropriate referrals to other services. A care plan could include a set of goals for the patient to manage risk and stay relatively healthy for as long as possible, such as stopping smoking, controlling blood pressure and cholesterol and taking aspirin as prescribed.

As with a number of long-term conditions, access to information and education about self-management is vital. The patient and their carer should be given access, or signposted, to sources of peer support in the community and voluntary sector for more information about dementia and education on coping strategies. Information is important in helping people to live well with dementia for as long as possible in the community (Department of Health 2009d). The individual and their carer should be given high-quality information, and support to understand it, to suit the different stages of the illness:

I think that the third sector has quite a large place to play in terms of early intervention and support... There's no doubt that behavioural and psychological symptoms are a frequent cause of extreme distress to the relatives, which... can sometimes lead on to people getting admitted [to hospital]... If you can have psychosocial intervention and psychological intervention at that stage, it decreases the admissions.

GPSI in dementia care

Once diagnosis has been made and various interventions have been implemented, the patient will need ongoing monitoring by the different teams involved. Further, the individual and their carer should be able to access information and support as and when required. A pilot scheme is currently being implemented for 'dementia advisors', who act as a named contact person for the individual and their carers following discharge from secondary care. Their purpose is to help the individual and their carer to navigate the health and social care system, so they have easy access to care, support and advice.

Individuals with dementia should have access to high-quality care in all locations. That is, the individual should be enabled to live well in their home through the use of assistive technology, telecare and home visits, as appropriate. The individual is also entitled to high-quality, patient-centred physical and social care in care homes and in hospital settings. The focus on

high-quality care tailored to the individual's needs should apply equally when it becomes clear that he or she is entering palliative and end-of-life care.

Alongside the high-quality care described for the individual with dementia, health and social care staff must also consider the needs of the carer. This could begin with a formal assessment of his or her physical and emotional capacity to provide care to the patient with dementia. The health and social care team must always be aware of the health and emotional well-being of the carer throughout the patient's journey – particularly when it is evident that he or she is experiencing difficulty in coping. Carers should have access to information and support when they need it, including periods of respite during which a care assistant can provide cover.

What is the role of general practice?

The vast majority of first diagnoses for suspected dementia occur in general practice. A typical GP practice can expect their list to include between 12 and 20 people with dementia. According to the NAO (2007a), GPs have 'ultimate' responsibility for each patient with dementia, regardless of whether they are living in their own residence or in a care home. The GP is the constant during the patient's journey with dementia. The GP often carries out a co-ordinating and monitoring role, and acts as a gateway to services that provide the necessary and appropriate intervention and support.

From an assessment of the literature, the guidelines and the views of our expert informants, the role of the general practice in providing high-quality care to people with dementia can be outlined as follows.

- **Awareness of risk factors and symptoms** GPs and practice nurses should be aware of the risk factors for dementia and the appropriate action to take – for example, providing advice – and should review those patients with modifiable risk factors such as smoking, obesity or hypertension. They must be aware of various warning signs and recognise that dementia affects a number of people under the age of 65 as well as the elderly. Symptoms should be taken seriously, and should be discussed in further detail with the patient and, if possible and appropriate, a specialist.
- **Proactive case finding** General practices should take a proactive role in screening all patients for suspected dementia, whether or not this is suggested by the patient or their carer.
- **Assessment** Where dementia is suspected, GPs with the appropriate level of training and knowledge could administer blood tests and standardised cognitive assessments to establish a baseline of information. This could then be provided to a specialist team, which may then wish to carry out subsequent tests before making a formal diagnosis. Practice nurses could be trained up to administer cognitive assessments.
- **Prompt and appropriate referral** Whether or not preliminary assessment tests are carried out in general practice, an early referral must be made to specialist units (for example, memory clinics) with the aim of obtaining an early diagnosis. Formal diagnoses of dementia should be made by specialists. The diagnosis should be communicated

to the general practice, and a register of patients with dementia should be kept there.

- **Shared and proactive care** General practices should have shared care arrangements with specialist services to exchange information. GPs and practice nurses then provide continuity of care, through proactive monitoring and managing the progression of the disease. General practice notes should be kept up to date and synthesised with notes from specialist care teams. Since the individual with dementia is likely to be in contact with a number of different health care professionals, social care providers and other support services, it is important for general practice to work in partnership with these colleagues by sharing and seeking information. General practice plays a vital role in ensuring that the individual can be looked after in the community for as long as they wish – for example, by advocating on behalf of the patient and/or supporting care-home staff.
- **Patient and carer information and supported self-care** As the professional responsible for ongoing care, the GP should discuss the diagnosis with the individual and their carer(s) sensitively. He or she should ensure that the individual understands as much as possible about the diagnosis, its implications and how the management of dementia is likely to proceed. It may be appropriate to signpost the individual and/or their carer to a specialist service for further advice and support in coming to terms with the diagnosis. It should be made clear to the individual that they can also contact the general practice for information if they wish to do so, and that their requests will be given due consideration and treated sensitively.
- **Care planning** General practices should ensure that a care plan with the individual and their carer is undertaken and recorded. The care plan must be tailored to the individual, and might include targets for controlling cholesterol and blood pressure and ensuring medication is taken, as prescribed by the specialist or GP. The care plan should also be seen as an ongoing process to take any changes into account.
- **Ongoing care** The general practice team, in partnership with shared care providers, should carry out holistic assessments of individuals with dementia and his/her primary carer. This information should be used to make referrals to members of the multidisciplinary team, such as community matrons, district nurse teams, social services and voluntary and community-sector support organisations where peer support and education can be accessed. Assessments of the individual with dementia and carer should be ongoing in order to pick up on any changes in circumstances, such as depression or fatigue.

A thorough review of dementia patients should be taken every six or 12 months, depending on need and severity. This should cover physical health such as co-morbidities, infections, weight, blood pressure and cholesterol, as well as psychological issues and social care needs. The GP, practice nurse or dementia advisor based in general practice should be proactive in contacting the individual in between reviews to determine whether there have been any developments.

The various aspects of the role played by general practice described here are underpinned by training in dementia care and knowledge of (and availability of) specialist dementia services. All staff working within general practice should have the appropriate training and skills to deliver high-quality care to individuals with dementia. GPs and practice nurses should be aware of the NICE/SCIE guidance and the national dementia strategy, and practice managers and receptionists should be sensitive to the needs of patients or carers when contacting the practice for information and appointments.

All staff within the general practice should know about existing services in the area for diagnosing and managing dementia and providing support to patients and carers. If there is a lack of specialist services in the area to deliver accurate diagnoses, GPs should be proactive in making sure they are commissioned.

The current quality of care in general practice

It is commonly reported that first contact and diagnosis of people with dementia often occur late in the illness and/or in crisis, when opportunities to manage the condition in order to maximise quality of life and prevent harm have passed (NAO 2007a). There are a number of factors contributing to diagnoses being made late. For example, survey data (Alzheimer's Society 2007) shows that:

- people can wait up to three years before reporting symptoms of dementia to their GP
- 70 per cent of carers report being unaware of the symptoms of dementia before diagnosis
- 64 per cent of dementia sufferers are 'in denial', with 58 per cent believing the symptoms 'just a part of ageing'.

Focus-group data shows that individuals can make a number of visits to the general practice before the GP recognises symptoms and makes a referral to a specialist or memory clinic (NAO 2007b). The same analysis showed delays in diagnosis that occurred because GPs did not act on the possibility of dementia being present in people under 65 years of age, or did not listen to carers' concerns due to patient confidentiality.

The NAO analysed 2006 data on expected and recorded prevalence of dementia in the population. This showed only five people per 1,000 aged 65–69 had been diagnosed with dementia, compared to the estimated actual prevalence of 13 per 1,000. In people aged 80 years and over, only 60 people per 1,000 were diagnosed, compared to the estimated actual prevalence of 122 per 1,000 (NAO 2007a).

The level of UK diagnosis and treatment of people with dementia is not only low, but there is significant variation. For example, one study uncovered a 24-fold variation in activity between the highest and lowest activity by PCT (Knapp *et al* 2007). International comparisons have placed the United Kingdom in the bottom third of European performance in terms of diagnosis and treatment, with less than half the activity of France, Sweden, Ireland and Spain (Knapp *et al* 2007). Late diagnosis means that people with dementia and their carers are less able to make informed plans for their future, and do not gain access to the help, support and treatments that can help.

The experts interviewed in this study often discussed the lack of (or late) dementia diagnoses being made in general practice and the possible reasons for this. Their evidence suggests that most GPs are either unable to recognise dementia symptoms and so make referrals for diagnoses, or unwilling to take action when they do recognise symptoms due to the feeling that little can be done to help.

The interviewees felt there was a lack of specialist services to which patients could be referred, reflecting the findings of the NAO (2007a) report, although some welcomed the development of memory clinics if this led to more speedy and reliable access to such support.

Where GPs were unable to recognise symptoms, expert informants often attributed this to natural signs of ageing and/or argued that such symptoms were easily confused due to their association with other disorders. This view is again backed up in the NAO (2007a) report, which found that only 31 per cent of GPs believed they have received sufficient basic and post-qualification training to diagnose and manage people with dementia appropriately – a lower figure than was reported five years previously (Audit Commission 2002). This shows there is a need to raise awareness and training in dementia care in general practice.

Where GPs were unwilling to take action when they suspected dementia, this is because they assume there is no merit in obtaining a formal diagnosis. For example, the incidence of dementia in residential and nursing homes is likely to be high. However, the research evidence suggests that GPs may not seek to make diagnoses among a population in which a diagnosis will not necessarily add anything to the care they are already receiving (Koch and Illiffe 2009). In other cases, the reluctance to take any action could be due to the GP feeling that the diagnosis will be too distressing for patients who may already be frail and vulnerable, or that they may not fully understand. In other cases, the GP might feel the diagnosis will have a negative impact on the therapeutic relationship:

I think there's also a misconception that dementia is an endpoint and that people have no insight once they have it. 'What's the point of the telling someone they'll lose their ability to remember things, to reason, to look after themselves?' and... 'Why tell people about impending doom when, actually, they can just get on with their lives?'. Of course, we know that people with dementia have very good insight for quite a long time into their condition, so that's not actually true at all.

Representative of national dementia charity

Where dementia has been diagnosed, there also appears to be a lack of ownership of dementia care in general practice. For example, a study into the skills and knowledge of GPs in dementia care found that one-third of GPs surveyed believed dementia care to be the remit of a specialist team (Turner *et al* 2004). Another qualitative study indicated that GPs were more resistant than other professionals to shared care due to staffing and time constraints, lack of experience and lack of confidence in making the diagnosis (Illiffe *et al* 2006).

The experts we interviewed as part of the study emphasised the presence of poor continuity of care in general practices and a lack of willingness to take on the role of case management. Consequently, respondents suggested that

'only the minimum was being done' to review dementia patients, in order to meet the 15-month QOF requirements.

The most recent research to highlight these problems was reported through a cohort study that examined the health records of dementia patients in 353 general practices (Rait *et al* 2010). The study concluded that under-recognition of dementia syndromes persists in primary care, and that greater engagement of primary care in earlier and better detection of dementia is needed. In addition, they found that GPs often record the diagnosis of dementia in a non-specific way, not differentiating between Alzheimer's disease and vascular dementia. This is an important distinction that may affect management, including the use of anticholinesterase inhibitors, and should be covered in educational initiatives or through incentives.

The research suggested that further work was needed to explore factors underlying GPs' decision to record a diagnosis of dementia and enter it on a dementia register, as well as to understand why the mortality rates are higher during the first year after formal recording of a diagnosis.

There are several examples in England where general practices have taken the initiative and sought to minimise the number of late dementia diagnoses. The approaches taken include:

- the provision of 'in-reach' into care homes
- work with multi-disciplinary teams to make an initial assessment
- cognitive testing using standardised assessments (Kock and Illiffe, 2009)

The box below provides one such case example – the Gnosall Memory Clinic.

Case study: Gnosall Memory Clinic

With the assistance of the Alzheimer's Society Hearts and Brains Project, one general practice in Staffordshire has implemented a streamlined pathway for the assessment and care of dementia. The pathway essentially provides the assessment function of a memory clinic within primary care, so that patients have relatively faster and easier access to expert assessment (Koch and Illiffe 2009; Greening *et al* 2009).

The aim of the Gnosall Memory Clinic is to facilitate the diagnosis of patients with suspected dementia in association with vascular disease. The centre has focused on people with vascular problems because these risk factors are the same as for Alzheimer's disease. The GP or practice nurse identifies patients who are beginning to experience problems with memory, concentration and other symptoms. Identification occurs either when patients present with concerns about their memory or other factors, or through routine screening of all patients with known potential vascular risk. Information is then captured during this appointment with the GP or nurse and is subsequently added to by a health visitor. The information gathered includes clinical status, previous history, family history, and details of functional and social needs. The health visitor is the link between the patient, the general practice and the memory clinic, and is a constant during the patient's journey.

A consultant in old-age psychiatry has been commissioned to provide one clinical session per month within Gnosall Memory Clinic. The consultant meets the patient and their carer at their home or at the general practice and makes a clinical assessment, using the information already captured by the GP, practice nurse and health visitor, supplementing this with cognitive tests and scans as necessary. The consultant is also available for discussion and advice over the telephone and via email. Those diagnosed are then referred to specialist teams to begin pharmacological or psychosocial therapies, and this information is shared with the general practice so that ongoing monitoring can be carried out there.

Between June 2006 and May 2008, 30 out of 41 patients who were referred to the clinic were diagnosed with dementia. The contact rate at the Gnosall Memory Clinic represents three times that reported in hospital-based clinics. The clinic expedites diagnosis and also provides a 'local, non-threatening and non-stigmatised' care environment (Greening *et al* 2009, p 22).

Measuring quality

Currently, there is no widespread use of any tool seeking to examine the quality of dementia care within general practice. However, audit criteria have been developed by NICE/SCIE (2006b) for use by PCTs and social care providers as an audit tool on whether dementia guidance is being followed. The tool recommends using a sample of 100 people presenting with suspected or diagnosed dementia over a period of 12 months, utilising data extracted from patient health records. It suggests that audits should be repeated frequently, to assess progress towards compliance with the guidelines over time. The audit would be able to uncover the percentage of people suspected or diagnosed with dementia who receive care compliant with each criterion.

Ten criteria are provided to represent high-quality care in the NICE/SCIE (2006b) tool, though none specify any particular responsible 'provider' – such as general practice. In brief, the criteria are:

1. Percentage of people diagnosed with dementia where the health record shows criteria for meeting patient consent have been achieved.
2. Percentage of carers who have been offered an assessment of needs.
3. Percentage of carers whose assessment of needs has established experience of psychological distress and negative psychological impact and who have been offered psychological therapy, including cognitive behavioural therapy, by a specialist practitioner.
4. Presence of jointly agreed, documented policies and procedures for dementia services, across local health and social care providers (shared care).
5. Percentage of people with a possible diagnosis of dementia referred to memory assessment services.
6. Percentage of people with dementia who are service users with a documented combined care plan, where there is evidence that:

- the care plan has been agreed and, as appropriate, reviewed at an agreed frequency, to take account of any changing needs for the person with dementia or their carers
 - there is a named health and/or social care worker assigned to operate the plan
 - the care plan has been endorsed by the person with dementia and/or their carer.
7. Percentage of people with suspected dementia for whom structural imaging (computed tomography [CT] scanning or magnetic resonance imaging [MRI]) has been undertaken as part of assessment and diagnosis.
8. Percentage of people with dementia who develop non-cognitive symptoms that cause significant distress to the individual, or who develop behaviour that challenges, including agitation, for whom their care plan demonstrates that a comprehensive assessment has been undertaken to establish the likely causes and influences that may generate, aggravate and improve the behaviour(s), covering:
- physical health
 - depression
 - possible undetected pain or discomfort
 - side-effects of medication
 - individual biography, including beliefs, spiritual and cultural identity
 - psychosocial factors
 - physical environmental factors
 - specific behavioural and functional analysis conducted by trained professionals in conjunction with family carers and care workers.
9. An individual care plan has been developed to help carers and staff to address the behaviour that challenges, and is documented in the notes.
10. Dementia-care training is available for all staff working with older people in the health, social care and voluntary sectors, appropriate to their different roles and responsibilities. All health professionals within general practice, potentially including medical secretaries, to have the training and necessary skills to provide the best quality of care for their role in this setting.

In terms of incentivising quality care in general practice, the QOF provides points for producing a register of patients with dementia, and for the percentage of patients who have received a review in the past 15 months. One of our interviewees described this as a 'good starting place' for drawing attention to dementia care in general practice, but others felt the QOF does not currently motivate GPs and nurses to provide the high-quality care described above.

The potential impact of quality improvement

The financial impact of dementia is considerable. The total annual economic burden of late-onset dementia for England has been variously estimated from £14.3 billion to £20 billion, which is more than stroke, heart disease

and cancer combined (Alzheimer's Society 2007; Comas-Herrera *et al* 2007; NAO 2007a; Alzheimer's Society 2010). Direct health and social care costs for dementia account for £1.17 billion and £2.13 billion respectively. The majority of the total financial burden of dementia falls on the families and carers of people with dementia in terms of lost employment, lower earnings and lost pension entitlements (Alzheimer's Society 2007; NAO 2007a). The national cost of dementia is estimated to rise to £50 billion within 30 years (Comas-Herrera *et al* 2007).

Economic models show the potential financial benefits of commissioning services that deliver early diagnosis and intervention in dementia that prevent admission into care homes and so provide long-term cost savings (Banerjee and Wittenberg 2009). Early diagnosis and intervention has also been estimated to significantly increase quality of life, by diverting approximately 10 per cent of people with dementia out of care homes (Banerjee and Wittenberg 2009).

There are thus clear benefits to dementia sufferers and their carers in ensuring people with dementia receive high-quality care in general practice, since it plays a pivotal role in early diagnosis, referral and ongoing holistic care.

5 Depression

Depression was chosen as a condition to focus on for several reasons:

- It is highly prevalent in general practice.
- For many patients it is a long-term condition that follows a chronic or relapsing course.
- General practice is where most people with depression are treated – only 10 per cent are referred onto specialist services.
- There appears to be considerable scope for quality improvement.

Depression is a highly common condition. In the most recent national psychiatric morbidity survey, 11.3 per cent of adults in England met diagnostic criteria for a form of depressive disorder (McManus *et al*, 2008). An estimated 30 per cent of people attending primary care services have a mental health component to their illness – most commonly, depression and/or anxiety (Jenkins *et al* 2002).

The lay term 'depression' refers to a number of distinct diagnoses. For the purposes of this study we focus on unipolar as opposed to bipolar or 'manic' depression. In terms of ICD-10 diagnoses, we include both 'depressive episode' and 'mixed anxiety and depressive disorder'.

The severity of depression varies markedly. At its worst, it can have a profound effect on people's ability to lead normal lives. In terms of disability-adjusted life years, unipolar depression is responsible for more disability and suffering in high-income countries than any other health condition – accounting for 13 per cent of the total 'disease burden' among adults (WHO 2008).

In addition to its effects on individuals' lives, depression imposes a heavy cost at the societal level. In the United Kingdom, depression and anxiety are estimated to cost the economy £17 billion each year through a combination of sickness absence, reduced productivity and increased staff turnover. The cost to the Exchequer is estimated at £9 billion per year as a result of lost tax receipts and benefits payments (Layard 2006).

Depression is not evenly distributed across the population. Consistent positive associations have been found between mental ill health and various markers of social and economic adversity such as low education, low income, low social status, unemployment and poorer material circumstances (Melzer *et al* 2004). There is a two-fold variation in the prevalence of depression between the highest and lowest quintiles of household income (McManus *et al* 2009).

Depression is strongly correlated with physical illness. People with depression are twice as likely to have a stroke, and four times as likely to have a heart attack or develop heart disease, as people who are not depressed – even when other risk factors, such as smoking, are controlled for (Hippisley-Cox *et al* 1998; Sederer *et al* 2006).

Evidence suggests that for up to half of people who experience depression, the condition becomes a chronic or relapsing one. In a major international study, 50 per cent of people with depression still had depression one year later (Simon 2002). In a long-term follow-up study, 37 per cent of people

with depression and/or anxiety experienced chronic or relapsing illness lasting for at least a decade (Lloyd 1996). Other evidence suggests that at least 50 per cent of people who recover from a first episode of depression go on to experience another episode, and of those who have a second or third episode, 70 per cent and 90 per cent respectively have further relapses (Kupfer 1991). Outcomes are particularly poor for those who experience depression early in life (van Weel-Baumgarten 2005).

Such evidence suggests there is a case for managing depression like a chronic disease (Scott 2006; Tylee and Walters 2007).

However, while there is merit in discussing depression as a long-term condition, it should be borne in mind that depression has many features that make it different from physical long-term conditions such as arthritis, diabetes or asthma. Most important among these is the observation that the status of depression as a medical 'condition' is highly contested. It is arguable that the term actually describes a highly heterogeneous set of experiences rather than a single condition.

Ninety per cent of people with depression are managed solely in primary care. Furthermore, many of those referred to secondary care visit only once and then return to primary care. This indicates a need for high-quality care for depression to be provided within general practice.

What does high-quality care look like?

Three distinct dimensions to quality were identified in the literature reviewed:

- the interventions provided
- the organisational framework within which these are delivered
- the quality of relationships between the patient and professionals.

This section describes the evidence relating to each of these dimensions.

The overall framework for delivering high-quality care

For people who experience depression over extended periods of time (either continually or in recurrent episodes), high-quality care involves being supported by a planned system of support rather than accessing care on an ad hoc basis. Reviews (Kates and Mach 2007; Gilbody *et al* 2003; Oxman *et al* 2005; Boardman and Walters 2009; Barbui and Tansella 2006; Katon and Seelig 2008) indicate a need for a systematic framework that combines the following elements:

- case management, with a single individual responsible for co-ordinating different components of care, monitoring the patient's condition and ensuring follow-up
- a structured care management plan, shared with the patient
- scheduled patient follow-up
- systematic identification of patients with depression– for example, using screening tools among high-risk groups

- a multi-professional approach that involves a GP, specialists and a case manager
- the introduction of mechanisms to enable closer working between primary care and specialists
- patient education and support for self-management
- the development of patient registries.

A number of care models based on chronic disease management principles have been used to provide such a framework. The approach with the strongest evidence base is the collaborative care model. This has achieved improved outcomes in the United States (Gilbody *et al* 2003; Katon and Seelig 2008) and the United Kingdom (Richards *et al* 2008). A review of effectiveness trials found that the model achieves two-fold increases in adherence to treatment, improvements in outcome lasting between two and five years, and higher patient satisfaction (Katon and Seelig 2008).

The term 'collaborative care' has been applied to a number of slightly different models, but the most important elements appear to be case management, systematic follow-up and improved integration of primary and secondary care (Gilbody *et al* 2003). There are a number of questions around what shape case management should take.

- How much mental health expertise does the case manager need? Outcomes for depression may be best if case managers have mental health expertise (Bower *et al* 2006), but given the extent of co-morbidity it may be best if case managers are generalists (such as practice nurses) who can manage the patients physical health care as well as mental health care (Belnap *et al* 2006; Kilbourne *et al* 2004).
- How much supervision is required from specialists? Oxman *et al* (2005) suggest that case managers perform best where there is regular and systematic supervision by a specialist.
- What functions should case managers perform? The central task is to ensure that patients have adequate monitoring and follow-up, but in some cases the role has been extended to include delivering brief psychosocial therapies.

The draft NICE guidelines currently recommend the use of the collaborative care model only for those patients with depression alongside other co-morbid physical long-term conditions (NICE 2009a, 2009b). One interviewee suggested that in practice this distinction may not be workable:

Most of the people we see have got co-morbid problems... it's a false dichotomy, because you don't run two different services for people with depression with or without co-morbidity.

Primary care psychiatrist

It should be noted that some patients may find chronic disease management approaches overly intrusive, so these models may not be suitable for all. Similarly, while evidence suggests that systematic case finding may help identify people with depression who present to primary care with other, physical symptoms, screening tools (normally taking the form of a few short questions about emotional state) would need to be used tactfully and integrated with general consultation processes.

The interventions delivered

NICE guidelines define high-quality care in terms of what interventions should be delivered to patients with depression. The guidelines describe a stepped care approach, with a range of interventions recommended at each step. The two most prominent forms of intervention are anti-depressant medication and psychological therapy – in particular cognitive behavioural therapy (CBT) and interpersonal therapy (IPT). For many patients, the evidence suggests that broadly equivalent outcomes can be achieved with medication or psychological therapy, and that the best outcomes can be achieved by allowing patients to choose their preferred form of treatment (Lin *et al* 2005).

The evidence is there that if you give patients the opportunity to make a choice, that in itself is very empowering. One of the things about depression is that people feel out of control of their own lives... and by even offering them the choice of an intervention so that they begin to take a bit of control over their disorder, that in itself is therapeutic.

GP and policy adviser

Guidelines suggest that in addition to pharmaceutical and psychological interventions, social interventions should play a part in high-quality care. These may include exercise prescriptions, befriending, peer support or assistance with housing or employment issues.

High-quality care should also involve the use of self-management approaches, in which the clinician's role is not limited to providing support or treatment but also includes giving patients the skills and confidence to support themselves and manage their condition (Bachman *et al* 2006; Boardman and Walters 2009; Callahan 2001). The aim of such approaches should be to empower, educate and motivate patients, and not a simple sub-letting of care from the professional to the individual. This is particularly important in the case of depression, where disempowerment, passivity and learned helplessness can play a powerful and pernicious role in the life-course of the condition.

Relational aspects of high quality

In addition to providing effective interventions within a planned, supportive framework, high quality requires that attention is paid to the manner in which care is delivered – to what might be termed 'relational' aspects of quality.

High-quality care involves sensitivity towards the patient's perception of the cause and nature of the problem (including whether or not they conceptualise it as 'depression'), and their preferences about what the focus of intervention should be – whether ameliorating symptoms, increasing functional ability or resolving social or cultural difficulties (Dowrick 2009; Gilmore and Hargie 2000). Professionals and patients need to be able to construct a shared understanding about the diagnosis and treatment plan (Boardman and Walters 2009; Johnston *et al* 2007).

This requires health professionals to have good communication skills, and to structure their work in a way that allows them to deploy these skills. Research suggests that even patients receiving evidence-based treatment achieve better outcomes when those who treat them have good communication skills (van Weel-Baumgarten 2005).

The mental health literature stresses the importance of adopting a strength-based approach, which sees the purpose of mental health care not solely in terms of giving treatment but also in terms of enabling recovery – recovery being the process of building a life beyond illness (Boardman and Walters 2009). Tools are available to assist with this, such as Wellbeing and Recovery Action Planning (WRAP). Professionals involved in delivering care for people with depression need to be able to conceptualise their role as an enabling one, facilitating an individually defined process of recovery, and need the skills to do this effectively.

A further aspect of high-quality care for depression is relational continuity. The importance of continuity varies from one patient to the next, but for many the continued presence of one or more professionals throughout their experience is highly important.

What is the role of general practice?

General practice is often considered a gatekeeper to mental health services, but for people with depression of mild to moderate severity it is a service provider itself – indeed it is the only service that many will access. First and foremost, GPs need to accept that dealing with depression is a core part of their role and feel confident about doing this. The scope of this role needs to go beyond diagnosis, prescription and referral to include elements of the following:

- providing information and advice to allow the patient to understand and manage their condition
- signposting to different sources of support available, including those outside the NHS
- co-ordinating the support provided by different individuals, acting as a relationship broker
- providing relational continuity.

Some of these roles may be taken on by other staff within general practice rather than GPs themselves. Practice nurses, in particular, have an important role to play.

For those patients who need it, general practice needs to be able to provide continuing, organised support through a collaborative care model or similar. With training, practice nurses could act as case managers, and a range of other individuals could be brought in to provide interventions of varying intensities. When a referral is made to secondary care, ideally there would be an ongoing role for professionals in primary care rather than a complete transfer of clinical responsibility.

GPs cannot be expected to be experts in non-health issues such as housing or employment, but there is scope for GPs to signpost to relevant sources of support that are outside the health system but yet intimately related to a person's experience of depression:

We need to be sophisticated enough to deal with the individual who has several sorts of problems rather than making the patient fit into our bureaucratic silos – employment over there and debt over there – we need to do more about joining up our services.

GP and policy adviser

The current quality of care in general practice

The Royal College of General Practitioners acknowledges that while arrangements for treating acute mental illness are relatively well-developed, 'there is a lack of clarity about who should lead on the care of those with chronic, complex and disabling non-psychotic problems', such as depression (RCGP 2009). There is a perception that patients who experience depression over extended periods of time but who do not warrant referral to specialist services often fall through the gap between primary and secondary care. Research indicates that GPs feel less confident about managing patients with depression than they do managing those with physical long-term conditions (Ford 2006).

There is also evidence of under-treatment – in the 2007 national psychiatric morbidity survey, only 23 per cent of people meeting diagnostic criteria for a depressive episode, or mixed anxiety and depression, had received any form of treatment for this (McManus *et al* 2009). It is not clear how much of this relates to GPs' failure to diagnose versus patients not seeking help.

In primary care, the treatment provided most commonly for depression is anti-depressant medication. Surveys repeatedly demonstrate that many patients would prefer psychological therapy to anti-depressants, but access to this is often extremely limited:

Most GPs will see somebody and dish out some anti-depressants, and occasionally somebody will have the courage to ask for counselling and they might access it. And the follow-up would be pretty minimal.

GPSI in mental health

This situation is being addressed through the Improving Access to Psychological Therapies (IAPT) programme launched in 2007. Through this programme several thousand new therapists are being trained, and service structures are being created across the country. IAPT services will deliver time-limited CBT for up to 16 weeks, within a stepped care framework. Once the treatment period has been completed, responsibility for patients will usually be transferred back to primary care. IAPT will improve the quality of care in general practice for some people with depression, but will not be the answer for those for whom CBT does not lead to remission, and who need structured support over a longer period of time.

There has been very little adoption of chronic disease management approaches towards depression, and for most patients there is little systematic follow-up:

The natural history of depression care at the moment, people with chronic depression, they're going in and out of care, often with great big gaps in between, and turning up when things are bad, rather than having more planned regular systematic follow-up for their care in the way that the diabetic or an asthmatic would.

GP and academic researcher

Our expert interviewees suggested that often GPs already possess many of the right skills to provide high-quality care for people with depression but in some cases lack the confidence to do so. One concern is that clinical training may not adequately prepare GPs for dealing with mental health issues in primary care because psychiatric experience in specialist services is so

different from the sorts of mental health problems encountered in general practice. Several suggested that GPs often feared that becoming more involved with patients' mental health issues would be like 'opening a can of worms'. There may also be attitudinal barriers regarding the nature and treatability of depression:

We've done quite a bit of research on this, and I think there is still a lack of belief in depression as a disorder amongst quite a lot of GPs. They see it as a direct result of social malaise, and they say 'We can't do anything about social malaise.'... GPs actually have a very social model of mental health problems, which in some ways is quite a positive thing, but in other ways it's quite nihilistic because it means 'There's nothing I can do.'

Primary care psychiatrist

Measuring quality

Developing quality measures within mental health is notoriously difficult (Sharp 2003). However, it is possible to identify a mixture of structural, process and outcome measures relating to the three dimensions of quality discussed above, as set out in Table 2.

Table 2: Potential quality measures in mental health care

	Structure	Process	Outcome
Organisational framework for care	Provision of case management	Organisation of scheduled follow-up appointments	
	Existence of practice registries for depression	Creation of a written care plan, shared with the patient	
Interventions delivered	Accessibility of psychological therapy	Compliance with NICE guidelines	Clinical improvement
		Ability to choose between evidence-based interventions	Social inclusion
		Provision of self-management tools	Quality of life
Relational aspects of quality		Measures of continuity	PROMs
		Use of WRAP plans	Patient satisfaction
		Measures of therapeutic alliance	Measures of patient self-efficacy

It should be noted that the IAPT programme will provide a new source of data on access to treatment and outcomes, including broader outcome measures relating to social inclusion and return to employment.

The potential impact of quality improvements

There is a significant potential to improve the quality of care provided in general practice for people with depression. A key lesson is that there needs to be structural change to the way services are delivered: clinician education and training alone is not sufficient to deliver lasting improvement (Gilbody

et al 2003). However, organisational change will need to be coupled with cultural change – tackling attitudes regarding what depression is, and whose role it is to deal with it.

As described above, there are a number of efficacious models for improving the quality of care for depression. However, several barriers will need to be overcome if these approaches are to have a significant impact in practice.

- Cost-effectiveness This may be a barrier to implementation of the collaborative care model (Oxman *et al* 2005). Current evidence suggests the model may be cost-effective for major depression but not for milder cases (Gilbody *et al* 2003, 2006). A potential solution would be to embed collaborative care within a stepped care model, reserving full support only for patients who want and/or need it.
- Professional relations Models such as collaborative care work best when built on pre-existing clinical relationships (Kisely and Campbell 2007), and when there are already good relationships between primary and secondary care (Gilbody *et al* 2003). In many parts of the NHS, these relationships are not as close as in the US managed-care organisations within which these models were developed. GPs may not feel confident enough to accept more responsibility for depression care without the specialist supervision and support that the collaborative care model suggests is required.
- Stigma Stigma and taboos surrounding mental health issues may mean that community support that exists for physical long-term conditions may not be present in the case of depression (Croghan *et al* 2006).

If these barriers are not addressed, they may act to reduce the impact of the changes proposed.

6 Diabetes

Diabetes (diabetes mellitus) is group of chronic and progressive disorders characterised by elevated blood glucose. Raised blood glucose occurs either when a person cannot produce insulin and/or cannot respond to it (Department of Health 2002). There are different types of diabetes, including the most commonly occurring types, on which this chapter focuses: type 1 and type 2.

- Type 1 diabetes is non-preventable, and develops if the body is no longer able to produce insulin (Department of Health 2002). Blood glucose builds up in the body and is passed out of the body in urine, causing increased thirst, tiredness and blurred vision. Type 1 diabetes develops most frequently in children, young people and young adults (Diabetes UK 2010). It is less common than type 2 diabetes, and makes up 5–15 per cent of total diabetes cases in England. The prevalence of type 1 diabetes is increasing in all age groups, but particularly among children under five (Gardner *et al* 1997). Treatment is based on daily injections of insulin and modification of diet and lifestyle to ensure that blood glucose levels are maintained at a 'normal' level.
- Type 2 diabetes develops if insulin-producing cells are not able to produce enough for the body's needs. Most people with type 2 are also resistant to insulin, or do not respond to insulin produced in the body (Department of Health 2002). Excess body fat is thought to be one risk factor for developing diabetes, as this causes cells to become less responsive to insulin.

Between 85 and 95 per cent people with diabetes have type 2. It usually occurs among people over 40 years of age, although it can occur after the age of 25 among South Asian and African-Caribbean people (Diabetes UK 2010). Treatment is based on lifestyle changes, such as losing weight, increasing levels of physical activity and modifying one's diet. Type 2 deteriorates over time which means that diet and exercise alone may become ineffective, in which case medication is prescribed to help the body break down glucose.

Diabetes is associated with other health problems in the long term (YHPHO 2008) including:

- cardiovascular diseases, such as heart disease or stroke
- retinopathy
- nephropathy
- neuropathy
- circulation problems
- depression.

The risk of developing physical health complications can be reduced by controlling blood glucose and cholesterol levels, being physically active and attending regular medical examinations and screenings. This requires

people to carry out a degree of self-management and requires health care professionals to ensure the condition is monitored.

In 2008, the Yorkshire and Humber Public Health Observatory (YHPHO) estimated that more than 2.4 million people in England had diabetes (either diagnosed or undiagnosed) (YHPHO 2008). The rate of diabetes will continue to rise, due to the rising rate of obesity and the ageing population. The YHPHO forecasts that by 2025 the number will have risen to more than 3.6 million (about 6.5 per cent of the population).

Diabetes is more likely to occur in areas experiencing greater levels of deprivation. The rate of diabetes complications is 3.5 times higher among people in social class V compared with those in social class I. People in deprived communities are more likely to be overweight or obese and physically inactive. Also, there is a strong association between deprivation and poorer blood glucose control, worse access to services, and referral bias. More men develop diabetes than women. However, diabetic women appear to be at relatively higher risk of dying than diabetic men (Department of Health 2007b).

People of South Asian and African-Caribbean descent in England are six and three times more likely (respectively) to have type 2 diabetes (Department of Health 2007b). Diabetes is also more common among people of Chinese descent and other non-Caucasian groups. Susceptibility to cardiovascular disease and retinopathy and the risk of mortality from diabetes is higher among black and minority ethnic groups (Department of Health 2007b).

People aged between 20 and 79 years who have diabetes are twice as likely to die as people without the condition. Among people with diabetes, the hazard ratios of dying are higher for those under 60 years of age, and the hazard ratios are higher for women than for men in all age groups (YHPHO 2008).

The impact of diabetes on the health care system is substantial. The total NHS expenditure on the diabetes care programme in 2006/7 was £1,043 million. Over half of this was accounted for by prescribing costs (YHPHO 2008). Diabetics are twice as likely to be admitted to hospital as others, and it is estimated that prolonged hospital stays among diabetics result in approximately 80,000 bed days per year (Sampson *et al* 2007). In 1998, nearly 6 million working days were lost due to diabetes in England and Wales. This would have cost £256 million in lost productivity (YHPHO 2008).

What does high-quality care look like?

For people who have been diagnosed with diabetes, there are a range of best-practice guidelines, an NSF and core standards of care written into the QOF payment system. The NSF for diabetes details an approach to improve service quality and reduce variations in care by setting national standards for diabetes care, ranging from prevention (of type 2) to the detection or management of long-term complications (Department of Health 2003 – see the box below/overleaf).

The NSF includes milestones, set to ensure that all people with diabetes are identified on an up-to-date register and offered annual retinal screening, and that a system of regular follow-up was followed to ensure that diabetic

patients were given the appropriate information, education and advice to help them support self-care.

NSF for diabetes: core standards

Standard 1: Prevention of type 2 diabetes

Standard 2: Identification of people with diabetes

Standard 3: Empowering people with diabetes

Standard 4: Clinical care of adults with diabetes

Standards 5 and 6: Clinical care of children and young people with diabetes

Standard 7: Management of diabetic emergencies

Standard 8: Care of people with diabetes during admission to hospital

Standard 9: Diabetes and pregnancy

Standards 10, 11 and 12: Detection and management of long-term complications

Source: Department of Health (2003)

NICE published best-practice guidance for type 1 diabetes in 2004 and updated it in 2010 (NICE 2004, 2010). The guidance set key priorities for treating type 1 diabetes for children and young people including:

- patient education
- prevention of diabetic ketoacidosis
- screening for complications and associated symptoms
- psychosocial support.

The guidance also set key priorities for treating type 1 diabetes in adults, including:

- education – for example, the Dose Adjustment for Normal Eating (DAfNE) course
- control of blood glucose and arterial risk factors
- dealing with late complications.

NICE provided best-practice guidelines for type 2 diabetes in 2008 (NICE 2008c). The guidance makes more than 100 recommendations for the different aspects of managing the condition. Among others, these included:

- education – for example, the Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND) course
- dietary advice
- managing depression
- setting targets with the patient
- clinical and self-monitoring
- oral medication and insulin prescription

- blood-pressure reduction targets
- monitoring cardiovascular risk, kidney, eye and nerve damage.

Common to both sets of guidance was the need for care and treatment to be delivered through a multidisciplinary team approach. This has been re-emphasised in guidance on the commissioning of diabetes services – the Diabetes Commissioning Toolkit (Department of Health 2006a) – and the policy *Making Every Young Person and Child with Diabetes Matter* (Department of Health 2007a).

Further articulation of the shared care model of service provision was developed in the Year of Care initiative, established by the Department of Health and Diabetes UK. The Year of Care sets out a pathway that aims to make consultation between people with diabetes (and other long-term conditions) and clinicians a more collaborative process, through personalised care planning and co-ordination. These care plans are intended to give the individual greater ownership of the management of diabetes through joint decision-making with health care professionals, in a way that makes it more relevant to their needs.

The experts interviewed as part of the Inquiry commonly reported that the Year of Care approach to diabetes management was approaching what best practice should look like, since it emphasised the roles that generalists and specialists alike should play in a person's ongoing care. They emphasised how awareness of options, training and advice about diabetes management should be available to staff who provide health care services. This was particularly necessary for staff working out of hours, where a lack of care continuity and experience might increase the likelihood that people with diabetes will be admitted to hospital when crises occur.

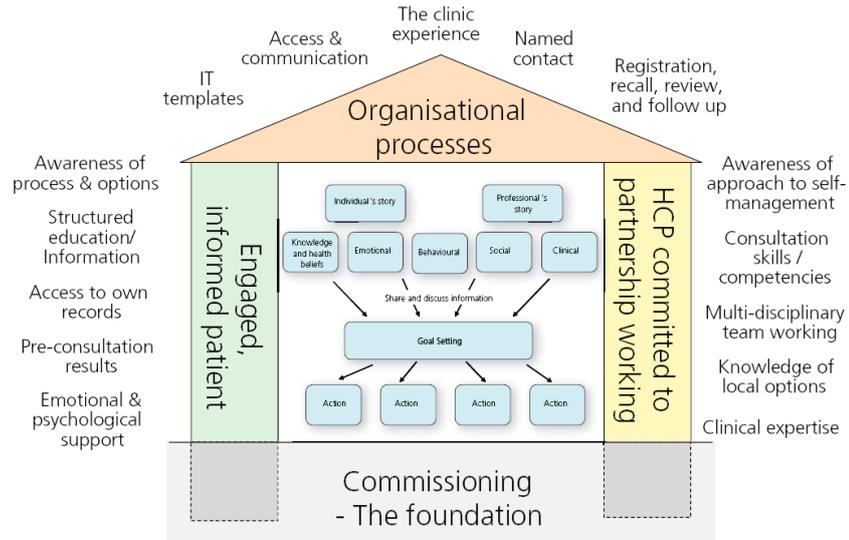
The need for effective care planning was another strong theme to emerge from the expert interviews – particularly where individuals had other complex care needs:

What we're talking about is a discussion between the health care professional and the patient about what's important to both types. So, actually, if the doctor's main thing is to get the patient to stop smoking but the patient's main problem is they're about to be evicted from their home, they're not going to listen to the 'give up smoking' advice. So you've got to have a discussion about what are the goals.

Representative of national diabetes charity

A diagrammatical representation of the components of the care planning process has been developed for people with diabetes, and is reproduced as Figure 2, below.

Figure 2 The components of care planning for people with diabetes



Source: Diabetes UK *et al* (2008, p 19).

Another key theme emerging from our interviews with experts was the expectation that in high-quality care, the patient would be supported to take responsibility for the self-management of their condition as set out in their care plan – for example, in terms of their ability to self-monitor and manage their blood glucose levels, weight and medication. The participants considered that providing information and support tools to enable patients to self-care was an important pre-requisite to achieve this, and reported that such information was already well advanced and available – for example, through access to the DAFNE and DESMOND courses.

As with other long-term conditions, expert informants argued that effective care for people with diabetes requires a long-term relationship between the individual and a range of health care professionals – not just those working in general practice. They regarded regular, streamlined contact between the individual and the health care team as being important for those with needs requiring multi-disciplinary care.

What is the role of general practice?

It was clear from the best-practice guidance and the expert interviews that general practice plays a pivotal and significant contribution to the effective management of diabetes, but that the nature and extent of their role and contribution in partnership with other care providers was less well articulated. At one level, a key role for general practice was seen as providing health promotional support to patients in order to help prevent the onset of diabetes. This took the form of providing advice and support to those with high risk factors, such as people who were overweight/obese and those with a family history of diabetes. Based on such assessments, the GP could consider referring patients for screening – for example, to examine impaired glucose tolerance – and could then follow this up with an appropriate intervention, such as lifestyle changes or medication (Gillies *et al* 2008).

As the report to the Inquiry by Boyce *et al* (2010) suggests, general practice cannot of itself deliver interventions that prevent the onset of conditions

such as diabetes, but they are well placed to at least provide information to encourage positive lifestyle changes, or to refer at-risk patients to appropriate support services.

The best-practice guidance, literature evidence and expert interviews suggest that the role of general practice should encompass the following key tasks.

- **Awareness of risk factors and symptoms** General practice professionals play the key role in recognising the symptoms of diabetes in patients and making an appropriate diagnosis.
- **Prompt and appropriate referral** For example, in cases where symptoms of type 1 diabetes are suspected in children and young people, GPs must make an immediate (same-day) referral to a multidisciplinary paediatric diabetes care team. The team can then confirm the diagnosis and begin immediate care.
- **Holistic assessment** The general practice team, in partnership with specialists, should be responsible for carrying out an holistic assessment of the patient, taking into consideration factors such as social support and employment (if applicable) as well as medical risks and needs. The assessment should be multi-disciplinary so that professionals and patients are aware of any co-morbidities and so can make referrals for further investigation and treatment if necessary. The GP can prescribe the relevant medication and be aware of any other medication prescribed to the patient by other health care professionals.
- **Information and advice** The GP must relay his or her diagnosis to patients honestly and clearly, so that they understand what diabetes means and how it will be managed. It may be appropriate to provide high-quality, individualised information about diabetes and healthy lifestyle changes, or to explain how the patient can access it themselves. In addition, the GP can make a referral for the patient to attend an education course such as DAFNE or DESMOND.
- **Personalised care planning** The care plan should ideally be a product of a supportive discussion between the professional and the patient about the goals for controlling diabetes and any related complications and healthy lifestyle changes. The professional has to consider what is realistic and achievable when discussing the care plan and should be willing to listen to the patient's point of view.
- **Ongoing monitoring and follow-up** Typically undertaken within general practice by nurse specialists or health care assistants, practices need to ensure that regular checks are made of the patient's blood glucose, blood pressure, cholesterol, weight, albumin level, creatinine level and foot care. They should ensure that the patient is referred for retinal screening and should encourage them to keep their appointments by emphasising their importance.
- **Emotional well-being** NICE guidance suggests that professionals working in general practice are responsible for the emotional well-being of patients as well as their physical health, and so should be alert to the development or presence of depression and/or anxiety

– particularly where this is impeding the individual's ability to self-manage.

- **Multi-disciplinary working** The needs of diabetes patients appear to be better met when staff in general practice work with specialists and other care providers in multi-disciplinary teams – particularly during the process of assessment and care planning. Good communication, open dialogue and shared information about patients between care providers also appears to help in providing patients with a better and more streamlined experience across the care pathway.

The current quality of care in general practice

Our review of the literature and interviews with experts suggests that some aspects of diabetes management have improved recently in general practice. The introduction of the NSF, NICE guidance and the QOF all supporting this improvement in care standards. However, the quality of care remains variable across England, and rarely meets all the aims of the 12 NSF standards and NICE best-practice guidance.

The proportion of people receiving all care processes has increased substantially over the past few years, yet for 2008/9 it was estimated that just 51 per cent of people with type 2 diabetes and 32 per cent of those with type 1 diabetes received all NICE-recommended care processes. This implies that 49 per cent and 68 per cent (respectively) did not (NHS Information Centre 2010). Meanwhile, compared to the Department of Health's NSF target of 100 per cent of diabetic people being offered an eye test for retinopathy by the end of 2007, in 2007/8 only approximately 65 per cent had received it (NHS Information Centre 2008). Similarly, where care processes are being carried out, there is variation in terms of type 1 versus type 2 (NHS Information Centre 2008, 2010), and there appears to be variation in terms of ethnicity (Soljak *et al* 2007; Gray *et al* 2007).

Generally, however, standards have improved. There has been an increase in recording of people with diagnosed diabetes in England since 2005 (YHPHO 2008), although an estimated 14 per cent of the total number of diabetics in the England remain undiagnosed. The expert informants provided anecdotal evidence that many GPs do not have enough experience of children and young people with type 1 diabetes to recognise symptoms in order to ensure an early diagnosis.

In terms of monitoring the physical health of people with diabetes and ensuring care processes are carried out, there have been some improvements in the quality of diabetes care, but these do not apply to all people. Studies have revealed inequalities in the recording of diabetes at general practices. For example, a short time after QOF was introduced, analysis of records from 237 general practices in England, Scotland and Wales showed that patients living in more deprived areas were less likely to have HbA1c, body mass index and smoking status recorded (Hippisley-Cox *et al* 2004).

As we have seen, many of the processes for the management of diabetes have been written into the QOF. The evidence from the QOF database shows that practice improved quickly in meeting the quality of care targets for people with diabetes in general practice – particularly those in more deprived localities whose performance was weakest (Campbell *et al* 2007; Tahrani

et al 2008). This analysis was extended to include performance data and examine a time-series effect between 1998 and 2007. This showed that the quality of care for diabetes had been increasing pre-QOF and then increased significantly following its introduction. However, the accelerated rate of improvement was not sustained after 2005, when it reduced to the pre-QOF rate (Campbell *et al* 2009).

The lack of initiation and implementation of care plans in general practice was a major issue for concern among the experts we interviewed, and the evidence suggests that this would be a significant area for improvement. They reported a view that professionals in general practice are not always able to develop care plans in partnership with patients or to provide the encouragement and motivation needed to ensure goals are met. In part, they saw this as being due to a reluctance among GPs and nurses to ask questions about why patients have not been able to meet certain goals or how the patient is feeling, because they are reluctant about 'opening a can of worms'.

In such cases, GPs and nurses could benefit from training in motivational interviewing skills, as highlighted in the report to the Inquiry by Greenhalgh and Heath (2010):

Logic alone suggests to me that if somebody has diabetes and they're having to look after themselves 97 per cent of the time, and they only need a health care professional 3 per cent of the time, they actually are much more an expert on their own care than the person they are consulting. So logic would suggest that the health care professional needs to be able to listen to what's important to that person. And... what's important to them changes all the time. So the concept behind the care planning approach, which is collaborative and partnerships and equal and informed, to me makes an enormous amount of logical sense. And those cultural skills, I believe, are not necessarily engrained in every GP or practice nurse.

NHS Diabetes stakeholder

The written evidence seems to support a lower-than-optimal level of care planning with diabetes patients. For example, a Diabetes UK survey of PCTs in 2007 showed that only 67 per cent required a care plan to be made (Diabetes UK 2008). Similarly, a review of health care services by the Healthcare Commission (2007) showed substantial variation in care planning across PCTs in England. The proportion of people with diabetes who reported having discussed their care plans and agreed self-care goals ranged from a low of 23 per cent to a high of 58 per cent.

Another strong theme to emerge from the research evidence is the need to share good information between professionals, in order to help them understand and respond to a patient's needs. It was felt that there were sometimes barriers to GPs and nurses accessing the information they need in sufficient time to provide this to patients, and that there are no easy methods for sharing information between general practice and specialist teams. This lack of integration means GPs and nurses cannot easily ask for advice about diabetes management or find out about medication prescribed to the patient by other teams.

Experts were also concerned about patients' access to high-quality information about diabetes and its management. For example, evidence from a Diabetes UK survey suggests that 23 per cent of its members (from

13,276 respondents) felt that improved access to information would improve their diabetes care (Diabetes UK 2009). An expert from the same charity, interviewed in this study, reported that patients often do not recall being given information by their GP or practice nurse. Therefore even if information has been given verbally or in written format, people do not necessarily retain it. People with diabetes need information to support them in making changes to their lifestyle and diets.

Measuring quality

Relative to other long-term conditions, there is a robust set of guidelines for best practice in the management of diabetes, and a number of best-practice measures and indicators that are collected to monitor and manage quality. However, the evidence shows these have not necessarily been successful in ensuring that people with diabetes receive high-quality and equal care for every component of their care needs, indicating the need for improvement in the quality of diabetes care management in general practice and in the multi-disciplinary care teams it should be working with.

Despite QOF leading to generally improved results in terms of diabetes care, the experts interviewed were in agreement that QOF had been more beneficial for 'putting diabetes on the map' than in making a step change towards better care management overall:

QOF isn't perfect, but it's changed the way diabetes care is managed in primary care... I think things are being done which weren't being done before it was there... a financial reward is the thing that works best, unfortunately.

Representative of national diabetes charity

However, the QOF quality indicators do not entirely reflect the combined picture of high-quality care provided in best-practice guidance. This suggests that the scope of QOF is not broad and flexible enough to incentivise key elements of best practice in general practice, including:

- the encouragement of type 2 diabetes prevention by addressing obesity and sedentary lifestyles
- the encouragement of achieving individual targets for HbA1c (which may be above the general target of 6.5 per cent set for people with type 2 diabetes)
- the provision of holistic care of the patient with diabetes
- the encouragement and facilitation of self-management
- the ability to work with other care providers in multi-disciplinary teams.

The potential impact of quality improvements

Efforts to improve the quality of care in the areas mentioned above are potentially beneficial to the health care system, the economy and individuals. Although robust cost-effectiveness data from long-term studies on diabetes care are lacking within a UK context (Simmons *et al* 2010), there is consensus that preventative measures in primary care (such as impaired glucose tolerance screening and medication or motivational interviewing)

have the potential to reduce the risk of diabetes in the community, and appear to be cost-effective (Gillies *et al* 2008; Greaves *et al* 2008; Waugh *et al* 2007).

7 Managing people with multiple long-term conditions

So far, this report has discussed high-quality care for people with a single long-term condition. However, a substantial proportion of people with long-term conditions experience co- or multi-morbidity – the presence of two or more conditions simultaneously. Indeed, research evidence suggests this is more often the rule than the exception. One study of patients attending general practice in Canada found that 69 per cent of 18–44 year olds, 93 per cent of 45–64 year olds and 98 per cent of those aged 65 and over had two or more long-term conditions (Fortin *et al* 2005a). As well as increasing with age, there is evidence that multi-morbidity is more prevalent among minority ethnic groups and groups with lower socioeconomic status (Ogle *et al* 2000).

A particularly common form of multi-morbidity is the existence of mental health problems such as anxiety or depression, or neurological problems such as dementia, alongside physical health problems such as diabetes, arthritis or cardiovascular disease (Chapman *et al* 2005; Evans *et al* 2005; McVeigh *et al* 2006; Roy-Byrne *et al* 2008). For some conditions, the association between mental and physical health is very strong. For example, in the United Kingdom depression has been associated with a fourfold increase in the risk of heart disease, even when other risk factors such as smoking are controlled for (Hippisley-Cox *et al* 1998; Osborn *et al* 2007).

Co-morbidities are also common between physical long-term conditions. For example, people with arthritis are twice as likely to suffer from obesity or heart disease as people in the general population, even after adjusting for age, sex and class (Kadam *et al* 2004). Similarly, people with diabetes are at increased risk of stroke (Mulnier *et al* 2006).

The impact of multi-morbidity is profound and multi-faceted. Patients with several long-term conditions have poorer quality of life, poorer clinical outcomes, longer hospital stays and more post-operative complications, and are more costly to health services (Fortin *et al* 2007). For example, diabetic people with co-morbidities show poorer adherence to treatment, more complications, and increased use of medical care relative to people with diabetes alone (Chapman *et al* 2005; Evans *et al* 2005; McVeigh *et al* 2006; Strujis *et al* 2006). There is evidence that the degree of multi-morbidity can be a greater determinant of a patient's use of health service resources than their diagnosis (Starfield *et al* 2003).

What does high-quality care look like?

There is little direct evidence demonstrating what would represent high-quality care for people with multiple long-term conditions – not least, because most research trials specifically exclude people with multi-morbidities. What research has been done on multi-morbidities is mainly epidemiological work looking at the prevalence and distribution of multi-morbidity rather than interventionist work testing ways of providing care for these people (Fortin *et al* 2005b). Furthermore, clinical practice guidelines generally have a single-disease focus, and fail to discuss the applicability of their recommendations to people with multiple conditions (Boyd *et al* 2005). They are therefore of limited use for describing high-quality care for such

people. An exception to this is the new NICE guidelines for the management of depression in people with chronic physical health problems (NICE 2009b), described in the following paragraph.

What evidence does exist suggests that a patient-centred approach that addresses a person's various needs in an integrated way leads to better-quality care. For example, collaborative care models that integrate mental health and primary care lead to better depression outcomes for people with medical co-morbidities (Narasimhan *et al* 2008). The draft NICE guidelines for the management of depression in people with chronic physical health problems (NICE 2009b) recommend that collaborative care models are used for more severe cases of depression, with case management, systematic follow-up, close collaboration between primary and secondary care, and co-ordination of mental and physical health care.

A promising model of care developed specifically for people with multiple conditions is the guided care model (Aliotta *et al* 2008). This is essentially an extension of the collaborative care model, with particularly intensive case management, featuring an emphasis on:

- self-management and carer support, comprising several hours of training for patient and carer alike, focusing on managing multi-morbidity
- home-based assessment of patient
- transitional care, comprising close, structured support through transitions in care (for example, after discharge from hospital)
- care managers trained in motivational interviewing
- predictive modelling, to identify multi-morbid patients.

Early evidence suggests that guided care can improve the quality of health care for people with multiple long-term conditions, although this evidence is US based, and relates mainly to older people (Boult *et al* 2008; Boyd *et al* 2008).

Several studies explore what people with multiple conditions want from their health care. Continuity of care appears to be particularly important, both in terms of relational and management continuity (Cowie *et al* 2009). Indeed, the value that patients place on continuity increases with the number of co-morbidities (Nutting *et al* 2003).

A key area of concern is around potential adverse interactions between medications prescribed for different conditions. Qualitative evidence suggests that these can have a significant impact on people's lives (Noel *et al* 2005). The NICE guidelines state that prescribers should be vigilant for such interactions (NICE 2009b).

Self-management approaches are also important, with evidence indicating that willingness to learn such approaches is higher among people with multiple conditions than among those with a single condition (Noel *et al* 2007). In particular, people with multiple conditions express the need for approaches that enable them to manage their medications, cope with stress, manage pain, and change their diet and lifestyle (Noel *et al* 2005). Our expert interviewees stressed that this support should go beyond providing written information, and should aim to genuinely empower patients:

There are two radically different versions of self-care. The first, which is most commonly used in medicine (general practice in particular) is getting patients to do stuff that doctors haven't got the time or energy [to do], or can't be bothered to do themselves. So it's a sort of a sub-letting of care from the professional to the patient... [The second] is about a view of patients as people who can organise and lead their lives and sort things out.

GP and academic researcher

There may be some scope to exploit synergies by identifying interventions of mutual benefit for several conditions. For example, dietary change and exercise prescription is recommended for treatment of depression (NICE 2009a, 2009b) and can also be expected to help in the management of some physical long-term conditions.

Multi-morbidity also poses a challenge to methods used for case finding. Chronic disease management approaches that identify patients on the basis of the severity of a single condition may miss multi-morbid patients who would stand to benefit greatly from improved co-ordination of care (Starfield *et al* 2003).

What is the role of general practice?

The various challenges posed by multi-morbidity underline the importance of generalists in the health care system, and suggest that there is a need for changing the role of general practice to develop new ways for primary and secondary care can work together more closely (Starfield *et al* 2003).

Our expert interviewees agreed that there is an important role for general practice in supporting people with multiple long-term conditions rather than transferring clinical responsibility to specialist teams. However, as many of these patients are likely to need specialist input at least some of the time, the interface between general practice and specialist care is also crucial:

I think general practice has got a very important role. But there are, obviously, interface issues: people do go into hospital, and do need to be brought home again in a timely way and with the right care and support around them. So those interface issues are very important.

Department of Health programme lead

There is a particularly strong case for case management for people with multiple long-term conditions, to provide the relational continuity and co-ordination of care that the evidence suggests is highly important to this group. General practitioners themselves may not need to take on this role – practice nurses or community matrons may be more appropriate – but GPs will need to work closely with whoever does provide case management, and to maintain clinical responsibility for the patient. (For more detail on this point, see Section 8, p 61.)

In most places it's not a good use of GP time to deliver chronic disease case management because its expensive, so a nurse is better, better skilled, [and] more cost-effective and efficient at doing it.

Nurse practitioner with a special interest in depression and LTCs

[GPs] do need to draw in the help of other people, whether it's their practice nurse, local community nursing service, local diabetic nurse... whoever it is... But the GP – I think – has to, sort of, hold the ring.

Department of Health programme lead

Medicines management forms a core part of the GP role in providing care for people with multiple long-term conditions. GPs should be aware of the potential for drug interactions, and for poorer compliance with treatment among these patients. There is a strong case for GPs to provide access to self-management tools that assist with medication management and other aspects of patients' lives.

Our interviews highlighted the need for GPs to pay particular attention to the psychological and emotional aspects of physical long-term conditions, as well as to the physical health care of people with long-term mental health problems. The interviewees saw identifying and responding to patients' psychological needs in primary care as being vital to improve the quality and cost-effectiveness of care. This may include screening people with physical long-term conditions for psychological and mental health problems:

There are a whole range of issues where managing the psychological consequences of the long-term condition improves the outcome. When long-term conditions account for 70 per cent of NHS expenditure, not looking at the psychological consequences that would improve their management is downright bonkers... The economic case, as well as the moral case... is just so strong.

GP and policy adviser

It should be something that's automatically considered when someone has long-term conditions. Automatically after someone's had a stroke, automatically after someone's had heart problems, [there should be] some screening and expectation that they will need some advice around depression.

Mental health nurse and policy adviser

I think that's the big thing that's missing from not just primary care but all care, is that sort of emotional, psychological aspects of care, it's totally under-resourced, and in any long-term condition, no matter what it is, that element needs to be provided, and the primary care would be a very good place to provide that at a certain level.'

Director, voluntary sector organisation

The current quality of care in general practice

There is evidence that people with multiple long-term conditions get poorer treatment from health services. People with depression in addition to heart disease have lower rates of revascularisation surgery than people with heart disease alone despite equivalent clinical need (Kisely *et al* 2007), while also having poorer access to care for their depression than people with depression alone (Nuyen *et al* 2008).

People with multiple conditions may suffer from (Noel *et al* 2005):

- adverse interactions between drugs used to treat different conditions
- being perceived by service providers as 'problem patients'

- non-recognition of a co-morbid condition due to it being overshadowed by an existing diagnosis.

Several studies have found that people with multiple conditions experience more aggravation in interacting with the health care system (Noel *et al* 2005; Parchman *et al* 2005). Patients report disagreements between them and their doctor regarding which of their health problems is most important and requires attention first. Some report that consultation times are not always sufficient to allow their multiple conditions to be discussed (Noel *et al* 2005).

In the case of patients with physical long-term conditions and co-morbid mental health problems, developing high-quality care may currently be impeded by a lack of clinicians who have skills in both mental health and long-term conditions:

What we lack are psychological therapists with a knowledge of some of those co-morbid physical illnesses or [of] working with chronic illness.

Primary care psychiatrist

Measuring quality

Potential measures of quality of care for people with multiple long-term conditions are similar to those that exist for people with single conditions. However, the evidence suggests that particular emphasis should be given to developing quality measures that relate to the following dimensions:

- continuity
- access to self-management approaches
- structured support for carers
- integrated treatment of physical and mental health care needs
- provision of case management
- absence of adverse interactions between drugs.

Such measures of quality are hard to measure and quantify, and so most would not lend themselves to indicators for use in a balanced scorecard or QOF-based system of quality assurance. The QOF does contain some measures that are of relevance to co-morbidity (particularly in linking screening for depression to conditions such as diabetes). However, achieving high-quality care for people with multiple long-term care needs is unlikely to improve unless these wider dimensions of quality can be valued, measured and used to represent how care quality is being achieved. Moreover, these measures should be applied not just to the general practice, but across providers who have a shared care role in managing people with multiple long-term conditions.

Given the importance of achieving high-quality and cost-effective care for people with multiple LTCs, there is a need to develop more effective ways of measuring, comparing and reflecting on performance. We return to this issue in our conclusions (Section 10), where we outline a number of possible ways in which these quality domains might be measured to enable quality improvements to be made.

8 Managing long-term conditions across a population

Relatively well-defined disease-specific pathways are in place for individuals with certain diagnoses – and, to a lesser extent, for those with multiple long-term conditions. However, these approaches still rely on the patient seeking out treatment. Such approaches can result in reactive episodic care, where a patient only seeks help when in crisis.

One means of addressing this is population management – an approach that seeks to reduce expensive and distressing emergency admissions, by promoting high-quality proactive care for patients. The term refers to any strategic activity that attempts to proactively identify individuals at risk of deterioration in the future, with the intention of preventing or slowing that deterioration. It is based on the theory that early intervention has potential to reduce downstream utilisation.

This section considers what evidence there is for population management. It examines the structures and interventions that could be put in place, and are being put in place, to proactively manage patients with long-term conditions. Finally, it seeks to define what the role of the GP might be in a population management programme.

Evidence for population management in primary care

The LTC model outlined at the beginning of this report emphasises the importance of upstream interventions in primary and community care that can enable downstream resource savings, by maintaining well-being and avoiding costly and distressing unplanned admission. The model recognises that only a small number of patients will require high-intensity care, and that it is possible (and necessary) to stratify a population into different risk categories. These range from the very high-risk patients, who need high-intensity case management, through patients who are moderately high users of health services and who might need some support to self-manage, right down to individuals who are not yet deemed high risk but who might become high users of care in future.

Although the NSFs and NICE guidance have been useful in setting standards for individual pathways of care once a diagnosis has been reached, population management advocates moving a step further upstream, to assess whole-population needs, with a view to targeting different interventions at individual risk groups.

Evidence as to the quality and cost-effectiveness of such an approach is rather patchy. What is clear from the evidence is that a population management model must consist of two elements.

- There must be a reliable way of effectively stratifying a population in order to identify which patients in a population will be at high risk of emergency admission to hospital in future.
- Once the level of risk of admission is identified, there must be an appropriate and cost-effective intervention that reduces the individual's risk of emergency admission and promotes patients' ability to become less dependent generally on health care interventions.

Identifying the right patients

Evidence from the United Kingdom and the United States suggest that accurate identification of patients appropriate for interventions is crucial to the success of any population management programme (Billings *et al* 2006b). Without a reliable method of stratifying populations into risk groups, it is likely that care will be targeted at patients who do not need the care, and will potentially miss those who do.

A case in point is the Evercare pilot in the United Kingdom, whose evaluation indicated that the programme cost over £3.7m yet had 'no significant effect ... on rates of emergency admission, emergency bed days, or mortality' (Boaden *et al* 2006). Some commentators surmised that the lack of impact could be at least partly explained by the fact that the case-finding method did not identify the correct patients (Gravelle *et al* 2006). This was due to a phenomenon known as 'regression to the mean' (identifying patients at the height of their usage of medical care, rather than those most likely to be high users in the future), and it is imperative that any method of identifying risk takes this issue into account (Curry *et al* 2005).

Various predictive models are now available to the NHS. Availability of, and access to, data is key to these models. Some of those models (for example, The King's Fund's PARR and Dr Foster's HUM) use only inpatient data to predict risk of re-admission among the highest-risk population, while others (for example, the combined predictive model) link GP data with hospital data, to stratify an entire population from very high risk to low risk.

Some commentators argue that the use of GP data models has the potential to have a greater impact on admissions, by enabling intervention much further upstream (Wennberg *et al* 2006). If timely data is available, such models also enable real-time identification of at-risk patients in practice settings, so that practice-based teams can target follow-ups and make appropriate interventions quickly and effectively to patients on their list.

What has emerged in recent years is the importance of having high-quality data available for needs assessment and service planning. In this context, GP data-based models offer a much richer insight into the needs of a population. Competency 5 in the world class commissioning documents cites predictive modelling as an integral part of 'managing knowledge and assessing needs' (Department of Health 2007b). The move to GP commissioning from 2010 onwards is likely to promote further the need for such information. The role of general practice in keeping and providing high-quality data and information (in order to support predictive risk tools that help target case management at appropriate individuals) seems to be a highly important issue for the future.

Developing an effective intervention

The second element of population management is the development of appropriate and cost-effective interventions that reduce the risk of admission, or re-admission, among individuals in each risk segment. Evidence of what interventions might be effective is beginning to emerge but is, at present, very limited. Several different initiatives exist or are being piloted, including:

- case management through community matrons

- telehealth and telecare
- telephone health coaching
- collaborative care models.

Such interventions vary from the very intensive case-management programmes targeted at the very high-risk groups to lower-intensity self-management support programmes targeted at the low-to medium-risk groups. It is important that the intensity of the intervention is appropriate to the level of risk, because the upstream costs should be offset by the downstream care that is avoided (Hutt *et al* 2004).

Case management

Case management is a widely used approach in primary and community care, and is usually a package of home-based care with the broad aim of developing 'cost effective and efficient ways of coordinating services in order to improve the quality of life' (Hutt and Rosen 2005). One format that is beginning to emerge throughout England is the 'virtual ward' – a programme of case management that uses information from predictive modelling tools to target interventions. These are most often built around the GP practice and the patients registered within them.

Evidence is mixed as to whether case management is an effective approach to long-term conditions management. A Department of Health report in 2004 found that one such model, in the United States, had achieved a 50 per cent reduction in unplanned admissions (Department of Health 2004). Similarly, an article in the *British Medical Journal* drawing on observations from the United States concluded that case management is 'very cost effective' (Lewis *et al* 2004).

However, other papers have found that the Kaiser Permanente integration model and Pfizer Health Solutions – both of which include elements of upstream case management – have lower bed usage than the NHS. However, Ham *et al* highlight that the factors contributing to that low bed use tend to be very closely linked to the structural, organisational and financial context that is specific to certain parts of the US system (Ham *et al* 2003).

Further studies have also been equivocal as to the effectiveness of case management. A paper that examined the evidence from 19 studies of case management targeted at older people found only weak evidence that this approach reduced hospital admissions (Hutt *et al* 2004). In addition, the evaluation of Evercare – the US case management programme for older people – found that the programme had no significant impact on emergency admissions (Boaden *et al* 2006).

A systematic review commissioned by Birmingham and Black Country Strategic Health Authority in 2006 found a mix of evidence, with some studies concluding that case management has potential to reduce admissions and length of stay while others found that it had no effect (Ham 2006). Similarly, a more recent paper, which reviewed 10 papers focusing on case management, concluded that there was inconclusive evidence about the effectiveness of case management (Offredy *et al* 2009).

Population-based management in England: six case studies

The current policy of GP commissioning for the NHS in England implies that, as members of commissioning organisations responsible for meeting the needs of local communities cost-effectively, the general practices of the future will become population oriented. For example, an unpublished survey undertaken by The King’s Fund suggested that in spring 2009 at least half of all PCTs were using some sort of predictive modelling tool.

In the disease-specific interviews, we asked GP respondents specific questions about whether their general practices were involved in any programmes that attempted to identify patients at risk of deterioration or unplanned admission to hospital. We also asked them to identify the sorts of interventions being employed as a result. (See Appendix 2, question 7.)

In order to explore the issue of population management more directly, we undertook a purposeful sample of six case sites for further investigation. These case studies (described in Table 3) were known to be proactive in population management, and were selected to identify leading-edge approaches to population-based management in primary care and the role that general practice could, and should, play in delivering that.

Each of the six case sites visited had a slightly different model for population management and organisation of services. None have been fully evaluated, so effectiveness cannot be compared, but some elements that are common to all have emerged. These provide an indication of what might constitute effective population management.

Table 3: Population-based management in six English PCTs

Site	Case-finding technique used	Intervention implemented	Progress
Croydon	Combined predictive model	10 virtual wards across the PCT. Virtual wards mirror hospital ward and aim to target home-based case management at high-risk individuals. Each ward run by community matron	Model in place since 2004. Wards rolled out from 2005
Devon	Combined predictive model	Piloting one virtual ward for population of 18,000. GP leading development	Model in place since April 2009. In early stages of setting up ward
Lambeth	Combined predictive model	None. Model outputs being used to identify clinical variation between practices. Practices are told where there are gaps and it is up to them how they close them. PCT led	Model in place since late 2008. Systems and incentives being developed
Norfolk	Combined predictive model	Telephone health coaching for individuals identified as high risk	Coaching ran as pilot for 2 years. PCT no longer funding it
Wandsworth	PARR++ (inpatient data only)	4 virtual wards set up. Each ward has a full-time GP attached to it. GP-led	Model in place since late 2008. Wards developing since early 2009
Nene commissioning (PBC cluster)	None: district nurses and GPs refer to the programme	Proactive Care programme launched – similar to idea of virtual wards	Programme launched in April 2009

Of the six sites, four were pursuing a GP data-based predictive model. However, only one (Croydon) had yet developed a full and centralised system that included electronic GP data from every practice. Of the remaining two sites, one was using a predictive model that uses inpatient data only. The sixth was not using a predictive model, and was relying on clinicians to identify appropriate individuals.

In terms of interventions, all but two of the six case-study sites were in the early stages of implementation. Even the two more developed models (Croydon's virtual wards and Norfolk's telephone health coaching) had not been fully evaluated. However, interviews revealed that the models had three common elements that appeared to be essential to functional population management:

- effective use of available data
- integration and co-ordination across organisational boundaries
- flexibility of, and ability to personalise, services.

Each of these is described below.

Effective use of data

As suggested by the evidence, effective use of available data was key in all the case-study sites. All sites were extracting, sharing and analysing data. Interviewees stressed the importance of using data to understand their population needs. In an ideal world, that GP data would be integrated into the model. Five of the six sites had implemented predictive models – four in order to identify patients suitable for an intervention, and one to identify gaps or variations in clinical care. All interviewees stressed the need to understand their population before embarking on any sort of proactive care.

Nene Commissioning, a practice-based commissioning consortium, was the only site not to have adopted a particular model or approach to case finding. Instead, it had been allowing community matrons, district nurses and GPs to refer into the intervention based on their opinion of the likely risk of the individual. Evidence suggests that this approach is not particularly accurate in identifying the correct individuals in advance, and the group's management team commented that it was considering adopting a more systematic approach.

Interviewees highlighted the advantages of using predictive tools, and the risks of not doing so. One GP, in Devon, said that although GPs get to know certain patients over time, these are not necessarily the patients who will be at risk in future, and so are not necessarily the ones who should be targeted. He explained:

They access more care, you get more paperwork back from the hospital, you're more aware of them, you think they're going into hospital more, you're seeing [them] more, and so they naturally come up your awareness.

GP, Devon

There is then a risk that other patients who are not regularly accessing care may be neglected by the GP – and that these may be the patients whose

risk of admission is rising, and who should be enrolled in a preventive intervention. The GP in question referred to this situation as 'a kind of inverse care law'. In his opinion, using a predictive model ensures 'a level playing field for everyone'.

Some interviewees had been surprised by which patients had been identified as high risk, underlining the importance of using data to assess need. One community matron said:

At the outset of the project, we assumed the most complex patients would be the oldest and frailest, but what we found was that a large number of these people had drug and alcohol problems and mental health problems. So we rapidly had to re-skill our community matrons ... They all had physical conditions as well, but the critical factors around risk were those two.

Community matron, Devon

Interviewees also talked about how linking different datasets can provide an insight into individual needs and can aid decision-making about appropriate care, acknowledging that not all patients can be cared for outside hospital:

It's about saying there are people who can be managed in hospital and people who can be managed in the community – how are we going to have systems in place that either stop that happening or, if they do pitch up at hospital, [ensure that] they get out into the community with the right support?

Manager, Nene

Several sites had experienced difficulties in implementing predictive risk models and new models of preventive care. Many spoke of data issues, including the complexities of extracting data from various different GP systems, the absence of data-sharing agreements and, in some areas, an initial lack of interest among other GPs and/or the PCT. Many mentioned the varying levels of enthusiasm for the approach among GPs, and stressed the importance of engaging with GPs and persuading them to see the power of sharing and using data.

Integration and co-ordination

All but one of the case-study sites saw integration of general practice with other care services as a key element of proactive LTC management. Many felt that at present there was confusion among GPs about service availability, with patients falling through gaps as a result of poor continuity of care. As a result of these issues, some respondents reported patients ending up in a 'cycle of re-admissions' that undermines their independence and ability to self-manage their conditions:

Rarely do those patients come out from hospital any better than when they went in. The acute phase may be stabilised, but actually their condition is a lot worse, and they have been put through another barrage of tests. They have met a whole new range of doctors who want to use them as pin cushions, and it is awful – really awful.

GP, Croydon

Once they're in [hospital], it's inordinately difficult to then get people back into their own homes because they go off their legs. They lose their independence.

PBC-lead, Nene

Far from calling for major restructuring of general practice, or the creation of new teams or posts, all the interviewees we spoke to felt that the key thing was better co-ordination and integration of existing services. Only one site had actually developed a wholly new service (health coaching). The four that were in the process of implementing virtual wards were largely streamlining access to existing services and co-ordinating care across the professions. One GP explained how GPs had become confused by the array of services available and had endeavoured to set up a system where there was a single point of access to all services:

It's more about processes, really. It's trying to formalise the processes but not over-complicate them... You go from one extreme, where people aren't co-ordinated, and you could have prevented admission or prevented someone maybe [from] ending up in long-term social care. ...[Now], you can just refer to the co-ordinator who then discusses it, gets information, if you think it's a likely crisis then goes to Rapid Response, and ... they can bring it back to court where we can discuss them... Just to make it simpler, really.

GP, Devon

What we want is a model that integrates the community matrons and the GP practices. What the GPs, in particular, didn't want was community matrons going off and doing their own thing in isolation of the practice. It didn't feel like that was a model that was going to work.

PBC lead, Nene

However, others saw the potential of extending the concept of integration beyond primary and community care and into mental health, social care, secondary care and the voluntary sector:

There's a need in primary care certainly to work with secondary care, get rid of those... very artificial boundaries, and actually say 'OK, who's going to do what at each step of this person's journey?' There are loads of people out there that could actually do more, but we're very ringfenced in terms of who does what and how it all works.

Community matron, Croydon

Others felt that the integration and co-ordination had to be even wider, and talked of a whole-systems approach to proactive care:

I think we have to have a whole-systems approach. I don't think community matrons on their own will make that much difference. I think the whole-system approach is where you'll get big swings.

Director of Nursing, Croydon

Certainly, existing evidence would support the move away from single disease-focused initiatives. A high proportion of individuals at high risk of admission have multiple conditions, and many of these individuals have mental health needs (Billings *et al* 2006a).

Personalisation and flexibility

The third key element was the ability to use services flexibly to enable personalisation. Although there might be scope to segment a population into risk groups, individuals within each group are likely to have very different needs. In all five patient-focused models there was a strong emphasis on care planning and needs assessment. Interviewees stressed the importance of being able to put together a personalised care package, drawing on different expertise as and when required.

A key enabler of this was the existence of a central contact point for patients. Patients were given a named care manager to look after their care package and co-ordinate their care. Since many people with long-term conditions do not need specialist clinical input, the approach was considered appropriate in enabling patients to self-manage their own conditions. In order to build this confidence, the care managers or co-ordinators in the case-study sites reported spending considerably more time with patients than GPs and nurses in practices would normally have had available. As one GP put it:

A big selling point for the GP [is that] actually it makes things a bit easier. If you've got complex patients who are higher up the list, they tend to have more appointments, they tend to ring you up more because they're unsure, and you end with more visits... So the idea is, a lot of this is burden, in a way. It's not totally transferred on to the team or the matron, but they have more time to deal with it. So that's where you get things like health coaching and expert patients, because community matrons have more time to discuss their needs with them, break down what's going on and actually change behaviours. And I think it's the changing behaviours that takes time.

GP, Devon

What is the role of general practice?

Although in all six case studies general practice clearly plays a key role, what is also clear is that in most cases, the models have actually enabled GPs to step away from the hands-on care of these patients and for the care co-ordinators to provide that input. GPs have tended to take on a more peripheral, advisory role where they are still responsible for their patients' clinical well-being, and where they input into care planning and provide care when required, but they are freed up to focus on other patients.

Out of the six case studies we investigated, only two placed GPs at the centre of the service.

- **The Wandsworth model** The PCT is running the predictive model centrally but then sending the outputs to four GPs, who are employed to work on the virtual ward full time. GPs then assess the model outputs and undertake assessments of those patients who are identified, in order to put together a package of care. This model is similar to other virtual ward models except that the care co-ordinator is a GP rather than a community matron or nurse.
- **The Lambeth model** The PCT is running the predictive model centrally and sending results to PBC cluster managers. Those managers are then using the outputs to identify clinical gaps, and

targets for closing those gaps are agreed with the PCT. It is then up to the individual GPs or practices to decide how to close those gaps.

The other case studies all involve GPs to some extent, but it was the importance of the general practice as the organising unit that appeared to be crucial, rather than the GPs themselves undertaking the activities. Other than in the Norfolk telephone health coaching, which was run by the PCT with very little direct input from general practice, GPs remained responsible for the clinical well-being of their patients, while the operational and co-ordination side was run by community matrons or nurses.

In the four virtual ward examples, the GP role involves the following.

- **Being the central unit of organisation** For example, virtual wards are organised around catchment areas of practices. This gives the intervention a geographical limit, for planning purposes, and longitudinal data can be gained on the registered list of patients enrolled with them.
- **Playing a leadership role** Under PBC, and now under GP commissioning, GPs need to lead the implementation of proactive care and the system that are required to support it. GPs play an increasingly important role in bringing together the different professions and services to provide proactive care.
- **Being a source of data and sharing that data** The data must be shared with other practices and the PCT in order for it to be used in a predictive model.
- **Championing predictive models** This involves championing and encouraging use of evidence-based predictive models.
- **Analysing outputs** The GP must analyse (or jointly analyse, with the care co-ordinator) outputs from the model in order to identify any patients unsuitable for the intervention and agreeing a case list. (For example, in some sites this might involve excluding young people with mental health problems who are known to the specialist service.) He or she must also analyse population data, to identify emerging and unmet need and act on this information.
- **Linking in with services** The GP must play a leadership role in mapping out what services are available and forging links and partnerships across organisational boundaries.
- **Having clinical input into the care plan of an individual** This might involve visiting the individual, but would usually involve discussing the case with the care co-ordinator and advising on clinical aspects of their care. Some of the role might involve outreach to patients who do not often come forward for care.
- **Maintaining an overview of their patient's well-being** This involves regularly liaising with the care co-ordinator while delegating the day-to-day management of patients to the care co-ordinator. It also involves empowering care co-ordinators to make informed decisions.
- **Being part of a multi-disciplinary team** The GP will attend regular meetings or 'ward rounds' where patients on the 'ward' are discussed and the level of care required decided.

- **Clinical responsibility** The GP maintains responsibility for the clinical well-being of their patients.
- **Playing an evaluative and quality assurance role** This is intended to make sure that the intervention is delivering appropriate care and has the intended impact. This might be carried out in partnership with the PCT, but it seems to be important that the GP recognises the importance of evaluation and participates fully. Under GP commissioning, this role will become even more important.

Of all of these tasks, what appears to be most critical to a proactive population-based intervention is not a fundamental change in the infrastructure of general practice and its model of practice. It is a shift in attitudes and culture – from one where the GP is the sole reactive caregiver to one where the GP takes on a more expert advisory role. This advisory role involves working closely with other professions, to help offer the patient a co-ordinated, seamless package of care. GP engagement and involvement is important to the development of the service. In most examples, GPs have played a key role in brokering and building relationships across organisational divides.

Of course, the structure of proactive models will vary according to a number of factors – one of which will be the size and structure of the practice. Our case studies did not seek to draw conclusions about such factors, but it is likely that small and single-handed practices might not have capacity to deliver such care alone, so the idea of co-ordination, integration and networks of care will become even more critical.

Evidence suggests there is potential in population management for improving care quality to patients with long-term care needs, and there is some potential that the approach can lead to cost savings when targeted at the right people. As GP commissioning takes over from PCT-led commissioning, reducing unscheduled hospital and care-home admissions will become a key priority for general practice, and its partners and population management will become an essential tool in achieving cost reductions without compromising on care quality. The high-quality general practice of the future will be judged as much for its role and contribution in managing population health cost-effectively and proactively as it will on the care and services it traditionally provides to patients.

9 Conclusions

The aim of this study was to attempt to establish what best practice in long-term conditions management should look like, the role of general practice in delivering high-quality care, and the generic measures that might be used by those in general practice to enable quality improvement.

This research has revealed that there is a significant amount of guidance and expert agreement on what should constitute high-quality care across the dimensions of LTC care examined. However, there is relatively little agreement on what role general practice should play with other partners in the health and social care system to deliver it. Moreover, apart from certain clinical indicators included in the QOF, there is very little data and information available to make a comparative judgement of the current quality of LTC care – whether in general practice, or between general practice and its key partners.

What the evidence suggests is that improvements have indeed been made over the years – particularly in diabetes. There are also indications that the QOF has contributed to practices giving more attention to the ongoing management of patients with diabetes and other chronic illnesses such as heart disease and COPD.

However, the evidence also suggests that care quality is currently sub-optimal and highly variable, and could be significantly improved through a better understanding of long-term conditions among primary care professionals and a more proactive approach to care management. What is clear is that responsibility for delivering high-quality care to patients should be shared across care settings and multi-professional teams, and that general practice has a core role to play as part of that continuum of care. The overall picture, therefore, appears to be one of improvement, but also of a lost opportunity to redesign primary and community care to better meet the needs of those with long-term chronic care needs – for example, in the ways described by the NSF for long-term conditions (Department of Health 2005a).

Measuring quality

It is clear that many of the dimensions of quality that could be used for promoting LTC management in general practice are hard to measure, and do not lend themselves readily for development into an objective measure or indicator. This is not least because the data and information required to collect such information is currently not available within general practice or other datasets (or, if it is available, it is not currently used). It would need to be collected through bespoke local audits, patient surveys and/or the development of specific measurement tools.

However, we believe that measures of quality need to be developed to support general practice (in partnership with its health and social colleagues) to improve the quality and cost-effectiveness of care to people living with long-term conditions. This should be seen as a policy priority – the NHS is long past the tipping point where the option of not redesigning care to meet the needs of those with complex chronic illnesses is tenable, and the

development and use of credible quality markers would almost certainly be an asset for use as a tool for change.

We have, therefore, given some thought to the various generic dimensions of quality in LTC management and care that are important in general practice. These are presented below, together with an assessment as to whether general practice as a whole is active in these areas.

- **Evidence of practice registries** Practice registries for patients with long-term conditions needs to be established in general practice, to support the management of all patients with chronic illness. This has improved across all general practice in recent years as a result of QOF incentives. However, not all LTCs are covered and few practices take an active interest in keeping or updating registries for other conditions – especially to those with multiple care needs.
- **Evidence for proactive case finding** Proactive case finding across practice populations, through regular analysis of data with community nurses and other partners, appears important in enabling a better multi-professional understanding of practice populations and so helps to target services at individuals in needs of care. The evidence suggests that currently very few general practices are proactive in this area, and that many have not been willing to contribute practice data and information to support such activities. Even in 'go-ahead' sites, the evidence suggests that GPs have taken a peripheral interest, leaving the work to community matrons and others.
- **Availability of practice-level data** Practices should make practice-level information and data at the practice level available. This is because evidence of practices' ability to extract high-quality patient data, and to share that data with other care providers regularly, is a prerequisite to effective population management.
- **Problem recognition, early diagnosis and appropriate swift referral for an early intervention** Problem recognition, early diagnosis and swift referral generally result in the better management of people with LTCs. However, it is clear that problem recognition among many GPs can be highly variable. For example, the evidence on care for people with arthritis, dementia and depression suggests that many GPs and nurses in general practice may need further education and training in order to identify symptoms and to ensure prompt referrals to appropriate follow-on care.

The evidence also indicates a significant challenge in the lack of specialist support for many GPs, compounded by a lack of time during the consultation in making an effective diagnosis. Hence, general practice faces a number of barriers in diagnosing diseases – especially those such as dementia. GPs will not necessarily encounter a high number of cases of people presenting with early signs of these complex illnesses. Combined with a lack of specific skills and training, this can make it difficult for them to identify potential cases.

For patients presenting with symptoms requiring specialist diagnosis and/or treatment, a regular audit of practice-level records (for example, to ascertain whether timeliness of referrals was meeting NICE or other treatment guidelines) could be one approach to examining care quality in this area.

- **Patient information** Providing patients with information about their LTCs can be effective in helping them self-manage and/or prevent deterioration in illness. This is a common element in most NICE guidance. However, the quality of information provision is currently variable. One way to ensure this was being routinely undertaken would be to examine patient records to assess the percentage of patients with symptoms of LTCs whose notes state that written information was provided.
- **Supported self-care** General practice should provide supported self-care, such as remote monitoring of the patient's condition or enrolling them in an education or peer support group. They should also help to provide or signpost patients to receive this, since there is strong evidence to suggest that this approach can improve outcomes – particularly for people with multiple LTCs.
- **Support for carers** Providing support for carers is particularly important. General practices, with their key care partners, should be tasked with ensuring that carers are also offered access to education and support.
- **Regular follow-up appointments** Another core component of good LTC management is a system of regular follow-up appointments, ensured through an organised process. Some QOF measures pick this up, though generally only for a single follow-up. Evidence suggests that regular follow-ups to those who need them is variable. General practice needs to ensure that it monitors the percentage of patients who meet the criteria for follow-up appointments who are actually offered and receive one.
- **Patient-centred care plans** It has been a policy commitment since 2006 that all LTC patients should have patient-centred care plans written for them. QOF (MH06) measures this for patients with psychosis. To encourage proactive care planning and follow-up, such care planning needs to be a feature of all those with a limiting long-term condition. The patient records within general practice should ensure that these are recorded as having been provided, and by whom.
- **Multi-disciplinary care planning** The care-planning process needs to be multi-disciplinary in order to identify issues to do with the 'whole person', including the presence of other long-term illnesses or social care needs. This is important, since evidence suggests that patients with LTCs often have more than one LTC and so have needs that span care sectors. One way to establish whether this was being undertaken would be to set up a system of noting in a patient's care record that a care plan has been developed and provided to patients, with appropriate input from professionals outside of general practice. Another method of assessment might be feedback from patients (for example, on whether they received, contributed and understood the care plan).
- **The planning process as a single point of entry** Using the planning process as a single point of entry to a range of services would help patients receive a more integrated service. This might require general practice to ensure that patients are receiving the support of a

designated care co-ordinator to help case manage their illness, even if general practice itself does not undertake the co-ordination role.

- **Case management** One measure for whether the planning process is used as a single point of entry might be to record the percentage of patients meeting criteria who are offered or provided with case management. This is because evidence suggests that targeted case management can improve outcomes for some people with LTCs.
- **Multi-disciplinary working** Working in a multi-disciplinary team is important in many aspects of care delivery for those with LTCs – for example, in having a single or co-ordinated assessment process or care plan (see above), or in screening those with physical and mental health care needs. People with physical co-morbidity have a high prevalence of depression. At present, this can result in poorer quality of care and outcomes than might be the case through closer partnership working.
- **Patient satisfaction** The quality of patient care is often considered less good for people with multiple LTCs, so practices should measure patient satisfaction among those patients. Practice-level surveys, undertaken as part of GP contract requirements, could be cross-referenced with patient histories to examine the experiences of these groups of patients. This is important, since there is some evidence to suggest that patients who come away from consultations feeling more empowered and informed about their illness are less likely to require formal care in the future.
- **Outcome measures** It is useful to track outcome measures such as patient experiences (for example, on quality of life or social inclusion), clinical outcomes and/or emergency hospital admissions and lengths of stay, since key outcomes measures of interventions would be whether these have improved. It would be particularly informative to be able to compare outcomes for people with multiple long-term conditions with those with a single disease.

This long list of quality markers above should be treated with great caution. It is not intended to represent a set of measures or indicators that could be used to hold general practice (or any other provider) to account. Instead, the markers should be seen as the key domains through which the quality of LTC management could be examined in a general practice context.

What is more, the list is not exhaustive, since our research picked up on other quality issues (including the quality of doctor–patient relationships, equity of treatment, and care continuity) that have been addressed in more detail in other report in the GP Inquiry series (see Freeman and Hughes 2010; Greenhalgh and Heath 2010; Hutt and Gilmour 2010).

However, what the list does presuppose is that general practice cannot be expected (or, indeed, allowed) to deliver high-quality care to those with LTCs without good systems of integrated care working with other care providers – an overarching systemic problem that this research has uncovered, and one that needs urgent attention.

The future role of general practice in meeting the challenge

There are a number of challenges for general practice if they are to deliver a higher quality of care to people with long-term chronic illnesses. These challenges refer to two main issues: the current knowledge and skills levels within general practice, and the way in which general practice is configured, since the care planning and care co-ordination processes imply the need for integrated care with other services and professionals.

The current knowledge and skill levels within general practice

One of the most pressing issues raised by the evidence is the ability for an early diagnosis of LTC patients to be undertaken in general practice settings, and/or for a referral to be made that leads to an appropriate and early intervention from a specialist.

As generalists, it is understandable that GPs and practice nurses do not necessarily have extensive or detailed knowledge of every LTC and how these should be managed. Yet there must be access to accredited and standardised training in LTC management in general practice and/or systems that enable nurses and GPs to refer patients to a local specialist team for advice and care where needed. This professional development of staff employed in general practice is vital, given that the management of long-term conditions is being pushed further into the community.

It is fair to say that a very high level of input would be needed from GPs, practice nurses and other general practice staff to deliver all the different aspects of high-quality care for the range of long-term conditions that need to be managed. Meeting the LTC agenda places a strain on their ability to manage the needs of complex patients, since they require trade-offs in the time they might otherwise have for other patients. Put simply, there is a lot for GPs or nurses to cover in a single 10- or 15-minute appointment. This increases the likelihood of some aspects of care being overlooked – particularly those requiring more in-depth discussion, such as for care planning for those with multiple LTCs and associated depression.

Gaps in knowledge and skills also apply to GPs' and nurses' abilities in the care-planning process, since their role in acting as patient guide and advocate to access the multiple providers of the care they might need is not sufficiently embedded in the culture of general practice. Care-planning skills must be included in the professional development of GPs and practice nurses in the future, so that they are able to:

- produce the care plan collaboratively
- review the care plan regularly
- handle the situation of patients not meeting their goals sensitively and constructively
- provide praise and motivation to the patient when they have achieved their goals.

There are other barriers that are more personal to GPs and practice nurses, such as attitudes and beliefs. For example, one survey estimated that only 60 per cent of GPs believed it was important to look for early signs of dementia, with only half of the sample believing that 'much can be done to improve

the quality of life for people with dementia' (NAO 2007, p 27). Many of the experts we interviewed suggested that GPs and nurses in general practice are often unaware of the various services and resources in the community and voluntary sector from which patients with LTCs could benefit.

Given the expectation that general practice should take on responsibility for providing high-quality care to patients with long-term conditions, this range of structural and workforce challenges needs urgent attention. A substantial amount of community-based care will need to be taken on in an attempt to shift care out of hospitals and nursing homes and into the primary care or home environment.

How general practice is configured

The workload and workforce implications in managing people with LTCs are profound. Most general practices are not in a position to deal with such demand adequately, unless they are well networked with other practices and the rest of the system. There are some potential skill-mix solutions to this situation that could be employed. One example would be to develop longer, group consultations to talk to, say, six patients or more about – for example – diabetes and/or anxiety management. Meanwhile, health care assistants could take responsibility for monitoring patients' blood pressure and weight, providing written information or signposting to sources of information if appropriate.

The most significant issue for general practice in meeting the LTC challenges will be to embrace specialist support during the consultation process, during care planning, and in ongoing care in a way that makes patients feel like equal partners in their care, better supporting them to manage their own illness. However, a two-fold problem exists:

- the lack of time, skills and capacity in general practice to make an effective diagnosis for all people with LTCs
- the lack of communication with (and availability of) specialist services.

Budget constraints also impede the commissioning of self-management sessions, physiotherapy or physical exercise sessions.

It is unlikely that these challenges can be met without more fundamental structural changes to the way general practice operates. The shift to larger group practices, polyclinics and those working in 'federations' of practices has already begun. However, general practice needs to become more closely integrated with the care and delivery of other providers and, potentially, seek to develop 'integrated care organisations' that overcome the NHS design flaw of the separation between primary, community and hospital care (Lewis *et al* 2010).

Such structural changes to the nature of general practice would be controversial because they present a different future for GPs and their specialist colleagues. However, given the needs of population management, rooting such organisations around general practice and the registered list would appear to be the most logical way forward, since it comes closest to the image of an organisation that could effectively co-ordinate the care for people with LTCs across multiple care services.

The coalition government's plans for GP commissioning would suggest a move towards creating a more population-based focus to the role of general practice, as it becomes responsible for the health and welfare of communities in addition to their traditional responsibilities to enrolled patients. Even so, general practice would have a significant distance to travel to fulfil the vision, since the managerial capacity of a small business will be wholly unable to meet the challenge. For many GPs, integrated care will be a step too far and they will remain content to offer face-to-face clinical services.

Achieving higher quality care to people with LTCs requires the evolution of multi-specialty local clinical partnerships and a shared care model of working – as examined in a recent Nuffield Trust/NHS Alliance report (Smith *et al* 2009). In this way general practice might find its way to becoming a full partner in what might be called population-oriented primary care.

References

Aliotta SL, Grieve K, Giddens JF, Dunbar L, Groves C, Frey K, Boulton C (2008). 'Guided care: a new frontier for adults with chronic conditions'. *Prof Case Manag* 13 (3): 151–58.

Alzheimer's Society (2010). *Updated Estimates on the Numbers of People With Dementia in the UK Based on Data in the Dementia UK Report*. Briefing paper. London: Alzheimer's Society.

Alzheimer's Society (2007). *Dementia UK. The full report*. London: Alzheimer's Society. Available at: www.alzheimers.org.uk/downloads/Dementia_UK_Full_Report.pdf (accessed on 26 August 2009).

Arthritis and Musculoskeletal Alliance (2009). *Joint Working? An audit of the implementation of the Department of Health's musculoskeletal services framework*. London: ARMA. Available at: www.arma.uk.net/policy.html (accessed on 5 November 2009).

Arthritis and Musculoskeletal Alliance (2004a). *Standards of Care for People with Inflammatory Arthritis*. London: ARMA. Available at: www.arma.uk.net/pdfs/ia06.pdf (accessed on 23 June 2009).

Arthritis and Musculoskeletal Alliance (2004b). *Standards of Care for People with Osteoarthritis*. London: ARMA. Available at: www.arma.uk.net/pdfs/oa06.pdf (accessed on 23 June 2009).

Arthritis Care (2008). *Living with Rheumatoid Arthritis*. London: Arthritis Care. Available at: www.arthritiscare.org.uk/AboutArthritis/Conditions/Rheumatoidarthritis (accessed on 23 June 2009).

Arthritis Care (2007). *The Impact of Arthritis (statistics)*. Factsheet. London: Arthritis Care. Available at: www.arthritiscare.org.uk/PublicationsandResources/Arthritisbasics/Arthritisstatistics (accessed on 23 June 2009).

Arthritis Research UK (2008). *Arthritis in the UK – Key facts*. Chesterfield: Arthritis Research UK. Available at: www.arthritisresearchuk.org/pdf/Arthritis%20Key%20Facts.pdf (accessed on 23 June 2009).

Arthritis Research Campaign (2002). *Arthritis. The big picture*. Derbyshire: ARC.

Audit Commission (2002). *Forget Me Not. Developing mental health services for older people in England*. London: Audit Commission. Available at: www.audit-commission.gov.uk/nationalstudies/health/mentalhealth/pages/forgetmenot.aspx#downloads (accessed on 26 August 2009).

Bachman J, Swenson S, Reardon ME, Miller D (2006). 'Patient self-management in the primary care treatment of depression'. *Adm Policy Ment Health* 33 (1): 76–85.

Banerjee S, Willis R, Matthews D, Contell F, Chan J, Murray J (2007). 'Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model'. *International Journal of Geriatric Psychiatry* 22 (8): 782–88.

Banerjee S, Wittenberg R (2009). 'Clinical and cost-effectiveness of services for early diagnosis and intervention in dementia'. *International Journal of Geriatric Psychiatry* 24 (7): 748–54.

Barbui C, Tansella M (2006). 'Identification and management of depression in primary care settings. A meta-review of evidence'. *Epidemiol Psychiatr Soc* 15 (4): 276–83.

Belnap B, Kuebler J, Upshur C, Kerber K, Mockrin DR, Kilbourne AM, Rollman BL (2006). 'Challenges of implementing depression care management in the primary care setting'. *Adm Policy Ment Health* 33(1): 65–75.

Billings J, Mijanovich T (2007). 'Improving the management of care for high-cost Medicaid patients'. *Health Affairs* 26 (6): 1643–54.

Billings J, Mijanovich T, Dixon J, Curry N, Wennberg D, Darin B, Steinort K (2006a). *Case Finding Algorithms For Patients at Risk of Re-hospitalisation PARR1 and PARR2*. London: The King's Fund. Available at: www.kingsfund.org.uk/current_projects/predicting_and_reducing_readmission_to_hospital/#resources (accessed on 10 July 2010).

Billings J, Dixon J, Mijanovich T, Wennberg D (2006b). 'Case finding for patients at risk of readmission to hospital: development of algorithm to identify high risk patients'. *British Medical Journal* 333: 327.

Billings J, Mijanovich T, Dixon J, Williams M, Curry N, Wennberg D, Hall C, Darin B (2005). *Case Finding Algorithm for Patients at Risk of Hospitalisation*. London: The King's Fund.

Billings J, Zeitel L, Lukomnik J, Carey TS, Blank AE, Newman L (1993). 'Datawatch: impact of socioeconomic status on hospital use in New York City'. *Health Affairs (Millwood)* 12 (1): 162–73.

Boaden R, Dusheiko M, Gravelle H, Parker S, Pickard S, Roland M, Sargent P, Sheaff R (2006). *Evercare: Evaluation of the Evercare approach to case management: final report*. University of Manchester: National Primary Care Research and Development Centre.

Boult C, Reider L, Frey K, Leff B, Boyd CM, Wolff JL, Wegener S, Marsteller J, Karm L, Scharfstein D (2008). 'Early effects of "Guided Care" on the quality of health care for multimorbid older persons: a cluster-randomized controlled trial'. *J Gerontol A Biol Sci Med Sci* 63 (3): 321–27.

Boardman J, Walters P (2009). 'Managing depression in primary care: it's not only what you do it's the way that you do it'. *Br J Gen Pract* 59 (559): 76–78.

Bower P, Gilbody S, Richards D, Fletcher J, Sutton A (2006). 'Collaborative care for depression in primary care. Making sense of a complex intervention: systematic review and meta-regression'. *Br J Psychiatry* 189: 484–93.

Boyce T *et al* (2010). *The Quality of Health Promotion and Ill Health Prevention in General Practice*. The King's Fund: London.

Boyd CM, Boult C, Shadmi E, Leff B, Brager R, Dunbar L, Wolff JL, Wegener S, (2007). 'Guided care for multimorbid older adults'. *Gerontologist* 47 (5): 697–704.

Boyd CM, Darer J, Boult C, Fried LP, Boult L, Wu AW (2005). 'Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases: implications for pay for performance'. *JAMA* 294 (6): 716–24.

- Breedveld F (2004). 'Osteoarthritis – the impact of a serious disease'. *Rheumatology*, 43 (suppl 1): i4–i8.
- Broadbent J, Maisey S, Holland R, Steel N (2008). 'Recorded quality of primary care for osteoarthritis: an observational study'. *British Journal of General Practice* 58 (557): 839–43.
- Brown I, Thompson J, Tod A, Jones G (2006). 'Primary care support for tackling obesity: a qualitative study of the perceptions of obese patients'. *British Journal of General Practice* 56 (530): 666–72.
- Callahan CM (2001). 'Quality improvement research on late life depression in primary care'. *Med Care* 39 (8): 772–84.
- Calvert M, Shankar A, McManus RJ, Lester H, Freemantle N (2009). 'Effect of the quality and outcomes framework on diabetes care in the United Kingdom: retrospective cohort study'. *BMJ* 338 (262): 1363–72.
- Campbell S, Reeves D, Kontopantelis E, Middleton E, Sibbald B, Roland M (2007). 'Quality of primary care in England with the introduction of pay for performance'. *New England Journal of Medicine* 357 (2): 181–90.
- Campbell SM, Reeves D, Kontopantelis E, Sibbald B, Roland M (2009). 'Effects of pay for performance on the quality of primary care in England'. *New England Journal of Medicine* 361 (4): 368–78.
- Chapman DP, Perry GS, Strine TW (2005). 'The vital link between chronic disease and depressive disorders'. *Prev Chronic Dis* 2 (1): A14.
- Comas-Herrera A, Wittenberg R (eds) (2003). *European Study of Long-Term Care Expenditure*. Report to the European Commission, Employment and Social Affairs DG. London: Personal Social Services Research Unit, London School of Economics.
- Comas-Herrera A, Wittenberg R, Pickard L, Knapp M (2007). 'Cognitive impairment in older people: future demand for long-term care services and associated costs'. *International Journal of Geriatric Psychiatry* 22 (10): 1037–45.
- Cousins MS, Shickle LM, Bander JA (2002). 'Introduction to predictive modelling'. *Disease Management* 5 (3): 157–167.
- Cowie L, Morgan M, White P, Gulliford M (2009). 'Experience of continuity of care of patients with multiple long-term conditions in England'. *J Health Serv Res Policy* 14 (2): 82–87.
- Croghan TW, Schoenbaum M, Sherbourne CD, Koegel P (2006). 'A framework to improve the quality of treatment for depression in primary care'. *Psychiatr Serv* 57 (5): 623–30.
- Curry N, Billings J, Darin B, Dixon J, Williams M, Wennberg D (2005). *Predictive Risk Project: Literature review*. The King's Fund: London.
- Darzi A (2008). *High Quality Care for All: NHS next stage review final report*. London: Department of Health.
- Department of Health (2010). *Equity and Excellence: Liberating the NHS*. London: Department of Health.
- Department of Health (2009a). *Your Health, Your Way: A guide to long-term conditions and self care*. London: Department of Health

Department of Health (2009b). *Personal Health Budgets: First steps*. London: Department of Health.

Department of Health (2009c). 'Integrated care pilots'. Department of Health website. Available at: <http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/IntegratedCare/Integratedcarepilots/index.htm> (accessed on 10 August 2010).

Department of Health (2009d). *Living Well with Dementia. A national dementia strategy*. London: Department of Health.

Department of Health (2007a). 'Case management'. Department of Health website. Available at: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Longtermconditions/DH_4130655 (accessed on 10 August 2010).

Department of Health (2007b). *World Class Commissioning: Vision*. London: Department of Health.

Department of Health (2007). 'The Expert Patients Programme'. Department of Health website. Available at: www.dh.gov.uk/en/Aboutus/MinistersandDepartmentLeaders/ChiefMedicalOfficer/ProgressOnPolicy/ProgressBrowsableDocument/DH_4102757 (accessed on 10 September 2009).

Department of Health (2007a). *Making Every Young Person with Diabetes Matter*. Department of Health website. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073674 (accessed on 10 August 2009).

Department of Health (2007b). *Who Gets Diabetes – Health inequalities*. London: Department of Health. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4899972 (accessed on 10 August 2009).

Department of Health (2006a). *Diabetes Commissioning Toolkit*. London: Department of Health. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4140285.pdf (accessed on 9 April 2010).

Department of Health (2006b). *Our Health, Our Care, Our Say: A new direction for community services*. London: Department of Health.

Department of Health (2006c). *The Musculoskeletal Services Framework*. London: Department of Health. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138413 (accessed on 22 June 2009).

Department of Health (2005a). *Supporting People with Long-Term Conditions*. London: Department of Health.

Department of Health (2005b). *The National Service Framework for Long-Term Conditions*. London: Department of Health.

Department of Health (2004a). *Chronic Disease Management – A compendium of information*. London: Department of Health.

Department of Health (2004b). *The NHS Improvement Plan: Putting people at the heart of public services*. London: Department of Health.

Department of Health (2003). *National Service Framework for Diabetes: Delivery strategy*. London: Department of Health.

Department of Health (2002). *National Service Framework for Diabetes: Standards*. London: Department of Health.

Department of Health (2001). *National Service Framework for Older People*. London: Department of Health. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4071283.pdf (accessed on 26 August 2009).

Diabetes UK (2010). 'Causes and risk factors'. Diabetes UK website. Available at: www.diabetes.org.uk/Guide-to-diabetes/Introduction-to-diabetes/Causes_and_Risk_Factors/ (accessed on 20 April 2010).

Diabetes UK (2009). *Diabetes UK Survey of People with Diabetes and Access to Healthcare Services 2009*. London: Diabetes UK. Available at: www.diabetes.org.uk/Professionals/Publications-reports-and-resources/Reports-statistics-and-case-studies/Reports/At-a-glance-Diabetes-UK-Survey-of-People-with-Diabetes-and-Access-to-Healthcare-Services-2009 (accessed on 14 April 2010).

Diabetes UK (2008). *The National Service Framework (NSF) for Diabetes. Five years on... are we half way there?* London: Diabetes UK. Available at: www.diabetes.org.uk/Documents/Reports/Five_years_on_-_are_we_half_way_there2008.pdf (accessed on 10 August 2009).

Diabetes UK/Health Foundation/NHS National Diabetes Support Team (2008). *Getting to Grips with the Year of Care: A practical guide*. London: Diabetes UK. Available at: www.diabetes.org.uk/Professionals/Service-improvement/Year-of-Care/The-Year-of-Care-concept/Year-of-Care---care-planning/ (accessed on 13 April 2010).

Dixon J, Lewis R, Rosen R, Finlayson B, Gray D (2004). *Managing Chronic Disease: What can we learn from the US experience?*. London: The King's Fund.

Downs M, Turner S, Bryans M, Wilcock J, Keady J, Levin E, O'Carroll R, Howie K, Iliffe S (2006). 'Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study'. *BMJ* 332:692

Dowrick C (2009). 'Depression: beyond the disease era'. *London Journal of Primary Care* 2: 24–27.

Emery P, Breedveld FC, Dougados M, Kalden JR, Schiff MH, Smolen JS (2002). 'Early referral recommendation for newly diagnosed rheumatoid arthritis: evidence based development of a clinical guide'. *Annals of Rheumatic Diseases* 61: 290–97.

Emery P (2006). 'Clinical review: treatment of rheumatoid arthritis'. *BMJ* 332: 152–55.

Evans DL, Charney DS, Lewis L, Golden RN, Gorman JM, Krishnan KR, Nemeroff CB, Bremner JD, Carney RM, Coyne JC, Delong MR, Frasurre-Smith N, Glassman AH, Gold PW, Grant I, Gwyther L, Ironson G, Johnson RL, Kanner AM, Katon WJ, Kaufmann PG, Keefe FJ, Ketter T, Laughren TP, Leserman J, Lyketsos CG, McDonald WM, McEwen BS, Miller AH, Musselman D, O'Connor C, Petitto JM, Pollock BG, Robinson RG, Roose SP, Rowland J, Sheline Y, Sheps DS, Simon G, Spiegel D, Stunkard A, Sunderland T, Tibbits P Jr, Valvo WJ (2005). 'Mood disorders in the medically ill: scientific review and recommendations'. *Biol Psychiatry* 58 (3): 175–89.

- Ford DE (2006). 'Primary care physician perspective on management of patients with depression'. *J Manag Care Pharm* 12 (2): 10–13.
- Fortin M, Bravo G, Hudon C, Vanasse A, Lapointe L (2005a). 'Prevalence of multimorbidity among adults seen in family practice'. *Ann Fam Med* 3 (3): 223–28.
- Fortin M, Lapointe L, Hudon C, Vanasse A (2005b). 'Multimorbidity is common to family practice: is it commonly researched?'. *Can Fam Physician* 51: 244–45.
- Fortin M, Soubhi H, Hudon C, Bayliss EA, Akker M v d (2007). 'Multimorbidity's many challenges'. *BMJ* 334 (7602): 1016–17.
- Gardner SG, Bingley PJ, Sawtell PA, Weeks S, Gale EAM (1997). 'Rising incidence of insulin dependent diabetes in children aged under 5 years in the Oxford region: time trend analysis'. *BMJ* 315: 713–17.
- Gilbody S, Whitty P, Grimshaw J, Thomas R (2003). 'Educational and organizational interventions to improve the management of depression in primary care: a systematic review'. *JAMA* 289 (23): 3145–51.
- Gilbody S, Bower P, Whitty P (2006). 'Costs and consequences of enhanced primary care for depression: systematic review of randomised economic evaluations'. *Br J Psychiatry* 189: 297–308.
- Gillies CL, Lambert PC, Abrams KR, Sutton AJ, Cooper NJ, Hsu RT, Davies MJ, Khunti K (2008). 'Different strategies for screening and prevention of type 2 diabetes in adults: cost effectiveness analysis'. *BMJ* 336 (7654): 1180–85.
- Gilmore KA, Hargie O (2000). 'Quality issues in the treatment of depression in general practice'. *Int J Health Care Qual Assur Inc Leadersh Health Serv* 13 (1): 34–41.
- Goyder E, Wild S, Fischbacher C, Carlisle J and Peters J (2008). 'Evaluating the impact of a national pilot screening programme for type 2 diabetes in deprived areas of England'. *Family Practice* 25 (5): 370–75.
- Gravelle H, Dusheiko M, Sheaff R, Sargent P, Boaden R, Pickard S, Parker S, Roland M (2006). 'Impact of case management (Evercare) on frail elderly patients: controlled before and after analysis of quantitative outcome data'. *British Medical Journal* 334: 31.
- Gray J, Millett C, Saxena S, Netuveli G, Khunti K, Majeed A (2007). 'Ethnicity and quality of diabetes care in a health system with universal coverage: population-based cross-sectional survey in primary care'. *Journal of General Internal Medicine* 22: 1317–20.
- Greaves CJ, Middlebrooke A, O'Loughlin L, Holland S, Piper J, Steele A, Gale T, Hammerton F and Daly M (2008). 'Motivational interviewing for modifying diabetes risk: a randomised controlled trial'. *British Journal of General Practice* 58 (553): 535–40.
- Greenhalgh T, Heath I (2010). *Measuring Quality in the Therapeutic Relationship*. London: The King's Fund. Available at: www.kingsfund.org.uk/current_projects/gp_inquiry/dimensions_of_care/the_therapeutic.html (accessed on 18 August 2010).
- Greening L, Greaves I, Greaves N, Jolley D (2009). 'Positive thinking on dementia in primary care: Gnosall Memory Clinic'. *Community Practitioner* 82 (5): 20–23.

- Griffiths C, Foster G, Ramsey J, Eldridge S, Taylor S (2007). 'How effective are expert patient (lay led) education programmes for chronic disease?'. *British Medical Journal* 334: 1254–56.
- Gupta S, Hawker GA, Laporte A, Croxford R, Coyte PC (2005). 'The economic burden of disabling hip and knee osteoarthritis (OA) from the perspective of individuals living with this condition'. *Rheumatology* 44 (12): 1531–37.
- Ham C (2006). *Reducing Unplanned Admissions to Hospital: What does the literature tell us?*. Birmingham: HSMC, University of Birmingham.
- Ham C, York N, Sutch S, Shaw R (2003). 'Hospital bed utilisation in the NHS, Kaiser Permanente, and the US Medicare programme: analysis of routine data'. *British Medical Journal* 327: 1257.
- Health Dialog (2006). *Combined Predictive Model: Final report*. London: The King's Fund. Available at: www.kingsfund.org.uk/research/projects/predicting_and_reducing_readmission_to_hospital/#tab4 (accessed on 10 September 2009).
- Healthcare Commission (2007). *Managing Diabetes. Improving services for people with diabetes*. Service review. London: Healthcare Commission.
- Hippisley-Cox J, Fielding K, Pringle M (1998). 'Depression as a risk factor for ischaemic heart disease in men: population based case control study'. *British Medical Journal* 316: 1714–19.
- Hippisley-Cox J, O'Hanlon S, Coupland C (2004). 'Association of deprivation, ethnicity, and sex with quality indicators for diabetes: population based survey of 53,000 patients in primary care'. *BMJ* 329 (7477): 1267–69.
- Hutt R, Rosen R, McCauley J (2004). *Case Managing Long Term Conditions*. London: King's Fund.
- Hutt R, Rosen R (2005). 'A chronic case of mismanagement?'. *Journal of Health Services Research Policy* 10 (4): 194–95.
- Illiffe S, Wilcock J, Haworth D (2006). 'Obstacles to shared care for patients with dementia: a qualitative study'. *Family Practice* 23: 353–62.
- Jagger C, Matthews R, Spiers N, Brayne C, Comas-Herrera A, Robinson T, Lindesay J, Croft P (2006). *Compression or Expansion of Disability? Forecasting future disability levels under changing patterns of diseases*. Wanless Social Care Review research report. Leicester: Leicester Nuffield Research Unit.
- Jenkins R, McCulloch A, Friedli L, Parker C (2002). *Developing a National Mental Health Policy*. Maudesley monograph 43. Hove: The Psychology Press.
- Jessep SA, Walsh NE, Ratcliffe J, Hurley MV (2009). 'Long-term clinical benefits and costs of an integrated rehabilitation programme compared with outpatient physiotherapy for chronic knee pain'. *Physiotherapy* 95 (2): 94–102.
- Johnston O, Kumar S, Kendall K, Peveler R, Gabbay J, Kendrick T (2007). 'Qualitative study of depression management in primary care: GP and patient goals, and the value of listening'. *Br J Gen Pract* 57 (544): 872–79.
- Jordan KM, Sawyer S, Coakley P, Smith HE, Cooper C, Arden NK (2004). 'The use of conventional and complementary treatments for knee osteoarthritis in the community'. *Rheumatology* 43 (3): 381–84.

Kadam UT, Jordan K, Croft PR (2004). 'Clinical comorbidity in patients with osteoarthritis: a case-control study of general practice consultants in England and Wales'. *Ann Rheum Dis* 63 (4): 408–14.

Kates N, Mach M (2007). 'Chronic disease management for depression in primary care: a summary of the current literature and implications for practice'. *Can J Psychiatry* 52 (2): 77–85.

Katon WJ, Seelig M (2008). Population-Based Care of Depression: Team Care Approaches to Improving Outcomes. *JOEM*, 50 (4), 459–167.

Kilbourne AM, Schulberg HC, Post EP, Rollman BL, Belnap BH, Pincus HA (2004). 'Translating evidence-based depression management services to community-based primary care practices'. *Milbank Q* 82 (4): 631–59.

Kisely S, Campbell LA (2007). 'Taking consultation-liaison psychiatry into primary care'. *Int J Psychiatry Med* 37 (4): 383–91.

Kisely S, Smith M, Lawrence D, Cox M, Campbell LA, Maaten S (2007). 'Inequitable access for mentally ill patients to some medically necessary procedures'. *CMAJ* 176 (6): 779–84.

Knapp M, Comas-Herrera A, Somani A, Banerjee S (2007). *Dementia: International comparisons*. Summary report. London: National Audit Office. Available at: www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx (accessed on 26 August 2009).

Koch T, Illiffe S (2009). 'Implementing the National Dementia Strategy: case studies from primary care'. *Journal of Dementia Care* 17 (6): 26–29.

Kumar K, Daley E, Carruthers DM, Situnayake D, Gordon C, Grindulis K, Buckley CD, Khattak F, Raza K (2007). 'Delay in the presentation to primary care physicians is the main reason why patients with rheumatoid arthritis are seen late by rheumatologists'. *Rheumatology* 46 (9): 1438–40.

Kupfer DJ (1991). 'Long-term treatment of depression'. *Journal of Clinical Psychiatry* 52 (5): 28–34.

Layard R (2006). 'The case for psychological treatment centres'. *BMJ*, 332: 1030–32.

Lewis R, Dixon J (2004). 'Rethinking management of chronic diseases'. *British Medical Journal* 328: 220–22.

Lin P, Campbell DG, Chaney EF, Liu CF, Heagerty P, Felker BL, Hedrick SC (2005). 'The influence of patient preference on depression treatment in primary care'. *Ann Behav Med* 30 (2): 164–73.

Linsell L, Dawson J, Zondervan K, Randall T, Rose P, Carr A, Fitzpatrick R (2005). 'Prospective study of elderly people comparing treatments following first primary care consultation for a symptomatic hip or knee'. *Family Practice* 22: 118–25.

Lloyd KR, Jenkins R, Mann A (1996). 'Long-term outcome of patients with neurotic illness in general practice'. *BMJ* 313 (7048): 26–28.

Luqmani R, Hennell S, Estrach C, Basher D, Birrell F, Bosworth A, Burke F, Callaghan C, Candal-Couto J, Fokke C, Goodson N, Homer D, Jackman J, Jefferson P, Oliver S, Reed M, Sanz L, Stableford Z, Taylor P, Tood N, Warburton L, Washbrook C, Wilkinson M (2009). *British Society for Rheumatology and British Health Professionals in Rheumatology Guidelines for the Management of Rheumatoid Arthritis (After the First Two Years)*.

London: British Society for Rheumatology. Available at: www.rheumatology.org.uk/guidelines/clinicalguidelines/raposttwo (accessed on 23 June 2009).

MacLean CH, Saag KG, Solomon DH, Morton SC, Sampsel S, Klippel JH (2004). 'Measuring quality in arthritis care: methods for developing the Arthritis Foundation's quality indicator set'. *Arthritis and Rheumatism* 15 (2): 193–202.

Mauro M, Taylor V, Wharton S and Sharma AM (2008). 'Barriers to obesity treatment'. *European Journal of Internal Medicine* 19 (3): 173–80.

McGovern MP, Williams DJ, Hannaford PC, Taylor MW, Lefevre KE, Boroujerdi MA, Simpson CR (2008). 'Introduction of a new incentive and target-based contract for family physicians in the UK: good for older patients with diabetes but less good for women?'. *Diabetic Medicine* 25 (9): 1083–89.

McHugh GA, Luker KA, Campbell M, Kay PR, Silman AJ (2007). 'A longitudinal study exploring pain control, treatment and service provision for individuals with end-stage lower limb osteoarthritis'. *Rheumatology* 46 (4): 631–37.

McManus S, Meltzer H, Brugha T, Bebbington P, Jenkins R (2009). *Adult Psychiatric Morbidity in England, 2007. Results of a household survey*. Leeds: NHS Information Centre.

Sederer LI, Silver L, McVeigh KH, Levy J (2006). 'Integrating care for medical and mental illnesses'. *Prev Chronic Dis* 3 (2): A33.

Melzer D, Fryers T, Jenkins R (2004). *Social Inequalities and the Distribution of the Common Mental Disorders*. Maudsley monographs. Hove: Psychology Press.

Memel DS, Somerset M (2003). 'General practitioner and specialist care: the perceptions of people with rheumatoid arthritis'. *Primary Health Care Research and Development* 4 (1): 29–37.

Mezuk B, Eaton WW, Albrecht S, Golden SH (2008). 'Depression and type 2 diabetes over the lifespan: a meta-analysis'. *Diabetes Care* 31 (12): 2383–90.

Mulnier HE, Seaman HE, Raleigh VS, Soedamah-Muthu SS, Colhoun HM, Lawrenson RA, de Vries CS (2006). 'Risk of stroke in people with type 2 diabetes in the UK: a study using the General Practice Research Database'. *Diabetologia* 49 (12): 2859–65.

Narasimhan M, Raynor JD, Jones AB (2008). 'Depression in the medically ill: diagnostic and therapeutic implications'. *Curr Psychiatry Rep* 10 (3): 272–79.

National Audit Office (2009). *Services for People with Rheumatoid Arthritis*. London: NAO. Available at: www.nao.org.uk/publications/0809/rheumatoid_arthritis.aspx (accessed on 20 July 2009).

National Audit Office (2008). *Pay Modernisation: New contracts for general practice services in England*. London: NAO. Available at: www.nao.org.uk/publications/0708/new_contracts_for_general_prac.aspx (accessed on 6 August 2009).

National Audit Office (2007a). *Dementia Focus Group Findings*. Final report. London: PricewaterhouseCoopers LLP/NAO. Available at: www.nao.org.uk/publications/0607/dementia_services_and_support.aspx (accessed on 26 August 2009).

National Audit Office (2007b). *Improving Services and Support for People With Dementia*. London: NAO. Available at: www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx (accessed on 26 August 2009).

Narasimhan M, Raynor JD, Jones AB (2008). 'Depression in the medically ill: diagnostic and therapeutic implications'. *Curr Psychiatry Rep* 10 (3): 272–79.

National Institute for Health and Clinical Excellence (2010). *Type 1 Diabetes: Diagnosis and management of type 1 diabetes in children, young people and adults*. Clinical guideline 15. (Originally dated July 2004, updated April 2010). London: NICE. Available at: <http://guidance.nice.org.uk/CG15/NICEGuidance/pdf/English> (accessed on 30 July 2010).

National Institute for Health and Clinical Excellence (2009a). *Depression: The treatment and management of depression in adults (update)*. NICE guideline. Draft for consultation. London: NICE.

National Institute for Health and Clinical Excellence (2009b). *Depression: The treatment and management of depression in adults with chronic physical health problems*. NICE guideline. Draft for consultation. London: NICE.

National Institute for Health and Clinical Excellence (2009c). *Rheumatoid Arthritis. Costing report. Implementing NICE guidance*. NICE website. Available at: www.nice.org.uk/nicemedia/pdf/CG79CostingReport.pdf (accessed on 22 June 2009).

National Institute for Health and Clinical Excellence (2009d). *The Management of Rheumatoid Arthritis in Adults*. Clinical guideline 79. NICE website. Available at: www.nice.org.uk/nicemedia/pdf/CG79NICEGuideline.pdf (accessed on 22 June 2009).

National Institute for Health and Clinical Excellence (2008a). *Osteoarthritis. Costing report. Implementing NICE guidance*. Available at: www.nice.org.uk/nicemedia/pdf/OsteoarthritisCostingReport.pdf (accessed on 22 June 2009).

National Institute for Health and Clinical Excellence (2008b). *The Care and Management of Osteoarthritis in Adults*. Clinical guideline 59. NICE website. Available at: www.nice.org.uk/nicemedia/pdf/CG59NICEguideline.pdf (accessed on 22 June 2009).

National Institute for Health and Clinical Excellence (2008c). *Type 2 Diabetes. National clinical guideline for management in primary and secondary care (update)*. NICE website. Available at: www.nice.org.uk/nicemedia/pdf/CG66FullGuideline0509.pdf (accessed on 10 August 2009).

National Institute for Health and Clinical Excellence (2007). *Donepezil, Galantamine, Rivastigmine (review) and Memantine for the Treatment of Alzheimer's Disease (amended)*. NICE technology appraisal guidance 111. NICE website. Available at: www.nice.org.uk/nicemedia/pdf/TA111fullversionamendedSept07.pdf (accessed on 26 August 2009).

National Institute for Health and Clinical Excellence (2004). *Type 1 Diabetes: Diagnosis and management of type 1 diabetes in children, young people and adults*. Available at: www.nice.org.uk/nicemedia/pdf/CG015NICEGuidelineUpdate.pdf (accessed on 10 August 2009).

National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006a). *Dementia. Supporting people with dementia and their carers in health and social care*. NICE clinical guideline 42. NICE website.

Available at: www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf (accessed on 26 August 2009).

National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006b). *Audit Criteria – Dementia*. NICE clinical guideline no 42. London: NICE/SCIE.

Nell VPK, Machold KP, Eberl G, Stamm TA, Uffmann M, Smolen JS (2004). 'Benefit of very early referral and very early therapy with disease-modifying anti-rheumatic drugs in patients with early rheumatoid arthritis'. *Rheumatology* 43 (7): 906–14.

NHS Choices (2010). 'Dementia: Introduction'. NHS Choice website. Available at: www.nhs.uk/conditions/Dementia/Pages/Introduction.aspx (accessed on 26 August 2009).

NHS Diabetes (2009). *NICE and Diabetes: A summary of the relevant guidelines*. London: NHS. Available at: www.diabetes.nhs.uk/tools_and_resources/reports_and_guidance/ (accessed on 15 April 2010).

NHS Information Centre (2010). *National Diabetes Audit. Executive summary*. NHS diabetes specialist library website. Leeds: NHS Information Centre. Available at: www.library.nhs.uk/Diabetes/ViewResource.aspx?resID=379534 (accessed on 3 August 2010).

NHS Information Centre (2008). *National Diabetes Audit. Executive summary. Key findings about the quality of care for people with diabetes in England and Wales*. Report for the audit period 2007/8. Leeds: NHS Information Centre. Available at: www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/7121_National%20Diabetes%20Audit_final.pdf (accessed on 10 August 2009).

Noel PH, Frueh BC, Larme AC, Pugh JA (2005). 'Collaborative care needs and preferences of primary care patients with multimorbidity'. *Health Expect* 8 (1): 54–63.

Noel PH, Parchman ML, Williams JW Jr, Cornell JE, Shuko L, Zeber JE, Kazis LE, Lee AF, Pugh JA (2007). 'The challenges of multimorbidity from the patient perspective'. *J Gen Intern Med* 22 (3): 419–24.

Nutting PA, Goodwin MA, Flocke SA, Zyzanski SJ, Stange KC (2003). 'Continuity of primary care: to whom does it matter and when?' *Ann Fam Med* 1 (3): 149–55.

Nuyen J, Spreuwenberg PM, van DL, den Bos GA, Groenewegen PP, Schellevis FG (2008). 'The influence of specific chronic somatic conditions on the care for co-morbid depression in general practice'. *Psychol Med* 38 (2): 265–77.

Offredy M, Bunn F, Morgan J (2009). 'Case management in long term conditions: an inconsistent journey'. *British Journal of Community Nursing* 14 (6): 252–7.

Ogle KS, Swanson GM, Woods N, Azzouz F (2000). 'Cancer and comorbidity: redefining chronic diseases'. *Cancer* 88 (3): 653–63.

Olfson M, Mechanic D, Boyer C, Hansell S, Walkup J Weiden P (1999). 'Assessing Clinical Predictions of Early Rehospitalization in Schizophrenia'. *Journal of Nervous and Mental Diseases* 187 (12): 721–729.

Osborn D, Levy G, Nazareth I (2007). 'Relative risk of cardiovascular and cancer mortality in people with severe mental illness from the United Kingdom's General Practice Research Database'. *Archives of General Psychiatry* 64: 242–49.

Oxman TE, Dietrich AJ, Schulberg HC (2005). 'Evidence-based models of integrated management of depression in primary care'. *Psychiatr Clin North Am* 28 (4): 1061–77.

Parchman ML, Noel PH, Lee S (2005). 'Primary care attributes, health care system hassles, and chronic illness'. *Med Care* 43 (11): 1123–29.

Porcheret M, Jordan K, Jinks C, Croft P (2007). 'Primary care treatment of knee pain – a survey in older adults'. *Rheumatology* 46 (11): 1694–1700.

Rait G, Walters K, Bottomley C, Petersen I, Iliffe S, Nazareth I (2010). 'Survival of people with clinical diagnosis of dementia in primary care: cohort study'. *BMJ* 341: c3584.

Rheumatology Futures Group (2009). '18 week Commissioning Pathway Inflammatory Arthritis (Joint Pain)'. NHS 18 weeks website. Available at: www.18weeks.nhs.uk/Content.aspx?path=/achieve-and-sustain/Specialty-focussed-areas/rheumatology/inflammatory-arthritis/ (accessed on 22 July 2009).

Richards DA, Lovell K, Gilbody S, Gask L, Torgerson D, Barkham M, Bland M, Bower P, Lankshear AJ, Simpson A, Fletcher J, Escott D, Hennessy S, Richardson R (2008). 'Collaborative care for depression in UK primary care: a randomized controlled trial'. *Psychol Med* 38 (2): 279–87.

Rogers A, Kennedy A, Bower P (2008). 'The United Kingdom Expert Patients Programme: results and implications from a national evaluation'. *Med J Aust* 189 (10): S21–S24.

Roland M, Dusheiko M, Gravelle H, Parker S (2005). 'Follow up of people aged 65 and over with a history of emergency admissions: analysis of routine admission data'. *British Medical Journal* 330: 289–92.

Royal College of General Practitioners (2009). *Care of People with Mental Health Problems*. RCGP curriculum statement 13. London: RCGP.

Roy-Byrne PP, Stein MB, Russo JE, Craske MG, Katon WJ, Sullivan G, Sherbourne CD (2005). 'Medical illness and response to treatment in primary care panic disorder'. *General Hospital Psychiatry* 27 (4): 237–43.

Sampson MJ, Dozio N, Ferguson B, Dhatariya K (2007). 'Total and excess bed occupancy by age, specialty and insulin use for nearly one million diabetes patients discharged from all English Acute Hospitals'. *Diabetes Research and Clinical Practice* 77 (1): 92–98.

Scott J (2006). 'Depression should be managed like a chronic disease'. *BMJ* 332: 985–86.

Sederer L, Silver L, McVeigh K, Levy J (2006). 'Integrating care for medical and mental illnesses'. *Preventing Chronic Disease* 3 (2): 1–3.

Segal L, Day SE, Chapman AB, Osborne RH (2004). 'Can we reduce burden of disease from osteoarthritis?'. *Medical Journal of Australia* 180 (5), S11–17.

Sheppard J, Kumar K, Buckley CD, Shaw KL, Raza K (2008). "I just thought it was normal aches and pains": a qualitative study of decision-making

- processes in patients with early rheumatoid arthritis'. *Rheumatology* 47 (10): 1577–82.
- Simmons RK, Unwin N, Griffin SJ (2010). 'International Diabetes Federation: an update of the evidence concerning the prevention of type 2 diabetes'. *Diabetes Research and Clinical Practice* 87 (2): 143–49.
- Simon GE, Goldberg DP, Von Korff M, Ustun TB (2002). 'Understanding cross-national differences in depression prevalence'. *Psychological Medicine* 32 (4), 585–94.
- Soljak MA, Majeed A, Eliahoo J, Dornhorst A (2007). 'Ethnic inequalities in the treatment and outcome of diabetes in three Primary Care Trusts'. *International Journal for Equity in Health* 6:8. Available at: www.equityhealthj.com/content/6/1/8/abstract (accessed on 22 June 2009).
- Starfield B, Lemke KW, Bernhardt T, Foldes SS, Forrest CB, Weiner JP (2003). 'Comorbidity: implications for the importance of primary care in "case" management'. *Ann Fam Med* 1 (1): 8–14.
- Steel N, Maisey S, Clark A, Fletcroft R, Howe A (2007). 'Quality of clinical primary care and targeted incentive payments. An observational study'. *British Journal of General Practice* 57 (539): 449–54.
- Steel N, Bachmann M, Maisey S, Shekelle P, Breeze E, Marmot M and Melzer D (2008). 'Self reported receipt of care consistent with 32 quality indicators: national population survey of adults aged 50 or more in England'. *BMJ* 337 (132): 438–52.
- Steffens DC, Rama Krishnan KR (1998). 'Psychotherapeutic agents in older adults. Metabolism, bioavailability and drug interactions'. *Clinics in Geriatric Medicine* 14: 17–31.
- Steward K and Land M (2009). *Perceptions of Patients and Professionals on Rheumatoid Arthritis Care*. London: The King's Fund.
- Struijs JN, Baan CA, Schellevis FG, Westert GP, van den Bos GA (2006). 'Comorbidity in patients with diabetes mellitus: impact on medical health care utilization'. *BMC Health Serv Res* 6: 84.
- Tahrani AA, McCarthy M, Godson J, Taylor S, Slater H (2008). 'Impact of practice size on delivery of diabetes care before and after the Quality and Outcomes Framework implementation'. *British Journal of General Practice* 58 (553): 576–79.
- Turner S, Illiffe S, Downs M, Wilcock J, Bryans M, Levin E, Keady J, O'Carroll R (2004). 'General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia'. *Age and Ageing* 33: 461–67.
- Tylee A, Walters P (2007). 'We need a chronic disease management model for depression in primary care'. *Br J Gen Pract* 57 (538): 348–50.
- van Weel-Baumgarten EM (2005). 'Is depression a chronic illness? A response from the perspective of general practice'. *Chronic Illn* 1 (2): 113–15.
- Victor CR, Ross F, Axford J (2004). 'Capturing lay perspectives in a randomized control trial of a health promotion intervention for people with osteoarthritis of the knee'. *Journal of Evaluation in Clinical Practice* 10 (1): 63–70.

Waugh N, Scotland G, McNamee P, Gillet P, Brennan A, Goyder E, Williams R, John A (2007). 'Screening for type 2 diabetes: literature review and economic modelling'. *Health Technology Assessment* 11 (17): iii-iv, ix-xi, 1-125. Available at: www.hta.ac.uk/fullmono/mon1117.pdf (accessed on 15 April 2010).

Wagner EH, Simon GE (2001). 'Managing depression in primary care'. *BMJ* 322 (7289): 746-47.

Wennberg D, Siegel M, Darin B, Filipova N, Russell R, Kenney L, Steinort K, Park TR, Cakmakci G, Dixon J, Curry N, Billings J (2006). *Combined Predictive Model*. Final report. London: The King's Fund. Available at: www.kingsfund.org.uk/current_projects/predicting_and_reducing_readmission_to_hospital/#resources (accessed on 10 July 2010).

World Health Organization (2008). *The Global Burden of Disease. 2004 update*. Geneva: WHO.

Yorkshire and Humber Public Health Observatory (2008). *Diabetes in England*. York: YPHO. Available at: www.library.nhs.uk/DIABETES/ViewResource.aspx?resID=300742 (accessed on 11 August 2009).

Young A, Dixey J, Kulinskaya E, Cox N, Davies P, Devlin J, Emery P, Gough A, James D, Prouse P, Williams P, Winfield J (2002). 'Which patients stop working because of rheumatoid arthritis? Results of five years' follow up in 732 patients from the Early RA Study (ERAS)'. *Annals of Rheumatic Disorder* 61 (4): 335-40.

Young D, Furler J, Vale M, Walker C, Segal C, Dunning P, Best J, Blackberry I, Audehm R, Sulaiman N, Dunbar J and Chondros P (2007). 'Patient engagement and coaching for health: the PEACH study – a cluster randomised controlled trial using the telephone to coach people with type 2 diabetes to engage with their GPs to improve diabetes care: a study protocol'. *Biomed Central Family Practice*. 8 (20): 1-9. Available at: www.ncbi.nlm.nih.gov/pmc/articles/PMC1854904/ (accessed on 20 April 2010).

Appendix 1 Literature review study terms and example of results

All searches used a common 'base' (column A) plus topic-specific search terms (column B). Articles had to contain one term from column A, and one from B. The search was limited to the last 10 years only and title/abstract only (apart from depression which was title only).

A	B				
	Arthritis	Dementia	Diabetes	Depression	Co-morbidity
GP General practice General practitioner Primary care	Arthritis Inflammatory arthritis Joint pain Musculoskeletal Osteoarthritis Rheumatoid arthritis Rheumatism	Alzheimer's disease Dementia (and variants) Memory clinic Memory loss	Blood glucose Diabetes (and variants) Insulin	Depression Mental health Mental illness Mental disorder Psychiatric (and variants)	Co-morbidity Dual diagnosis Multi-morbidity Multiple needs Multiple care needs Multiple chronic Multiple long-term

Appendix 2 Sample protocol for interviews with expert informants

Expert informant: interview guide

[Sample]

Preamble:

Discuss the nature of the Inquiry, why they have been chosen to participate, what the interview is about, and how long it will take. Ask permission to record interview, stressing all data will be stored securely and only used for the purposes of the Inquiry. Ask the interview for any questions or points of clarification

Introduction – role, experience, expertise

To provide us with an understanding of your experience and expertise, I would like to start by asking you to say a bit about yourself – your role (current job), your experience and involvement with regard to the issue of quality of care for people with [insert long-term condition here] in general practice.

Condition-specific questions

I want to start by asking about high-quality care for people with [insert condition] generally, and then move on to focus specifically on the role of general practice within that.

1. In an ideal world, what would **high-quality care for people with [depression]** look like in general terms (in other words, regardless of location of care)?
 - In an ideal world what would *best quality care look like or contain for a patient with [condition]*? [prompt about care pathways]
 - Is there much *evidence or guidance* to tell us what best quality of patient care should look like?
 - How useful are *models of care* for managing these patients? [prompt – for example, collaborative care, care management]. What components of these are most important?
2. What do you think the **role of general practice** should be, in the delivery of such high-quality care for people with [insert condition]?
 - What things lie within the *core role of general practice*, and what enhanced roles could there be – for example, for *GPs with a special interest*? Enhanced services by a practice-based team?

[Prompt: Discuss GP role in advice giving, diagnosis, referral to services treatment, ongoing monitoring, supported self care].
 - What role does self-care play?

[Prompt: Self care is advice and support to enable people to live healthy and at home, ongoing relationship between patient and general practice].

- What role should *other staff* within the practice play – for example, staff nurses, practice managers, receptionists?
3. You've described what management of [insert condition] should look like in general practice – **how close are we to that, in reality?**
- What is your impression generally of the quality of care provided by general practices?
 - What is the extent of *variations in quality*? [Ask about variations in terms of area, deprivation, gender, ethnicity, practice size/level etc.]
 - What accounts for the variations? What *impedes best quality care* in general practice for people who suffer with [insert condition]?
 - What are the key areas in which *general practice as a whole could improve the quality of care* it provides to patients with [insert condition]?
4. What **quality improvement tools or approaches** could be used to improve the quality of care for [depression] in general practice?
- If you were attempting to measure the quality of care provided to people with [insert condition] by general practice, what would be the *key measures of quality* you might use?
 - Are there any *current measures* that you are aware of that are currently being used to measure quality? What are these? Are these measures suitable?
 - Is using measures and metrics a useful approach to quality improvement? What other approaches could be used?

People with multiple long-term conditions

I'd like to talk now about people with more than one long-term condition, and how their needs should be managed.

5. Would high-quality **care for patients with multiple LTCs be different than for people with a single condition?**
- Are there any particular *models of care* that are appropriate for people with multiple LTCs (eg 'guided care')?
6. How about the **role of general practice** – would that **look different** for people with multiple LTCs compared to those only with [insert condition]?
- How *close are we to that vision of best practice in reality?* Any areas for improvement? Extent of variations in quality, and reasons for this.
 - What areas would you focus on to make the biggest difference in care quality?
 - Are current *measures of quality of care* any different for people with *multiple LTCs*? How suitable are they for people with multiple LTCs?

Population management

I want to ask about taking proactive approaches to the management of people with LTCs. Proactive population management – identifying patients who might be at increased risk of developing long-term conditions, or identifying those with an existing diagnosis whose risk of deterioration is increasing.

7. [ONLY ASK IF THE INTERVIEWEE IS A PRACTISING GP]. Do you undertake any **proactive population management of your registered patients**?
 - Do you run any *screening/preventative/pre-emptive* programme to identify those most at risk of deterioration or unplanned admission to hospital for example?
 - How do you make sure you target this proactive care at the *right patients*? Is this an accurate method?
 - What sort of *interventions* do you offer to patients identified as being at risk? Do you offer different sorts of care to different patients, depending on the level of risk?
8. What are the **pros and cons** of GPs taking proactive approaches to managing all their registered patients for LTCs (not just those already identified with a LTC)?
 - How important do you think this proactive or pre-emptive work is in management of LTCs? Is it a key part of the role of the GP? If not, who should be offering it?

Implications for general practice

Finally, I'd like to ask about the implications of what we've been talking about for the general model of general practice used in this country.

9. Do you think the model of general practice needs to **adapt in a broader** or more **fundamental** sense in order to meet the needs of patients with [insert condition]?
 - If so, how should it adapt?
10. Do you know of any examples of best practice that would be worth investigating as a case example? [single LTC or multiple LTC]
 - Prompt for details and contacts.

Thank you for participating in this interview about the quality of long-term conditions management in general practice.

Would you be interested in attending an expert seminar in [give date if possible] to discuss the quality of long-term conditions management in general practice?

Appendix 3 Number and types of expert informants interviewed

Type of informant	B				Total
	Arthritis	Dementia	Diabetes	Depression	
GP or GP with a special interest	3	3	2	5	13
LTC nurse or other primary care professional	1	1	1	1	4
PCT commissioner	1	-	1	0	2
Policy-maker	1	1	1	1	4
Academic	3	2	2	2	9
Representative of patient group or society	2	4	2	1	9
Total	11	11	9	10	41

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