How to deliver high-quality, patient-centred, cost-effective care

Consensus solutions from the voluntary sector

Introduction

Those of us who work in health and social care are well aware of the serious long-term issues we face as a nation. An ageing population means a significant increase in the number of citizens living with multiple conditions. Life-style choices are resulting in an increased incidence of particular conditions. Patients expect the best available care that meets their personal needs. They also expect to participate actively in decisions about their care. All of these challenges need to be met within inevitable financial constraints.

This publication is the collective effort of ten of the leading health and social care organisations in the voluntary sector. Each organisation submitted evidence to The King's Fund, which independently analysed and assessed each submission and worked with the organisations to establish a common position. Together we have identified the five key themes that the health and social care system must embrace to be sustainable and to ensure quality. The themes are:

- co-ordinated care
- patients engaged in decisions about their care
- supported self-management
- prevention, early diagnosis and intervention
- emotional, psychological and practical support.

We have focused on principles that are shared across all the conditions and populations we represent, embracing both physical and mental health care and social care. Early intervention is as important for a patient with a mental health problem as for a patient with cancer. A care plan has as much impact on a patient with diabetes as on a patient with cardiac problems. While there are other considerations important to specific conditions, what we espouse here will, when implemented, improve the quality of care and support for all patients and carers.

We also present evidence of the financial benefit of a range of specific interventions and services, based on research and evaluations conducted by our ten organisations, which we believe collectively represent the significant financial benefit of a more co-ordinated and integrated system. Realising this will be dependent on two things. First, having a view of the entire cost of a pathway or patient journey is fundamental to decision-making in the future. Money should achieve quality and the best feasible outcomes. Second, the themes we have identified are linked. Quality will not be improved nor savings made by implementing changes piecemeal. Pathways and patient journeys must be commissioned as an integrated whole. The old ways must be shut down to avoid compromising improved quality and duplicating costs.

Recommendations for the voluntary sector, leaders in NHS and social care, clinicians and Department of Health policy-makers are also provided. Perhaps the most immediate next step is to use the advent of the Health Bill to start the move to the higher-quality, lower-cost system we want and need. We believe many of the proposals in the current White Paper have the potential to deliver huge benefits, if implemented sufficiently, robustly and ambitiously. A comprehensive outcomes framework highlighting variation and poor service provision could improve overall outcomes. An 'information revolution' that includes all the information patients need to live with their conditions has the potential to help patients self-manage. Local commissioning may make health and social care more patient-centred if the concept of 'no decision about me, without me' is truly embraced and commissioning boards and consortia include strong representation from patients, carers and voluntary organisations.

The role of the voluntary sector in driving innovation and delivering patient-centred care and support is unquestioned. Although we all face a period of transition as we adjust to the current state of public finances, in the longer term the health and social care system we help to create must be built on the themes this document highlights. Only in this way will quality continue to improve and the NHS and social care be sustainable.

As organisations and as individual policy leaders we pledge our commitment to making this change. We will work with local leaders of health and social care, national policy-makers, professional bodies, and local and national political leaders to ensure that the expectations of England's many millions of patients and carers are met. The next few years will be difficult, but it is our duty to support changes that address immediate issues, make the future affordable and put the patient truly at the heart of the health care system.

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Co-ordinated care

Despite clear policy ambitions to improve the co-ordination of care for people with chronic diseases and complex needs, people continue to be admitted to hospital for conditions that could be effectively managed in the community, and patients continue to report that they would like greater continuity in their care (Department of Health 2007).

Care planning

An essential element of co-ordinated care is care planning. For example, the Year of Care programme for diabetes aims to embed the concept of collaborative care planning within the management of diabetes and, subsequently, other long-term conditions, and ensure that systematic care planning is implemented within the routine care process for long-term conditions (Diabetes UK 2009). Importantly, care planning is not a one-off event at the start of a patient's journey. Many conditions, such as asthma and most neurological conditions, fluctuate, so the care plan needs to be regularly reviewed and to cover what to do in an emergency.

People with multiple conditions

Although co-ordinated care is important for patients with individual long-term conditions, it is essential for the substantial proportion of people who experience co- or multi-morbidity – the presence of two or more conditions simultaneously. This is particularly the case for older people. The impact of multi-morbidity is profound. Patients with several long-term conditions:

- have poorer quality of life
- have poorer experience of care
- have poorer clinical outcomes
- have longer hospital stays
- have more post-operative complications
- are more costly to health services.

(Fortin *et al* 2007; Cowie *et al* 2009)

In our ageing society, where the fastest-growing age group is those aged over 85, this is set to become an even greater challenge.

Collaborative care models, including case management, systematic follow-up and close collaboration both within organisations and between primary care, secondary care, social care and public health, are crucial to providing high-quality, cost-effective care for many patients. The National Institute for Health and Clinical Excellence (NICE) guidelines for the management of depression in people with chronic physical health problems (NICE 2009) recommends collaborative care models are used for more severe cases.

Case management and co-ordination roles and services

Although co-ordinator roles are in place for some conditions in some areas, there is a significant shortfall in the provision of such roles for all patients who would benefit from them. These roles can be carried out by health professionals such as GPs, specialist nurses, community matrons, case managers and allied health professionals, and by non-health care staff such as support workers and dedicated service co-ordinators. They can perform many important functions, including:

- co-ordinate a multidisciplinary team or steering group of health and social care professionals (including representation from out-of-hours and ambulance services where relevant) to conduct case conferences, discuss patients' needs and plan care
- assess patients and plan their care
- manage early supported discharge and act as a link between hospital and community care and other agencies, such as housing and transport
- support patients back into the community, enable referral back to therapeutic and specialist services when needed and help to prevent crises and emergency admissions
- maintain a single, trusted point of contact for patients, carers and families
- provide information and support for patients, carers and families
- listen to and communicate with patients to understand their needs and concerns
- enable patients to express, record and exercise choices, both for ongoing treatment and care and for end-of-life decisions, including choosing to die at home
- support self-management by providing patients with the necessary information and advice

- in the case of clinical roles, go beyond co-ordination to provide direct care in the community, such as monitoring symptoms and managing medication.

Heart failure nurses

British Heart Foundation health professionals have changed the face of community-based cardiac care across the UK by providing expert care, support and education for heart patients in the community, in hospital and in their homes.

They cover a wide range of specialties, including heart failure, acute coronary syndrome, paediatrics, arrhythmia, adults with congenital disease, genetics and palliative care. The BHF health professionals monitor patients' conditions, provide expert clinical and emotional support and advice, and also provide a vital interface between primary, secondary and tertiary care.

In 2009/10, 453 British Heart Foundation Specialist nurses saw a total of 111,645 patients, made 171,449 telephone calls to patients, delivered 9,658 teaching sessions and contributed to 8,438 hospital avoidances through nurse-led interventions.

A comprehensive evaluation by the University of York demonstrated that heart failure nurses reduce all-cause admissions by an average of 35 per cent, and an average saving of £1,826 per patient is gained after the costs of the nurse have been deducted (Pattenden *et al* 2008).

Heart failure specialist nurses have become the linchpin of a co-ordinated multidisciplinary community service to patients with heart failure. They see patients in their own home and in clinics to monitor their conditions, adjust their medication doses and provide information and support. One heart failure patient described the support as an 'absolute lifeline for us both, providing support, advice and practical assistance on many occasions. I am sure she helped us far above and beyond what you would expect of her.'

These roles and services can have a significant impact on the quality of care, patient outcomes and efficiency.

- Co-ordinated services have been found to improve patient-reported outcomes in multiple sclerosis (Edmonds *et al* 2010).

- Specialist nurse-led services have been shown to reduce re-admission rates in a host of conditions, including asthma (Chandler 2007), heart failure (Pattenden *et al* 2008), chronic obstructive pulmonary disease (COPD) (Forbes and While 2008) and epilepsy (Epilepsy Action 2010).

- Providing support for patients with dementia to leave hospital one week earlier than they currently do could result in savings of at least £80 million a year (Alzheimer's Society 2009).

- Research undertaken in Manchester by Macmillan Cancer Support and Monitor Group indicates that co-ordinated care could release about 10 per cent of cancer expenditure in the area. This would be achieved by improving follow-up, supporting patients to die at home, improving co-ordination so that patients can be moved into a less resource-intensive pathway, reducing length of stay, reducing avoidable emergency admissions and supporting patients to return to or stay in work (Macmillan Cancer Support 2010a).

The Stroke Association Life After Stroke Service – Pauline's story

Co-ordination services help to bring together health, mental health and social care services as well as to link patients to employment services and local voluntary organisations and businesses.

Pauline had worked as an actress prior to her stroke. Although she wanted to return to work, she was anxious about her residual left-sided weakness. Cameron, her co-ordinator from the Stroke Association Life After Stroke Service, encouraged her to develop some new, but related, skills. He introduced Pauline to an organisation that employs actors to read to stroke survivors in hospital and has supported her in finding additional employment with a company that trains businesses in dramatic skills. Thanks to Cameron's intervention and support, Pauline is beginning her return to the workforce.

(Stroke Association 2010)

Patients engaged in decisions about their care

Engaging patients and carers in discussions about care and ensuring that decisions about treatment are shared between health care staff and patients can improve the management of the condition, improve patients' experience of care and link commissioning decisions and improvement initiatives to the needs of service users. A major survey of what matters to patients indicated that being involved in decisions about their condition and treatment was the most important factor (Department of Health 2003).

This kind of patient engagement can take a variety of forms:
- supporting patients to understand their condition and care
- shared decision-making about treatment and care
- using patients' views to inform service design and improvement.

Supporting patients to understand their condition and care

Patients benefit from having information about their condition and treatment options and from having support to understand, interpret and translate that information. Information must be completely accessible to all patients, whatever their literacy skills or mental capacity. Clinicians need support to make this happen in practice.

There is good evidence that patients who are well-informed about their condition and their options for care and treatment are more likely to follow the agreed treatment plan (Marinker 1997). There is additional evidence that good communication between doctors and their patients enhances patient outcomes (Stewart 1995). Information is a pre-requisite to expressing preferences and exercising choice in relation to treatment.

Experiences across a number of disease areas suggest that patients may be most responsive to information when a health care professional guides them through the content and assists them to interpret and translate the information in relation to their particular situation. A review of studies or patients with cancer also found that tailoring information to a patient's needs means that it is more likely to be recalled by the patient in the future (McPherson *et al* 2001). A survey of patients with diabetes found that having support to interpret test results and put information into context was a key factor in enabling people to manage their condition successfully (Diabetes UK 2009).

Approximately one-fifth of the UK population cannot read or follow basic instructions on medicine labels and it has been estimated that more than half are unlikely to be able to understand the cancer information brochures routinely available in hospitals (Macmillan Cancer Support 2010b). It is essential that patients are supported to understand information about their condition; for example, the use of different media and formats to present information for those with limited literacy skills. It must be remembered that online information is not accessible to everyone. Those older than 65 have some of the greatest and most complex health needs, and more than 60 per cent of them have never accessed the internet (Office for National Statistics 2009). Health care professionals need to be trained to listen to and communicate with people with communication difficulties caused by a physical or cognitive disability.

Shared decision-making about treatment and care

Many patients are keen to be partners in maintaining their health, rather than passive recipients of care (Department of Health 2007). While not all patients want to be involved in decision-making (Coulter 2007), some patients at some stages of care do want greater involvement. Only half of patients responding to a national inpatient survey said they had definitely been involved as much as they wanted to be in decisions about their care (Picker Institute Europe 2009). This figure fell to one-third for mental health service inpatients (Care Quality Commission 2009). A survey of people who care for friends or relatives with dementia found that almost half said that neither they nor the person they were caring for were involved in decisions about care as much as they would like to be (Alzheimer's Society 2009).

Conversations about death and end-of-life care remain taboo for many patients and clinicians, but this makes it very difficult to take patients' preferences into account. Most people would prefer not to die in hospital (Department of Health 2008a), but more than 50 per cent of deaths still occur there (National End of Life Care Intelligence Network 2010). Almost half of GPs have said they would like support to help them deal with patients who are approaching the end of their lives (The King's Fund 2009).

Involving people in their care can improve not only

their experience but also their health outcomes. For example, there is good evidence that giving patients with depression a choice of treatment (Lin *et al* 2005) and communicating well with them (van Os *et al* 2005) improves the outcomes of treatment.

In the case of long-term conditions in general, supporting staff to develop skills that enable them to work in partnership with patients has been found to improve patients' confidence in managing their own condition (Powell *et al* 2009), which can mean a better experience for patients and reduced use of health care services. Simple tools can be used to support this. For example, a clinical nurse specialist in breast cancer developed a 'distress thermometer' questionnaire to facilitate conversations with women about their anxiety levels and to encourage radiographers to take into account patients' concerns and organise care around the needs of the patient (National Cancer Action Team 2010).

Year of Care programme – collaborative decision-making in diabetes care

The vast majority of care for people with diabetes is self care and management – and avoiding developing complications or unnecessary hospital admissions means getting that care right for the patient. The Year of Care programme is a partnership initiative between the Department of Health, Diabetes UK, the Health Foundation and NHS Diabetes. It aims to provide personalised care to people with diabetes to support them to self-manage their condition and to ensure that they can access the right services when they do need additional support.

Central to the programme is a collaborative approach to care planning and decision-making involving patients as well as their health care professionals in choosing the right care and support. Through discussion and joint decision-making, shared objectives can be developed for education programmes to support self-management; meaningful personal goals can be set for health improvement; appropriate care plans can be agreed; and the commissioning of services for local areas can be firmly based on the needs of patients (Diabetes UK 2010). As one patient put it, this approach allowed her to 'focus on the important things for me, and get help' (NHS Diabetes 2010).

Using patients' views to inform service design and improvement

Understanding the views of patients when making decisions about what services should be available and how they should be delivered links commissioning and service improvement efforts directly to the needs and experiences of service users. This can range from developing local, informal complaint mechanisms that allow patients to feed back on problems without lodging a formal complaint (such as Macmillan Cancer Support's Patient User Partnership) to using information gained from collaborative consultations with patients to inform commissioning decisions for particular disease groups.

Breakthrough Breast Cancer's Service Pledge initiative

Patients rarely know the standard of care they can expect from the NHS or how they can ask for improvements if the standard of care is found wanting. However, local breast cancer units involved in Breakthrough Breast Cancer's Service Pledge initiative provide all patients with a locally developed pledge about the quality of service they can expect and use surveys and interviews to identify areas patients want to see improve. This can result in the delivery of significant improvements to the quality of patients' experience at minimal cost. Low-cost innovations have included:
- formal buddying systems that enable patients to speak to others who have undergone the same treatment
- welcome boards showing photographs and the names of staff
- offering patients the opportunity to see photographs of the results of surgical treatments and options for reconstruction.

These changes have helped patients and increased the morale of staff, who reported the tremendous boost that they got from making changes to solve problems identified by patients.

(Breakthrough Breast Cancer 2010)

Supported self-management

The increasing prevalence of chronic conditions has huge implications for the levels of care, services and support that are needed to manage these conditions. Partly in response to this, there has been increasing interest in helping people manage their conditions themselves (Department of Health 2008b; Ham 2010).

Self-management means that people make choices and decisions about how to manage their life and their condition. However, to enable people to self-manage well requires support. The type of support people need will vary depending on how they are managing and whether they feel the need to access that support. The evidence demonstrates that the main elements of successful supported self-management include:

- personalised action plans
- structured education and information
- access to health care professionals and trained specialist advice in regular structured reviews when needed
- emotional, psychological and practical support, including from peers, family, friends and carers.

Personalised action plans

Personalised action plans or self-management plans are an important part of supported self-management. A major systematic review of asthma concluded that education in self-management, which involves self-monitoring, coupled with regular medical review and a written action plan, improves health outcomes for adults with asthma (Gibson *et al* 2009). For example, research shows that people who do not have a written personal asthma action plan are four times more likely to have an asthma attack requiring emergency hospital treatment than those who do (Adams *et al* 2000).

Action plans for people with long-term conditions are becoming more common and there are good examples of innovation. The Year of Care programme for diabetes has worked collaboratively with the Yorkshire and Humber Strategic Health Authority to develop the first ever templates in an electronic health record that systematically record a person's own goals and action plans and also enables commissioners to identify needs for services to support self-management.

Despite the policy commitment that everyone with a long-term condition should have a personal care plan, they are still not available for all patients who would benefit from them. A survey of primary care trusts (PCTs) conducted in 2008 found that only half of PCTs in England require personal care plans to be agreed with people with newly diagnosed diabetes (Diabetes UK 2009). Only 10 per cent of people in England with asthma say they have an action plan (Asthma UK 2010a). Only 20 per cent of patients with COPD currently receive self-care support of any kind (Department of Health 2010).

Structured education and information

Structured education, in either group or individual formats, involves specific aims and learning objectives that are shared with patients, carers and their families. Patient surveys and focus groups conducted by Diabetes UK identified access to structured education as one of the most important things that could support patients to self-manage (Diabetes UK 2009).

Expert patient programmes are one form of such support. When targeted at those with the greatest need of support, such as people with low confidence, expert patient programmes can lead to reduced health service utilisation and improve health-related quality of life for patients (Expert Patients Programme Community Interest Company 2010).

Studies point to one fewer admission to hospital for every 20 patients with asthma completing self-management structured education programmes, and one fewer A&E visit for every eight patients with asthma completing such a programme (Partridge and Hill 2000). In Leeds, a series of Getting Sorted self-care workshops for young people with asthma have helped them to learn about coping with asthma, increased their confidence in managing their condition and improved their ability to access support from their GPs and clinic services (Asthma UK 2010b).

Paediatric community matron service for children with asthma

In the Crewe area, the prevalence of asthma is approximately 20 per cent, according to local estimates. Paediatric community matrons attached to five general practices in the area provide an integrated structured education service to children

with asthma and their families at home. They work with them to empower self-management of the child's condition through the effective provision of tailored health education, support and advice.

The most recent patient survey that has been analysed indicates 100 per cent of families felt the service had been of benefit, 77 per cent said they saw the GP less and 69 said they had fewer hospital admissions. Also, 81 per cent of parents stated that since seeing the community matron their understanding of their child's condition had improved significantly.

Comments included: 'The community matron brought pictures showing how my child's lungs are when normal and when she is having an attack. By showing and teaching me new methods, I have developed new coping strategies.' (Allcock 2009, p 23)

In 2007, the service was given an award by Cheshire County Council for providing better information for more parents.

(Allcock 2009)

Access to health care professionals and trained specialist advice

People self-managing their condition should be offered a regular discussion with a health care professional. These can be offered in face-to-face consultations, but also over the telephone, online and through electronic monitoring systems. Specialist nurses can be valuable to patients as a source of more specialist advice than is possible from their GP (Pattenden *et al* 2008).

Health care professionals themselves also need support to be able to give patients the support they need. The Patient Partnership in Care programme for clinicians to support cancer patients to self-manage is based on established training tools and is currently being piloted with the pan-Birmingham Cancer Network and at Hillingdon Hospital (Powell *et al* 2009). Parkinson's UK and the *BMJ* have developed an online learning tool for GPs to assist them to diagnose Parkinson's disease and support patients with Parkinson's disease to cope with their condition (Parkinson's UK 2010). More than 9,000 GPs have participated to date.

Self-care for multiple sclerosis (MS) in the community

The Multiple Sclerosis International Federation outlines one of the principles to promote the quality of life of people with MS as follows: 'People with MS must be empowered to take control of the decisions affecting their lives and to self-manage the disease as much as possible… They should be able to access a broad range of information, advice, and education regarding the nature of MS, its treatment, and methods for improving quality of life' (Multiple Sclerosis International Federation 2002, p 21).

Self-care for MS patients in England has been shown to be effective. A randomised controlled trial of professionally guided self-care for people with MS found improved health outcomes for patients in terms of mental health and vitality scores, and that people with MS had maintained independence better and needed less intervention in daily living than the control group (O'Hara *et al* 2002).

Emotional, psychological and practical support

While the fifth priority in this document is devoted to issues around emotional, psychological and practical support, these issues are also a crucial part of effective supported self-management. Such services are often partnerships between the NHS and the voluntary sector. For example, Macmillan Cancer Support works in partnership with local voluntary groups and NHS organisations to run health and well-being clinics for patients with cancer and patients who have survived cancer. The clinics provide a range of support, such as buddying services, emotional support, information about local services and access to advice and advocacy.

Prevention, early diagnosis and intervention

Prevention is always better than cure. There is a huge potential to improve the quality of people's lives and to reduce long-term costs for the health service by focusing on prevention (Wanless 2002). General poor health, such as lack of physical exercise, a poor diet and smoking, increases the chances of suffering from diseases such as asthma, diabetes, dementia, cancer, heart disease and stroke. For example, it is estimated that half of all cancers in the UK are preventable (Cancer Research UK 2010). In a time of financial constraint, it is essential that efforts and resources are not distracted from prevention and public health services.

Informing and supporting people, particularly those at high risk, to improve their general health can reduce their chances of illness and save the health service from avoidable care costs. In the case of stroke, the Stroke Association's Life After Stroke service provides advice and support to ensure that people who have recently experienced a stroke reduce their risk of secondary stroke by making changes to their lifestyle. In the case of work-related illnesses, such as asthma, charities have worked with employers to ensure employees are protected from causes of the disease wherever possible (Asthma UK 2008).

When people do become ill, early diagnosis and early intervention can often reduce the severity of the illness, improve life chances and also save money. In cancer, it has been estimated that thousands of lives could be saved if patients were diagnosed and treated at an earlier stage in their illness (Richards 2009). The likelihood of developing severe disability for rheumatoid arthritis sufferers can be significantly reduced if treatment is started within three months of onset of symptoms (Emery *et al* 2002; Nell *et al* 2004; Luqmani *et al* 2009). In the case of dementia, early diagnosis allows staff and carers to help the individual with dementia to maintain their independence for as long as possible (NICE and SCIE 2006). And NICE guidelines for multiple sclerosis, Parkinson's disease and epilepsy all stress early diagnosis as an important part of cost-effective treatment.

Early diagnosis of COPD

Almost one million people in the UK have been diagnosed with COPD, but it is estimated that true prevalence figures may be more than three times that figure (British Lung Foundation 2009).

The British Lung Foundation Love Your Lungs campaign aims to raise awareness of COPD and its symptoms in order to encourage early diagnosis. The awareness campaign includes telemarketing, posters, leaflets and awareness stands offering free lung testing, and all are targeted towards areas where the population has been identified as being at risk of COPD.

A campaign in Hull saw almost one-quarter of those receiving a lung test being referred for a follow-up consultation, with one-third of those people being diagnosed with COPD. Catching these individuals while the disease is still relatively mild means a potential saving of £90,000 in avoided treatment and emergency admission costs (Lethbridge 2010).

Early diagnosis can be encouraged by raising public awareness of conditions, reducing stigma associated with illnesses and their treatment, and supporting health and other public service workers to recognise symptoms and direct people to appropriate support services.

NHS staff in Ealing have been working to improve community awareness of asthma, including working with local schools to ensure that staff are able to recognise the signs of acute asthma attacks and have access to emergency relief inhalers. Staff are also trained to recognise poor control of the condition and to direct students and their families to the appropriate support and advice, ensuring early intervention and supporting self-management.

Encouraging people to access mental health services

The Time to Change campaign, led by Rethink and Mind, is using social marketing techniques to challenge the stigma associated with mental ill health. It has been estimated that if the campaign results in even a very small (such as less than 2 per cent) increase in the number of people with depression accessing support services and gaining employment that results in improved health, then the economic benefits of the programme would outweigh the costs eight-fold. A 10 per cent increase in the number of people with psychosis receiving early intervention can generate annual savings of around £5.5 million (McCrone, forthcoming 2010).

Focusing resources on early intervention can also result in lower overall care costs, as the severity of illness may be less in the long term and effective early management can reduce the likelihood of emergency admissions to hospital. For example, economic modelling of the impact of early intervention in the case of psychosis care, in which intensive support and help are given at the point of a person's first psychotic episode, suggests that annual costs may be as much as a 45 per cent lower than for patients following traditional care pathways (McCrone et al 2009).

Emotional, psychological and practical support

While the direct clinical care needs of patients are crucially important, long-term conditions and acute disease can place people under significant and sometimes very severe emotional and psychological strain. They can also lead to a huge range of practical difficulties in daily living. Living with a serious health condition such as cancer or COPD can have direct financial costs. The shortness of breath experienced by people with severe asthma or heart failure can make undertaking the mundane activities that most people take for granted a real challenge. The constant need to make compromises for severe asthma, and the impact of caring for someone with asthma, can also apply stress to relationships (Asthma UK 2010c).

Emotional, psychological and practical support can take many forms, including:

- befriending, buddying and expert patient programmes as well as self-support groups and peer support
- both face-to-face and helpline services that take time to listen to patients' concerns and feelings and support them as they deal with the impact of their condition
- help to access further support, if needed, from specialist health services, mental health services, social services, financial advice services and employment services
- support and respite for carers and families
- support for patients, as well as their carers and families, at the end of life
- programmes to build confidence and re-connect people with their local communities
- aids and adaptation services in people's homes to support them to live independently with physical and cognitive disabilities.

Financial advice for people with cancer

More than 90 per cent of cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer, such as a loss of income through inability to work, increased heating and general domestic bills, increased travel costs to and from hospital and a change in dietary or clothing requirements. A person with cancer makes on average 53 trips to hospital, costing £325 during the course of their treatment.

There is widespread under-claiming of financial benefits by those eligible for them. A report prepared in 2005 indicated that 77 per cent of people with a diagnosis of cancer were not given any financial information during their cancer journey (National Audit Office 2005). In 2009, the 224 local financial support and advice advisers funded by Macmillan Cancer Support helped 50,000 people and identified more than £80 million in extra benefits for them. Ensuring people with a cancer diagnosis receive the financial benefits to which they are entitled helps them focus on their treatment and recovery and not be burdened by worries over how the next bill will be paid.

(Macmillan Cancer Support 2010c)

Meeting the emotional, psychological and practical needs of people with health problems is important, and has added benefits:

- it increases people's capacity to adopt healthy behaviours and self-manage their condition (Diabetes UK 2009)
- it improves health outcomes such as stress and anxiety (Macmillan Cancer Support 2010c)
- it supports people in returning to work.

Individual placement support (IPS) services play an important role in supporting people with mental health problems to find employment. The employment rate for IPS programmes is 61 per cent compared with 23 per cent for traditional employment schemes. Mental health spending for those who found work as a result of accessing an IPS programme fell by 60 per cent over 12 months. During a 10-year period, the cost for a person with schizophrenia fell by 50 per cent,

representing a saving of £50,000 (Sainsbury Centre for Mental Health 2009).

Emotional and practical support can help people live independently and has been shown to reduce the burden on the health service by avoiding unnecessary hospital admissions (Pattenden *et al* 2008; Forbes and While 2008).

The impact of the A Little Help service – a partnership between Age Concern Northamptonshire and Northamptonshire PCT

'A Little Help' is a support service to patients who are at risk of re-admission to hospital (Orellana 2009).

B has multiple sclerosis and receives twice-daily visits from carers. He was struggling with the housework. He found evenings difficult to cope with since his wife left and was hospitalised following suicide attempts. His television was broken and he was unable to do crosswords as his hand shakes uncontrollably. The A Little Help service co-ordinator suggested learning how to use a computer to do crosswords. They drew up an action plan with goals and how to achieve them. The team obtained a second-hand television and B attended a local free IT course. He now has a computer, obtained at minimal cost, with a key guard fitted to enable him to press only the required key. B also attended a Living Well course and set up weekly domestic care to help with the housework. He was given assistance with financial issues following a benefits check.

Over Christmas and New Year, the team visited and called regularly to support him through his first Christmas without his wife. B no longer worries about housework and is happy to invite friends to visit. He watches TV, and plays games and does crosswords on the computer. He has made new social contacts through the courses. He is more content and has a new outlook on life, and has not needed to go to hospital for several months. B said: 'Brilliant people, A1 gold star. I would be lost without them.'

Conclusion and recommendations

These priorities describe what should happen as well as what can and needs to happen if the government's vision for health and social care is to be realised. The examples and evidence given here demonstrate how much can still be done to improve outcomes and patients' experiences of care, and how significant the opportunities are for improving cost-effectiveness at the same time. They also demonstrate how consistent these priorities and opportunities are across a great range of both physical and mental health conditions. The collective impact of successfully implementing these priorities is potentially enormous. Results could include:

- improved patient confidence and coping ability, including enhanced quality of life and reductions in pain, anxiety and depression
- improved health outcomes and life expectancy
- improved patient experience of care
- improved adherence to treatment
- improved health behaviours
- more streamlined care pathways that are less resource-intensive
- reduced use of both primary and secondary care, and particularly urgent care
- cash savings and longer-term efficiency and productivity gains
- wider social and economic benefits, such as re-employment.

Achieving these changes will require a number of things. It will require a policy and regulatory framework that is designed to support the delivery of patient-centred care. It will require commitment, innovation and leadership from clinicians, managers and commissioners across the system. And it will require partnership in many forms; between patients and clinicians, and between different professions, organisations and sectors in health, social care, public health, wider public services, and the voluntary and private sectors.

Four specific recommendations are particularly important:
- greater accountability and rewards for patient-centred care
- partnership between the public and voluntary sectors to spread best practice and innovation

- commissioning that is informed by patients' voices and insights
- focus on co-ordinated care in commissioning and workforce planning.

Greater accountability and reward for patient-centred care

The NHS, public health services and social care sectors need to be held properly accountable (and be rewarded) for providing services that meet the priorities set out in this document. To do this, accountability, standard-setting and payment systems such as the Outcomes Framework, the NICE quality standards and the tariff need to be structured around ensuring patient-centred care. This can begin to be achieved by incorporating performance measures of the quality and cost of whole pathways of care that cross organisational boundaries, measuring care transitions, shared decision-making, access to information and self-management support, and reflecting the experiences, satisfaction and needs of patients with multiple conditions. If we continue to measure and reward organisations and services only in isolation from each other, and on the basis of limited dimensions of performance, it will remain very difficult to achieve the improvements in quality and value for money that we need.

Partnership between the public and voluntary sectors to spread best practice and innovation

Disseminating innovation is challenging in all industries, including health and social care. However, sharing evidence, information and examples of innovative, effective services and embedding innovation in the working culture of the NHS and social care is essential if we are to achieve change at pace and deliver consistently high-quality, cost-effective services across the country. Working with organisations such as NICE and NHS Evidence, and with the NHS Institute for Innovation and Improvement and its successors, we will help to share information about innovative services widely, to encourage and support NHS and social care leaders to adopt the ways of working and service models that we know work.

Commissioning that is informed by patients' voices and insights

The decisions of commissioning boards, at the local, regional and national level, must be informed by patients' experiences of care. We have a wealth of intelligence on patients' needs and experiences and will offer our advice and support to commissioners on all aspects of service design. Furthermore, if we are to realise the government's commitment that there should be 'no decision about me, without me', we believe that all commissioning boards at national and regional level must have a significant, not tokenistic, number of members drawn from those representing patients, carers and voluntary organisations, and that all GP commissioning consortia must demonstrate significant patient involvement and input.

Focus on co-ordinated care in commissioning and workforce planning

All patients with long-term conditions must have a right to choose a care-coordinator to oversee their care and act as a single contact point for the patient. This is an essential part of a health and social care service geared to deal with the burden of chronic disease in a way that is truly patient-centred and realises the cost and quality benefits of self-management. We are committed to supporting the relevant statutory authorities and professional bodies to ensure that these community-based roles and skills are developed. We will also support commissioners to ensure that local needs assessments identify where failings in care co-ordination exist and provide advice to aid the commissioning of services that promote care co-ordination as part of programmes of care for patients.

References

Adams RJ, Smith BJ, Ruffin R (2000). 'Factors associated with hospital admissions and repeat emergency department visits for adults with asthma'. *Thorax*, vol 55, issue 7, pp 566–73.

Allcock D (2009). 'Using a community respiratory service to reduce children's hospital admissions'. *Nursing Times*, vol 105, no 4, pp 22–3.

Alzheimer's Society (2009). *Counting the Cost: Caring for people with dementia on hospital wards*. London: Alzheimer's Society. Available at: http://alzheimers.org.uk/site/scripts/download_info.php?fileID=787 (accessed on 4 September 2010).

Asthma UK (2010a, in print). *National Asthma Panel 2010*. London: Asthma UK.

Asthma UK (2010b). *Getting Sorted – Leeds: Developing a series of self-care workshops to help young people with asthma learn more about how to manage their condition*. London: Asthma UK.

Asthma UK (2010c). *Fighting for Breath: The hidden lives of people with severe asthma*. London: Asthma UK. Available at: www.asthma.org.uk/document.rm?id=1054 (accessed on 4 September 2010).

Asthma UK (2008). 'Workplace Charter'. Asthma UK website. Available at: www.asthma.org.uk/all_about_asthma/ asthma_at_work/workplace_charter.html (accessed on 4 September 2010).

Breakthrough Breast Cancer (2010). *Third Sector Contribution to QIPP: Breakthrough Breast Cancer's Service Pledge for Breast Cancer*. London: Breakthrough Breast Cancer.

British Lung Foundation (2009). 'British Lung Foundation Briefing: COPD'. British Lung Foundation website. Available at: www.lunguk.org/ONESTOPCMS/Core/CrawlerResourceServer.aspx?resource=AE3065C9-58D0-43B5-B6E9-7DE FA532E862&mode=link&guid=b373e579272b4adc96011df4d472e3eb (accessed on 4 September 2010).

Cancer Research UK (2010). 'Cancer Facts Key Stats: All cancers combined'. Cancer Research UK website. Available at: http://info.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@sta/documents/generalcontent/ crukmig_1000ast-2750.pdf (accessed on 4 September 2010).

Care Quality Commission (2009). 'Mental Health Acute Inpatient Service Users Survey 2009'. Care Quality Commission website. Available at: www.cqc.org.uk/_db/_documents/2009_survey_of_mental_health_acute_inpatient_services_ Full_national_results_tables.pdf (accessed on 4 September 2010).

Chandler T (2007). 'Reducing re-admission rates for asthma: impact of a nurse-led service.' *Paediatric Nursing*, vol 19, no 10, pp 19–21.

Coulter A (2007). *Evidence on the Effectiveness of Strategies to Improve Patients' Experience of Cancer Care*. Oxford/ London: Picker/Macmillan.

Cowie L, Morgan M, White P, Gulliford M (2009). 'Experience of continuity of care of patients with multiple long-term conditions in England'. *Journal of Health Services Research and Policy*, vol 14, no 2, pp 82–7.

Department of Health (2010). *Consultation on a Strategy for Services for Chronic Obstructive Pulmonary Disease (COPD) in England: Consultation impact assessment*. London: Department of Health. Available at: www.dh.gov. uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_113279.pdf (accessed on 4 September 2010).

Department of Health (2008a). *End of Life Care Strategy. Promoting high quality care for all adults at the end of life*. London: Department of Health. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/ documents/digitalasset/dh_086345.pdf (accessed on 4 September 2010).

Department of Health (2008b). *Your Health, Your Way Resources*. London: Department of Health. Available at: http:// webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Longtermconditions/yourhealth/index.htm (accessed on 4 September 2010).

Department of Health (2007). *What Matters to our Patients, Public and Staff*. London: Department of Health.

Department of Health (2003). *Choice, Responsiveness and Equity National Consultation: Public Survey*. London: Department of Health.

Diabetes UK (2010). 'Year of Care Programme'. Diabetes UK website. Available at: www.diabetes.org.uk/Professionals/Service-improvement/Year-of-Care/The-Year-of-Care-programme/ (accessed on 4 September 2010).

Diabetes UK (2009). *Improving Supported Self-management for People with Diabetes*. London: Diabetes UK. Available from www.diabetes.org.uk/Documents/Reports/Supported_self-management.pdf (accessed on 4 September 2010).

Edmonds P, Hart S, Gao W, Vivat B, Burman R, Silber E, Higginson IJ (2010). 'Palliative care for people severely affected by multiple sclerosis: evaluation of a novel palliative care service'. *Multiple Sclerosis*, doi:10.1177/1352458510364632.

Emery P, Breedveld FC, Dougados M, Kalden JR, Schiff MH and Smolen JS (2002). 'Early referral recommendation for newly diagnosed rheumatoid arthritis: evidence based development of a clinical guide'. *Annals of Rheumatic Diseases*, vol 61, pp 290–7.

Epilepsy Action (2010). *Best Care: The value of the epilepsy specialist nurses*. A report on a study by researchers at Liverpool John Moores University on behalf of Epilepsy Action. Liverpool and Leeds: Epilepsy Action and Liverpool John Moores University.

Expert Patients Programme Community Interest Company (2010). *Self-care Reduces Costs and Improves Health – The evidence*. London: Expert Patients Programme Community Interest Company. Available from: www.expertpatients.co.uk/sites/default/files/publications/EVIDENCE%20FOR%20THE%20HEALTH.pdf (accessed on 4 September 2010).

Forbes A, While A (2008). *Evaluation of the British Lung Foundation Nurse Programme*. London: British Lung Foundation and King's College London.

Fortin M, Soubhi H, Hudon C, Bayliss EA, Akker M (2007). 'Multimorbidity's many challenges'. *British Medical Journal*, vol 334, no 7602, pp 1016–17.

Gibson PG, Powell H, Wilson A, Abramson MJ, Haywood P, Bauman A, Hensley MJ, Walters EH, Roberts JJL (2009). *Self-management education and regular practitioner review for adults with asthma. The Cochrane Collaboration*. Available at: www.thecochranelibrary.com/SpringboardWebApp/userfiles/ccoch/file/CD001117.pdf (accessed on 3 August 2010).

Ham C (2010). 'The ten characteristics of the high-performing chronic care system'. *Health Economics, Policy and Law*, vol 5, pp 71–90.

Lethbridge T (2010). *Executive Summary: NHS Hull Love Your Lungs Campaign*. London: British Lung Foundation. Available at: www.lunguk.org/ONESTOPCMS/Core/CrawlerResourceServer.aspx?resource=59DCE9B0-0A02-435A-BC25-561A338ADCAE&mode=link&guid=04f4cad10b0e4a46b90e8640ed805413 (accessed on 4 September 2010).

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'. *Annals of Behavioural Medicine*, vol 30, no 2, pp 164–73.

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 and Wilkinson M (2009). 'British Society for Rheumatology and British Health Professionals in Rheumatology Guidelines for the Management of Rheumatoid Arthritis (after the first 2 years)'. British Society for Rheumatology website.

Macmillan Cancer Support (2010a). *Briefing: Demonstrating the Economic Value of Co-ordinated Cancer Services: An examination of resource utilisation in Manchester*. London: Macmillan Cancer Support.

Macmillan Cancer Support (2010b). *Briefing: The Need for and Impact of Local Cancer Information and Support Services for People Affected by Cancer*. London: Macmillan Cancer Support.

Macmillan Cancer Support (2010c). *Briefing: The Need for, and Impact of, Financial Support and Advice Services for People Affected by Cancer*. London: Macmillan Cancer Support.

Marinker M (1997). *Working Party From Compliance to Concordance: Achieving shared goals in medicine taking*. London: Royal Pharmaceutical Society of Great Britain.

McCrone P (2010, forthcoming). Evaluation of 'Time to Change'.

McCrone P, Knapp M, Dhanasiri S (2009). 'Economic impact of services for first-episode psychosis: a decision model approach'. *Early Intervention in Psychiatry*, vol 3, no 4, pp. 266–73.

McPherson CJ, Higginson IJ, Hearn J (2001). 'Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials'. *Journal of Public Health Medicine*, vol 23, no 3, pp 227–34.

Multiple Sclerosis International Federation (2002). *Principles to Promote the Quality of Life of People with Multiple Sclerosis*. London: Multiple Sclerosis International Federation. Available from: www.msif.org/docs/PrinciplestoPromoteQualityofLife1.pdf (accessed on 4 September 2010).

National Audit Office (2005). *Tackling Cancer: Improving the patient journey*. London: National Audit Office.

National Cancer Action Team (2010, in print). *Excellence in Cancer Care: The contribution of the clinical nurse specialist. A guide for providers and commissioners*. London: National Cancer Action Team.

National End of Life Care Intelligence Network (2010). 'Variations in Place of Death in England'. End of Life Care Intelligence Network website. Available at: www.endoflifecare-intelligence.org.uk/view.aspx?rid=71 (accessed on 4 September 2010).

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*, vol 43, no 7, pp 906–14.

NHS Diabetes (2010). 'What do People Think?'. NHS Diabetes Year of Care website. Available at: www.diabetes.nhs.uk/year_of_care/what_do_people_think (accessed on 4 September 2010).

NICE (2009). *CG 91: The Treatment and Management of Depression in Adults with Chronic Physical Health Problems (partial update of CG 23)*. London: National Collaborating Centre for Mental Health commissioned by the National Institute for Health and Clinical Excellence.

NICE-SCIE (2006). *Audit Criteria – Dementia. NICE clinical guideline no 42*. London: National Institute for Health and Clinical Excellence and Social Care Institute for Excellence. Available at: http://guidance.nice.org.uk/CG42/AuditSupport/doc/English (accessed on 4 September 2010).

Office for National Statistics (2009). 'Internet Access: Households and individuals 2009'. Office for National Statistics website. Available at: www.statistics.gov.uk/pdfdir/iahi0809.pdf (accessed on 4 September 2010).

O'Hara L, Heather Cadbury H, De Souza L, Ide L (2002).'Evaluation of the effectiveness of professionally guided self-care for people with multiple sclerosis living in the community: a randomized controlled trial.' *Clinical Rehabilitation*, vol 16, pp 119–28.

Orellana K (2009). *Prevention in Practice – Service models, methods and impact*. London: Age Concern and Help the Aged.

Parkinson's UK (2010). 'Parkinson's resources for GPs'. Parkinson's UK website. Available at: www.parkinsons.org.uk/for-professionals/resources/resources-for-gps.aspx#onlinetraining (accessed on 4 September 2010).

Partridge MR, Hill SR (2000). 'Enhancing care for people with asthma: the role of communication, education, training and self-management'. *European Respiratory Journal*, vol 16, no 2, pp 333–48.

Pattenden J, Coulton S, Spilsbury K, Chattoo S, Cross B, Wadsworth V, Lewin B (2008). *The Development and Impact of the British Heart Foundation and Big Lottery Fund Heart Failure Specialist Nurse Services in England: Final report*. London: British Heart Foundation and University of York. Available from: www.bhf.org.uk/publications/view-publication. aspx?ps=1000625 (accessed on 4 September 2010).

Picker Institute Europe (2009). 'The Key Findings Report for the 2008 Inpatient Survey'. NHS Surveys website. Available at: www.nhssurveys.org/Filestore/documents/Key_Findings_report_for_the_2008__Inpatient_Survey.pdf (accessed on 4 September 2010).

Powell R, Powell H, Baker L, Greco M (2009). 'Patient partnership in care: a new instrument for measuring patient-professional partnership in the treatment of long-term conditions.' *Journal of Management and Marketing in Healthcare*, vol 2, no 4, pp 325–42.

Richards MA (2009). 'The size of the prize for earlier diagnosis of cancer in England'. *British Journal of Cancer*, vol 101, pp S125–9.

Sainsbury Centre for Mental Health (2009). *Commissioning What Works: The economic and financial case for supported employment*. London: Sainsbury Centre for Mental Health.

Stewart MA (1995). 'Effective physician-patient communication and health outcomes'. *Canadian Medical Association Journal*, vol 152, no 9, pp 1423–33.

Stroke Association (2010). 'Life After Stroke Services Model'. Stroke Association website. Available at: www.stroke. org.uk/professionals/life_after_stroke_services/las_interactive.html (accessed on 4 September 2010).

The King's Fund (2009). 'Doctors are no better than patients at facing up to personal end-of-life care decisions'. Press release. London: The King's Fund. Available at: www.kingsfund.org.uk/press/press_releases/doctors_and_eol.html (accessed on 4 September 2010).

van Os TW, van den Brink RH, Tiemens BG, Jenner JA, van der MK, Ormel J (2005). 'Communicative skills of general practitioners augment the effectiveness of guideline-based depression treatment'. *Journal of Affective Disorders*, vol 84, pp 43–51.

Wanless D (2002). *Securing our Future Health: Taking a long term view*. London: HM Treasury.

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