

From vision to action

Making patient-centred care a reality



Contents

3	Foreword
4	Summary
7	Co-ordinated care
9	Patients engaged in decisions about their care
13	Supported self-management
15	Prevention, early diagnosis and intervention
17	Emotional, psychological and practical support
19	Overarching priorities
20	References

Foreword

When our ten leading health and social care charities published our joint view on how high-quality, patient-centred, cost-effective care could be delivered, we were surprised how aligned our thinking was (Richmond Group of Charities and The King's Fund 2010). We agreed five themes on which the post-reform NHS should be based and within which productivity gains are possible:

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

Co-ordinated care is as important for patients following a stroke as it is for people with diabetes. An older person, a patient with cancer or someone with a mental illness will all want to be involved in decisions about their care. Self-management works for patients with heart conditions and for patients with asthma. Being encouraged and supported to live healthy lives is crucial for everyone, and this requires a flexible and responsive system that can diagnose and intervene early. Emotional, psychological and practical support is crucial to better health outcomes for patients with chronic lung disease, as is improved physical health care for patients with severe mental illness. And of course, as we age, many of us will have not only one condition, but several.

The importance of delivering on these themes cannot be overstated, and arguably has increased in recent months. The increasing prevalence of long-term chronic illness will lead to unsustainable costs for the taxpayer if we do not redesign how we deliver health and social care.

This financial challenge need not be a cause for despair. There is mounting evidence that efforts to prevent illness, avert a crisis, avoid a hospital admission and support a patient to manage their own condition will consume fewer overall resources while at the same time being better for patients. This in turn will lead to more care being provided closer to the home. Ultimately this should require fewer inpatient beds, fewer wards, and even fewer hospitals, with the savings available to help meet the challenges posed by demographic change, addressing previously unmet needs and responding to the possibility of exciting new treatments.

Our shared vision has yet to be delivered. The Health Select Committee recently warned the government that if standards of quality and access are to be maintained, system redesign is needed, rather than salami-slicing existing services or incremental improvement (House of Commons Health Committee 2012). We agree.

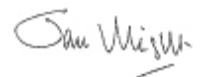
As leading charities that both advocate for and support the care of people with health and social care needs, we renew our commitment to working with colleagues locally and nationally, in policy and in service delivery, to build a sustainable model for the NHS and its partners. All of us wish to ensure the best care for those we represent. The longer it takes to put in place the building blocks we describe, the greater the risk to standards of quality, timeliness and access. We have a duty to support the changes that address the immediate issues, make the future affordable and put the patient truly at the heart of the system. We hope that there will be a growing consensus as to what high-quality, patient-centred, cost-effective care is, with the five themes at its heart.



Chris Askew
Chief Executive
Breakthrough Breast
Cancer



Peter Hollins
Chief Executive
British Heart Foundation



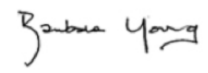
Tom Wright
Chief Executive
Age UK



Jon Barrick
Chief Executive
The Stroke Association



Paul Jenkins
Chief Executive
Rethink Mental Illness



Barbara Young
Chief Executive
Diabetes UK




Neil Churchill
Chief Executive
Asthma UK



Dame Helena Shovelton
Chief Executive
British Lung Foundation



Ciarán Devane
Chief Executive
Macmillan Cancer Support



Arlene Wilkie
Chief Executive
The Neurological Alliance

Summary

Our first report identified five key themes that the health and social care system must embrace to be sustainable and to ensure quality. This second report is intended to offer a clear strategic direction to achieve the transformational change that is so urgently needed. We have worked with The King’s Fund to translate our themes into outcomes for patients and set out the most important priorities for action to achieve these outcomes. The structure for this report is shown in Figure 1.

Figure 1: Report structure



Under each of our five themes, we have described the outcomes that we most want to achieve for patients. In order to achieve these outcomes, we have then selected the service improvements that, if met, will have a major impact on the quality and cost-effectiveness of care. These are by no means the only service changes that are needed to achieve the outcomes we would like to see, but we believe they are the most urgent and important. These are the things we can, and must, get on and do. The report then proposes some of the actions that different organisations, including

commissioners, providers and national bodies such as the Department of Health and the Royal Colleges, should take to deliver these service improvements. The outcomes and related service improvement priorities are summarised in Table 1 opposite.

Over and above these specific changes, our report ends with five important overarching priorities for action for the government, the nascent NHS Commissioning Board, health and wellbeing boards, clinical commissioning groups and the broad range of care providers working with the NHS and local authorities. These are summarised in Table 2 opposite.

Table 1: Outcomes and service improvements

Themes	Co-ordinated care	Patients engaged in decisions about their care	Supported self-management	Prevention, early diagnosis and intervention	Emotional, psychological and practical support
Outcomes	People feel that the care they receive is seamless because it is organised around them and their needs.	All patients and carers can take an active role in decisions about their care and treatment because they are given the right opportunities, information and support. Services reflect the needs of patients because patients and carers are meaningfully involved in service commissioning, planning, design and improvement.	People with long-term conditions can manage their condition appropriately because they have the right opportunities, resources and support.	Everyone can access services that support them to improve their health. People are supported to access services early to reduce or prevent episodes of crisis.	Everyone with long-term care needs, whether mental or physical, can access appropriate emotional, psychological and practical support to improve their health and well-being.
Priority service improvements	Everyone with long-term care needs that require a health or social care response should be guaranteed a written care plan encompassing health, social and preventive care, and the right to access a named care co-ordinator of their choice if they wish to. Patients need to be involved in developing the care plan, understand it, and have confidence about who to approach when they need support.	Training and monitoring is needed to help health care professionals embed shared decision-making in their daily clinical practice. Clear accountability is needed to ensure effective and meaningful patient involvement in both the commissioning and provision of services.	People with long-term conditions should be offered and have access to a range of flexible, responsive self-management support including tailored information and advice and structured programmes to help them manage their condition successfully.	Commissioners and providers should use tools such as risk registers to proactively find people at high risk of developing chronic and life-threatening conditions or complications from existing conditions, and offer them targeted screening and other interventions to encourage behaviour change. Patients who have spent time in hospital need to be followed up and supported in the community to ensure rehabilitation and re-ablement. Patients need to be supported to have greater control over accessing services at points of crisis.	Emotional, psychological and practical support should be routinely assessed during the care planning process to support facilitated access to services where this is needed. Health and social care commissioners must be accountable for ensuring that individuals with long-term care needs have the opportunity to access appropriate emotional, psychological and practical support.

Table 2: Overarching priorities

Measurement, monitoring and public accountability	Routine information is sorely lacking to monitor progress against both the outcomes we have identified and how people access and experience the services we have prioritised. Measuring, monitoring and the publication of performance information is crucial because it drives improvement and supports individuals to make choices.
Integrated care	The divide between different parts of the health system and between health and social care make it difficult for truly patient-centred services to develop. The government needs to focus on removing the policy and organisational barriers between health and social care to enable more co-ordinated, integrated and patient-centred services and ensure that social care funding is put on a long-term, sustainable footing.
Active commissioning and service redesign	As new commissioning structures develop, it is imperative that the potential for strong and active commissioning to drive service redesign at a local level is realised. Health and social care commissioners should have a collective duty to ensure access to the range of services that we identify in this report, and sufficient resource for innovation must be available. National strategies for major conditions must exist, together with strategies that support care to those with multiple care needs.
24/7 care	For many individuals, particularly those with complex health and social care needs that require ongoing support, the inability to access services 24/7 can lead to poor care experiences and unnecessary visits to hospital. Urgent care services, together with hospital and community services, need to prioritise improvements in consistency of access and quality at evenings, weekends and public holidays.
The mandate	We propose that the mandate charges the NHS Commissioning Board to implement the key themes we have highlighted with specific actions identified against the service improvement priorities. Equivalent priorities are required in social care and public health.

Co-ordinated care

The outcome we want to see

People feel that the care they receive is seamless because it is organised around them and their needs

Why this is important

People with long-term conditions and multiple, complex needs too often report that their interactions with the health and social care system feel confusing and poorly co-ordinated. While there are pockets of excellent practice in some parts of the country and for some patients, many people living with long-term chronic illnesses experience poorly co-ordinated care (Goodwin *et al* 2012). Typical problems include dealing with a range of different care professionals who have not shared information about them, appointments and visits that are poorly scheduled, patients feeling that they lack information and do not know who to contact for advice and support, as well as unnecessary repeat tests and failure to organise adequate community-based support after patients leave hospital (National Voices 2011).

Care planning and care co-ordinators are a crucial part of delivering better co-ordinated care. They are part of the national agenda on long-term conditions, but nevertheless recent surveys have found that fewer than half of people with a long-term condition who spent time in hospital have a care plan, and only 10 per cent of people with asthma, for example, have a personal asthma action plan (Department of Health/Ipsos MORI 2011; Asthma UK 2010).

Reviews of the research evidence conclude that significant benefits can arise from better integration of services where these are targeted at those client groups for whom care is currently poorly co-ordinated (Singh and Ham 2005; Curry and Ham 2010; Goodwin and Smith 2011; Rosen *et al* 2011). For example, strategies to co-ordinate care for people with multiple chronic illnesses in three local health boards in Wales helped reduce emergency admissions by as much as 27 per cent between 2007 and 2009 and achieved a cost reduction of more than £2.2 million (NHS Wales 2010).



Service improvement priority to achieve this outcome

Everyone with long-term care needs that require a health or social care response should be guaranteed a written care plan encompassing health, social and preventative care, and the right to access a named care co-ordinator of their choice if they wish to. Patients need to be involved in developing the care plan, understand it, and have confidence about who to approach when they need support.

Care planning involves addressing an individual's full range of needs. It takes into account their physical and mental health, personal, financial, social, economic, educational, ethnic and cultural background and circumstances. It also recognises that there are other issues in addition to medical needs that can impact on a person's total health and well-being (Department of Health 2009). The care plan document that captures these needs is not an end in itself. It is part of a wider care planning approach that should involve an integrated approach to the health, social care, practical

and emotional needs of the person. This should involve the joint setting of individualised targets and regular reviews with a named person acting as the care co-ordinator, who is responsible for ensuring that the care plan is followed, and who facilitates communication between different professionals and organisations. This co-ordinating function could be undertaken by any health care professional, or those outside the health sphere such as a social worker, voluntary sector care co-ordinator or paid advocate.

It is important to prioritise the formal care plan and accompanying co-ordinator role for patients with more complex health and social care needs. There is evidence that interventions targeted at a defined population, such as the Guided Care model for chronic care, are particularly cost-effective (Ross *et al* 2011). For those requiring less support, professionals in regular contact with the patient, such as GPs or specialist nurses, should strive to deliver a whole-person approach that assesses health and wider needs, and provide signposting to additional services or support where they are needed.

Actions to achieve this service improvement

Meaningful implementation of care planning and care co-ordination will require actions at a variety of levels. For example, the Department of Health and the NHS Commissioning Board should emphasise care planning in the long-term conditions outcomes strategy and use the NHS information strategy to support the sharing of information between clinical teams and with patients. To monitor progress, the Board should work with other relevant organisations to develop measures of access to care plans and care co-ordinators and ensure that appropriate indicators are incorporated into commissioning guidance and the NHS Outcomes Framework and Commissioning Outcomes Framework.

Local commissioners should use contracting and performance management more effectively to ensure that providers conduct joint care planning and assessment in collaboration with patients that is integrated across health and social care. These activities should be conducted within multi-professional teams with defined care co-ordinator roles sharing information

when appropriate. Commissioners should also work with their local health and wellbeing boards and HealthWatch to collect and review feedback on patient experience regularly and use this to performance manage providers.

Providers, particularly GPs, should offer all patients with long-term health and social care needs a care plan and ensure they have a named care co-ordinator if they wish to, particularly focusing on patients with complex needs. In primary care, this could be incentivised and measured as part of the Quality and Outcomes Framework.

‘Sometimes just having someone familiar on the end of the phone who you can ask a simple question to and get a straightforward answer is all you need.’

Patient with a heart condition

Patients engaged in decisions about their care

The outcomes we want to see

All patients and carers can take an active role in decisions about their care and treatment because they are given the right opportunities, information and support.

Services reflect the needs of patients because patients and carers are meaningfully involved in service commissioning, planning, design and improvement.

Why this is important

Involving patients and carers in decisions about their care and treatment is an integral part of providing truly patient-centred care (NHS Future Forum 2012). We know from survey evidence that many patients would like to be more involved in decisions about their own health care than they currently are. In 2010, only 52 per cent of inpatients felt they were as involved in decisions about their care as they wanted, and this proportion has not changed since 2005 (Care Quality Commission 2011). The King's Fund's inquiry into the quality of care in general practice presented evidence that almost 30 per cent of patients, on average, felt poorly engaged in making decisions about their own health in 2009/10, increasing to nearly 50 per cent in the worst-performing practices (The King's Fund 2011).

The challenge is to embed shared decision-making into mainstream clinical practice across the NHS. This means influencing the design of clinical and care processes so that opportunities are made to involve and share decisions with patients. It also means influencing health care professionals' attitudes, skills and behaviours (Coulter and Collins 2011).

While the financial benefits of shared decision-making with patients have not been extensively researched, evaluations of various forms of patient engagement



show that it can lead to improved knowledge and understanding, more accurate risk perceptions, greater comfort with decisions, fewer patients choosing major surgery, better treatment adherence, improved confidence and coping skills, improved health behaviours and more appropriate service use (Murray *et al* 2005; O'Connor *et al* 2009; Picker Institute Europe 2010). For example, health coaching has been shown to increase patient satisfaction and improve confidence, while the use of decision aids can improve adherence to treatment, which is particularly relevant for people with long-term or complex health needs (Picker Institute Europe 2010).

Alongside patient engagement in decisions about their own care, patients and carers can and should also be involved in wider decisions at all levels of the NHS. Services can better reflect the needs of patients when they have been meaningfully involved in commissioning and service design. While there are scattered examples of good practice at all levels of the system, too often patient involvement is still either absent or tokenistic.

Patient involvement in the development or redesign of services has also been shown to benefit those involved, through providing increased social contact, enhanced knowledge and skills and expanded opportunities for learning and self-esteem (Coulter 2007).

Service improvement priorities to achieve these outcomes

Training and monitoring is needed to help health care professionals embed shared decision-making in their daily clinical practice.

Shared decision-making techniques include communicating information effectively, treating people with dignity and respect as individuals, helping patients to weigh up the benefits and risks of treatment options, encouraging the use of patient decision aids and providing access to specialist health coaching or decision support. At the end of a consultation, the decision-making process should be documented in patient notes to ensure that all parties are clear about the agreed course of action.

Health care professionals should undertake regular training and education in the tools and techniques needed to help patients manage their own health and make informed decisions, ensuring that these skills are used to improve the quality and effectiveness of patient interactions. Often, trainees receive some limited training in this area only to find it not modelled by senior professionals in daily practice. Various studies have observed that, during consultations, clinicians may fail to explore the values and preferences of the patient, encourage patients to discuss their concerns or assess their understanding of information provided during the discussion (Corke *et al* 2005; Stevenson *et al* 2004).

Assessment of the quality of shared decision-making conversations should form part of health care professionals' regular appraisal. As part of this, patients' views should be sought to determine if this is reflected in their experiences.

Clear accountability is needed to ensure effective and meaningful patient involvement in both the commissioning and provision of services.

Patients and carers should be involved in identifying areas for improvement and designing or shaping services that meet their needs. For patient involvement to be effective, patient representatives need adequate support and training to be able to make a meaningful contribution. Patient and public involvement should be

representative across diverse and vulnerable groups. Providers and commissioners need to ensure that patient involvement is embedded at all levels and should be held to account publicly for the quality and impact of this involvement. For providers, this could be done through the development of effective systematic measures of the quality of involvement and through the inclusion of providers in formal reporting mechanisms such as quality accounts. For commissioners, the quality and impact of patient involvement activity must form part of annual performance assessment. Patient and public feedback should also form part of these assessments.

Actions to achieve these service improvements

Achieving the service improvements outlined above will require a concerted effort at all levels of the system, and this document is able to highlight only a few. Royal Colleges, professional societies and regulators such as the General Medical Council and the Nursing and Midwifery Council must ensure that shared decision-making and communication skills are incorporated into the curricula of undergraduate, postgraduate and ongoing professional development and form part of the medical revalidation process. The Department of Health should also incorporate relevant indicators into the proposed NHS Education and Training Outcomes Framework. The Quality, Innovation, Productivity and Prevention (QIPP) Right Care workstream should prioritise changing professional behaviours alongside work on decision aids and tools.

The NHS Commissioning Board should continue to act as an exemplar by embedding patient representation throughout the board, promoting patient and public involvement across the commissioning process and collaborating with the National Institute for Health and Clinical Excellence (NICE) to develop measures of the quality of shared decision-making against which performance can be assessed. The effective user involvement domain in both the authorisation of clinical commissioning groups and their ongoing performance assessment must be given a significant weighting and be expressed as a pivotal criterion for authorisation if behaviours in NHS commissioning are to be changed.

Commissioners must give due attention to the patient involvement duties detailed by the NHS Commissioning Board, and actively seek to involve service users' insights and experiences in their own activities. All commissioning decisions should clearly state how insight from service users has been influential. They should work with local HealthWatch and health and wellbeing boards to ensure that they have robust and effective involvement mechanisms. HealthWatch should champion patient and public involvement and its measurement and engage with the wider public to ensure it represents the local community effectively. Commissioners should include assessment of patient involvement and shared decision-making in their performance management of providers.

Health and social care providers should undertake service improvement work to review and co-design care pathways together with patients and service users, and evaluate their impact on user experience, with commissioners holding them to account if they fail to do so. Providers should critically assess their organisational culture, determine where experience and involvement of people in their own care is low and take a systematic approach to improvement of the culture and behaviours in those areas.

'Working with Breakthrough has provided an opportunity to collaborate with patients and staff to re-evaluate our breast care service. By listening to what our patients have to say, we can continue to deliver high-quality care.'

Breast cancer clinical nurse specialist

Supported self-management

The outcome we want to see

People with long-term conditions can manage their condition appropriately because they have the right opportunities, resources and support.

Why this is important

Self-management involves assisting individuals to make choices and decisions about managing their condition in order to improve their overall health, well-being and quality of life. The majority of people with a long-term condition (around 80–90 per cent), as well as their carers, can be supported to actively manage their own health (Da Silva 2011). Despite the presence of a number of well-established self-management programmes in the United Kingdom, the provision of self-management support is patchy, with little flexibility or choice. For example, only 43 per cent of people in England who had a heart attack, bypass surgery, or an angioplasty took part in cardiac rehabilitation, despite evidence that this can reduce mortality and improve quality of care. Less than 50 per cent of people with diabetes were given the opportunity to discuss their own goals for self-management (British Heart Foundation 2010; Healthcare Commission 2007).

The type and level of support people require will vary, but the main elements of successful supported self-management involve a mix of personalised information, such as information prescriptions, action plans, structured education and training, and the ability to access specialist advice from trained health care professionals and volunteers or through online or face-to-face peer support when needed (Wagner *et al* 1996). Proactive, structured and comprehensive patient education with an emphasis on self-management has been shown to be more effective than more limited interventions or conventional treatment (Côté *et al* 2001). Self-management programmes should include psychological and social care components to support participants and reduce their likelihood of developing mental health problems or experiencing difficulties in daily living.



Providing support and education to facilitate effective self-management where desired can have a number of benefits for the individual and the system. Individuals undergoing structured self-management programmes report improved health literacy and health behaviours, increased confidence in their ability to navigate the health system, better physical functioning and a greater understanding of the appropriate services available (Challis *et al* 2010). Attending peer-led support groups can also improve mental health and well-being, reducing the risk of suffering depression or anxiety. A recent review by the Health Foundation similarly concluded that self-management can improve people's motivation, the extent to which they eat well and exercise, their symptoms and clinical outcomes, and how they use health services (Da Silva 2011). It can also lead to reduced unplanned admissions to hospital, for example among patients with chronic obstructive pulmonary disease and asthma (Purdy 2010). The King's Fund placed active support for self-management as the first of its top ten priorities for health and social care commissioners in achieving higher-quality care at lower cost (Imison *et al* 2011).

Service improvement priority to achieve this outcome

People with long-term conditions should be offered and have access to a range of flexible, responsive self-management support including tailored information and advice and structured programmes to help them manage their condition successfully.

Increasing the breadth and availability of, and access to, services designed to support successful self-management should be a priority for commissioners and providers.

All patients and their carers with a long-term condition, regardless of its complexity, should be offered the opportunity and relevant information to help them develop a personalised self-management plan with a trained professional or peer, which is integrated into the formal care planning process. This would detail their needs, outline goals and actions and provide updates on their progress. The self-management plan would act as a gateway into a range of local services within the community and across primary, secondary and social care such as personalised advice, regular structured reviews, general and condition-specific self-management courses and peer-led support, as well as providing signposting to assistance with wider emotional, psychological and practical needs with approaches such as structured social prescribing.

It is essential that the information collated from self-management plans is used to inform commissioning decisions. Commissioners can use this information to identify gaps in services or difficulties with access and adjust their commissioning strategies accordingly or develop arrangements across localities.

Actions to achieve this service improvement

Health care professionals often do not receive any formal training in enabling patients and carers to manage their own health. Organisations such as the Royal Colleges and professional regulators must ensure that supported self-management skills are included in the curricula for undergraduate, postgraduate and ongoing professional

development and revalidation for doctors. These skills should also be included in the NHS Education and Training Outcomes Framework.

Nationally, the NHS Commissioning Board needs to stipulate that access to self-management support is prioritised by commissioners and incorporate measures into the NHS Outcomes Framework and Commissioning Outcome Framework. NICE could work to develop and promote quality standards on self-management and ensure that all relevant clinical guidelines include standards on supporting self-management. Delivery of effective self-management interventions could also be incorporated into contractual tools such as the Quality and Outcomes Framework.

At a local level, commissioners should work with providers and the voluntary sector to ensure sufficient self-management services are commissioned for patients, carers and health care professionals and consider self-management when commissioning integrated pathways of care across the entire system. Commissioners should monitor and report patients' access to and experience of self-management services. Providers and GP practices should ensure they are trained to enable patients to self-manage if they wish to, and monitor effectiveness and patient satisfaction.

'Going to rehabilitation was the absolute best thing ever – it feeds you back the confidence you lack.'

Patient with a heart condition

Prevention, early diagnosis and intervention

The outcomes we want to see

Everyone can access services that support them to improve their health.

People are supported to access services early to reduce or prevent episodes of crisis.

Why this is important

Improving our ability to prevent illness, and diagnose and intervene early before conditions become serious, has huge potential to improve outcomes while reducing long-term costs for the health service (Health England 2009). A significant proportion of all acute hospital activity is related to treating patients with conditions that could have been prevented through better management of their needs in primary and community-based settings (sometimes referred to as 'ambulatory care-sensitive conditions'). For example, in 2005/6, the total costs to the NHS were estimated at £1.3 billion for a core set of 19 ambulatory care-sensitive conditions (Imison *et al* 2011).

In terms of primary prevention, informing and supporting people to improve their general health by adopting healthy behaviours around physical exercise, diet and smoking reduces their chances of suffering from diseases such as diabetes, dementia, cancer, heart disease and stroke. Health checks and screening programmes can identify people at high risk or in the early stages of developing these conditions. Secondary prevention, following an acute phase of illness, is equally important in conditions like asthma, as is early diagnosis for many conditions, which can reduce the severity of illness, minimise the chances of suffering adverse complications, reduce the need for late stage complex interventions and improve outcomes. Spreading best practice in primary and secondary care prevention has been estimated to produce cost savings of up to £250 million in England through reductions in emergency admissions (NHS Institute for Innovation and Improvement 2011).

Preventative and early intervention services remain important throughout life for people with many types of



long-term condition, particularly those that can fluctuate, degenerate, recur or reach points of crisis. People can experience periods of crisis in their condition for a huge range of physical, mental and social reasons. Too many people with long-term conditions lack control over their access to appropriate services at these times and are unable to request the support services early enough that could prevent unnecessary emergency admissions. This is particularly a problem for people distanced from the health and social care system, such as isolated older people.

Service improvement priorities to achieve these outcomes

Commissioners and providers should use tools such as risk registers to proactively find people at high risk of developing chronic and life-threatening conditions or complications from existing conditions, and offer them targeted screening and other interventions to encourage behaviour change.

Primary and secondary prevention services are most effective when they are targeted towards high-risk

populations and commissioners need to ensure that services are available to meet their population needs. GPs and primary care providers should endeavour to identify individuals at high risk of developing illness or suffering relapse and readmission through the use of risk identification, stratification and other management tools. Health checks and national or targeted local screening programmes based in the community should be used for conditions such as hypertension, high cholesterol and diabetes. People at high risk should be supported with good-quality information to understand how behaviour change or accessing services could help them to improve their health.

Patients who have spent time in hospital need to be followed up and supported in the community to ensure rehabilitation and re-ablement.

If patients are at high risk of recurrence or deterioration, GPs and community services providers need to actively follow up these patients to ensure they have the care, support and advice they need to prevent readmission, in collaboration with social care services. It is vital that acute sector, primary and community-based services communicate with each other so that patients do not fall through the gaps once discharged.

Patients need to be supported to have greater control over accessing services at points of crisis.

Points of crisis or times where patients urgently need additional help and support can occur for patients with many different types of conditions. For example, in mental health conditions, early warning signs can signal the onset of crisis. Support when these early warning signs are identified is therefore crucial to help prevent full-blown crisis. Many long-term physical conditions, such as neurological conditions, heart failure and chronic obstructive pulmonary disease, can fluctuate and develop over time with periods of acute onset or the exacerbation of symptoms. Patients with these conditions need to be able to have prompt 24/7 access to effective community-based services when they notice their condition deteriorating. Commissioners should work with care providers to ensure that patients know where to seek help and can access the right services when needed.

Actions to achieve these service improvements

Realising these service improvements will involve co-ordination across a range of organisations and structures. Public Health England, the Department of Health and the NHS Commissioning Board should work together to develop the health and quality premiums so that both NHS and public health services are rewarded for work to improve the health of their populations. When commissioning primary care, they need to ensure that providers are managed as actively on their prevention and early intervention responsibilities as they are on their care for people with pre-existing conditions.

Commissioners will need to work closely and effectively with health and wellbeing boards to focus on prevention, early diagnosis and early intervention. Joint strategic needs assessments should cover these services, and commissioners should then focus their efforts on providing appropriate primary and secondary prevention and early intervention services to high-risk populations. To monitor progress, data on the services provided, how they are accessed, and how users are experiencing them need to be collected and used. Performance management, contract management and financial incentives can all be used to ensure that providers focus on these services.

To improve primary and secondary prevention, providers, particularly primary care providers, should use case finding and risk assessment approaches to conduct risk stratification, provide both proactive and opportunistic health advice and health checks, conduct regular reviews and targeted screening and make appropriate referrals to specialist support services. Patients at risk of periods of crisis or escalation in their need for support should be given information and advice to understand how to access care and support during times of crisis, at any time of day, at weekends and during public holidays.

‘When I was first diagnosed with asthma, nobody told me how to manage it and it got completely out of control... It made me angry because that would never have happened if I’d been fully informed about it in the first place.’

Claire Kavanagh, 35, a patient with asthma

Emotional, psychological and practical support

The outcome we want to see

Everyone with long-term care needs, whether mental or physical, can access appropriate emotional, psychological and practical support to improve their health and well-being.

Why this is important

Long-term conditions and acute diseases place people under significant and sometimes severe emotional and psychological strain. They can also lead to a huge range of practical difficulties in daily living, particularly during the recovery period after a hospitalisation when the need for rehabilitation and re-ablement is greatest. Mental health problems are common among people with long-term care needs. About 30 per cent of people attending their general practice have a mental health component related to their illness and people living with cardiovascular disease are up to three times more likely to suffer from depression (Jenkins *et al* 2002; Naylor *et al* 2012). By interacting with and exacerbating physical illness, mental health problems raise total health care costs by at least 45 per cent for each individual. For certain conditions, this can be much higher. For example, the total cost to the NHS for each person with diabetes and co-morbid depression is 4.5 times greater than for a person with diabetes alone (Egede *et al* 2002).

The practical aspects of daily living with a long-term condition can be as difficult as the medical aspects. Activities such as shopping, travel to hospital appointments and eating well can be difficult for people with a long-term condition. Practical solutions, such as financial advice to help people get their entitlements that will help pay for support where necessary or volunteer transport schemes, can all make a significant difference to the experience of people with long-term conditions. Support for carers is also vital and needs equal priority to that for the patient themselves.

Evidence supports giving users and carers a wide range of practical support to help them stay safe and well. For example, an evaluation of extra care housing (where



low-level support is provided to enable independent living among older residents) recently showed how this can have a positive impact on reducing levels of dependence and improving physical functioning, while being a more cost-effective approach than standard residential care (Netten *et al* 2011). A national evaluation of the Partnership for Older People's Projects similarly reported how a range of activities seeking to provide low-level practical support to older people in local communities can considerably improve quality of life (Windle *et al* 2009).

Providing emotional, psychological and practical support through formal collaborative care arrangements agreed between primary care and mental health services has been shown to have a range of benefits in terms of a person's ability to adopt healthy behaviours and to feel more able to self-manage their condition. As a result, such support can help improve health outcomes, such as levels of stress and anxiety, help people back to work with support, and potentially lower the risk of needing care and treatment in hospitals or nursing homes.

There could also be a significant impact on costs, with evidence suggesting that addressing underlying mental health or psychological needs can reduce costs related to physical long-term conditions (Naylor and Bell 2010). For example, provision of psychological support for angina patients in Liverpool achieved a reduction in hospital costs of £1,337 per patient per year (Moore *et*

al/ 2007). Recent research by The King's Fund (Naylor *et al* 2012) presents a compelling financial and quality case for service providers to make mental health assessments of patients with long-term conditions mainstream. They concluded that improved support for the emotional, behavioural and mental health aspects of physical illness could play an important role in helping the NHS meet its financial challenge.

Service improvement priorities to achieve this outcome

Emotional, psychological and practical support should be routinely assessed during the care planning process to support facilitated access to services where this is needed.

Currently, there is very little awareness among both service users and professionals that there might be services available locally that could help address emotional, psychological and practical needs. Such needs must be embedded during the care planning process with an associated ability to make and co-ordinate a 'social referral' that supports individuals to access such services. All individuals in need of emotional, psychological and practical support should be provided with tailored information on the services that are available locally.

Health and social care commissioners must be accountable for ensuring that individuals with long-term care needs have the opportunity to access appropriate emotional, psychological and practical support.

Despite the potential benefits of providing emotional, psychological and practical support, for many people there is either little or no opportunity to access such services. Commissioners should work with national and local organisations to ensure these are available locally and prioritise these services as part of their strategies to improve quality and productivity in care. This should include promoting access to psychological therapies, anxiety management, peer support, and befriending schemes; all of which are relatively inexpensive yet can have a long-term and positive impact on people's lives. It should also include access to practical support such as financial

advice, back-to-work advice, local transportation and carer support schemes as well as access to rehabilitation and re-ablement care packages to support facilitated discharge from hospital. These services help people to stay as independent and as safe as possible in their own home and/or in getting back to work. Practical advice should be available to ensure that individuals and their carers are aware that some of these services might incur a cost.

Actions to achieve these service improvements

The Department of Health and NHS Commissioning Board should support these service improvements by providing a right for individuals to access emotional, psychological and practical support where this will improve their health and well-being, for example, through the Commissioning Outcomes Framework and in the mandate given to the NHS Commissioning Board. Measuring and monitoring the availability of local services, and individuals' experience of being able to access them, should be undertaken routinely.

NICE could enable this by examining the evidence base and economic benefits of investing in emotional, psychological and practical support for people with a range of long-term care needs. This would include, where appropriate, the delivery of emotional, psychological and practical support in guidelines and quality standards.

Health and social care commissioners must be given accountability for ensuring that individuals with long-term care needs are provided with tailored information, such as information prescriptions, on the services that are locally available to them at any time of the day or night, and ensuring the opportunity for individuals to access appropriate non-acute emotional, psychological and practical support for both their high- and their low-level needs.

'Due to the strain of coping with the illness, my parents were in no position to start filling out forms. It was a huge relief to them when... the benefits adviser came to see them.'

Family member of a Benefits Advice Service user

Overarching priorities

This report has presented a selection of specific actions that we believe are most important to achieve the outcomes we have set out for high-quality patient-centred care. However, over and above these actions, we believe there are five important overarching priorities for the government and NHS Commissioning Board to focus on if they are really to deliver the improvements that patients want and need.

Measurement, monitoring and public accountability

The government's commitment to holding the health system to account for improving outcomes is welcome. However, while at one level the NHS is awash with data about clinical activity and to some extent about clinical outcomes and patient experience, information about whether people are accessing and how they are experiencing the sorts of services we prioritise in this report is much more limited. As this report argues, these things matter – indeed they are absolutely crucial to the development of a health and social care service that is fit and sustainable for the 21st century – and so they must be measured.

Measurement and monitoring, and the publication of performance against these measures, is vital because it drives improvement. Such information helps users, patients, carers, clinicians and service managers to collectively understand where and by how much services need to improve. Moreover, it supports commissioners to drive improvements where these are needed, and helps hold the NHS and local authorities to account for the care they provide to local populations. It is also important to provide patients and carers with the information they need to make decisions about their care and treatment options.

Measurement of individual services or isolated snapshots of how patients experience a particular element of their care is not enough to provide commissioners, providers and patients with the full picture they need of the quality of services. It is therefore crucial that efforts are made to connect and share data between providers, and between health and local authority services. Measures of patient experience across multiple care settings are also needed.

As the NHS Outcomes Framework and Commissioning Outcomes Framework develop, as commissioners locally develop their performance management of providers, and as providers themselves look to develop their services, clear measures that can be used to monitor progress against the outcomes and service improvements we have identified are urgently needed. Many, but not all, of these measures should be based on feedback from patients themselves.

Some examples of the sorts of measures needed include:

- the percentage of patients with long-term conditions reporting that their health professional worked with them to produce a written document recording decisions about managing their health condition
- the percentage of health care professionals undergoing regular reviews of their skills in supporting shared decision-making
- the percentage of patients with long-term conditions successfully completing a self-management programme
- the percentage of patients who feel that services are available and accessible to them at points of crisis and know how to access them
- the percentage of patients who feel that their emotional, psychological and practical needs were fully discussed during the care planning process
- the percentage of patients or carers reporting that they were as involved as they wanted to be in decisions about their care and treatment.

Integrated care

One of the most important themes in this report is the need for services to be more joined-up and to treat people as whole people, considering their health, mental health and social needs. But this is a major challenge. The divides between different parts of the health system and between health and social care, in terms of management arrangements, staff contracts and funding,

and professional barriers all make it difficult for truly user-centred services to develop. The government needs to focus on removing the policy and organisational barriers to enable new, more integrated services to develop that combine the support that the NHS, social care and voluntary sector organisations can provide. This must include shared funding to support the delivery of a more co-ordinated care service for individuals and populations, as well as enabling local access to packages of care that are tailored to individual needs.

An important block to progress in this area, however, is the issue of social care funding. As social care is means-tested at the point of access, unlike health care, this adds a further degree of complexity that can lead to gaps and failures in services. We must address the need for social care funding to be put on a long-term, sustainable footing, and so the government must prioritise implementing the Dilnot Commission recommendations (Commission on Funding of Care and Support 2011).

Active commissioning and service redesign

The ideas and priorities in this report are not new, and there are examples around the country of innovative and effective services that are delivering exactly the sort of services that we want to see made available to all. In theory, health and social care commissioners should be in a position to use their leverage as budget holders to achieve these service improvements. But in practice commissioning has tended to be a weak lever for change. As new structures for clinical commissioning groups and health and wellbeing boards develop, it is imperative that the potential for strong and active commissioning to drive service redesign at a local level is realised. Local commissioners and the NHS Commissioning Board will need to work together to ensure there is the strategic leadership in the new health and care system to deliver complex but much-needed service redesign.

Active commissioning can best be achieved when it is underpinned by a clear strategy for change that is based on sound evidence and focused on improving

outcomes. To this end, national outcomes strategies are needed both for specific conditions and for patients with multiple conditions.

Clinical networks need to be a central part of the new system. They have an important role to play in supporting commissioners to assess needs, plan and co-ordinate services, drive quality improvement and translate national strategies into local actions.

At a more local level, the range of services we identify in this report also needs active commissioning. Current provision is patchy and so commissioning effort is needed to address this. Health and social care commissioners need to work together under a collective duty to assess the local need for these services and identify and address gaps where they exist. Support and resources for innovation will be an important part of this.

24/7 care

The greatest failures that people experience in care co-ordination, integration and the provision of a genuinely patient-centred service often occur when they try to access support at night, at the weekend and during public holidays. For many individuals, particularly those with complex health and social care needs that require ongoing support, the inability to access care services 24/7 can lead to poor care experiences and unnecessary visits to hospital.

Developing a more integrated approach to urgent care for such individuals is important when they have an injury or illness that requires immediate attention but is not serious enough to warrant a visit to an accident and emergency department. This requires better co-ordination of the range of urgent care services available, greater sharing of clinical information across different agencies, and greater access to 24/7 community-based care to stop people falling into crisis and a subsequent need for hospital-based care.

Currently, where problems do escalate, the NHS and social care is not as consistently responsive as it should be. Even under existing case management schemes,

where ‘at risk’ individuals are cared for in the community by multidisciplinary teams of health and social care professionals, the lack of 24/7 coverage leads to spikes in emergency admissions at night, at weekends and during bank holidays (Ross *et al* 2011). Community-based care must be available 24/7 and all year round if it is to be effective, and hospitals too must operate consistently over weekends and public holidays to make the most efficient use of their skills and assets.

The mandate

As ten organisations, each supporting our own particular constituency, we could ask for detailed condition-specific outputs and outcomes to be hard-wired into the mandate that the Secretary of State for Health will set the NHS Commissioning Board. That detail, we believe, is better articulated in the NHS Outcomes Framework, outcomes strategies and the commissioning guidance that the NHS Commissioning Board will own. Rather, we propose that the mandate charges the NHS Commissioning Board with implementing the key themes we have highlighted with specific actions identified against the service improvement priorities. If we are to make the most impact for the most people, we must set a mandate for the NHS, and set equivalent priorities in social care and public health, that truly drives high-quality, cost-effective and patient-centred care.

References

- Asthma UK (2010). *National Asthma Panel 2010*. London: Asthma UK.
- British Heart Foundation (2010). *The National Audit of Cardiac Rehabilitation: Annual statistical report 2010*. Available at: www.cardiacrehabilitation.org.uk/nacr/docs/2010.pdf (accessed on 16 February 2012).
- Care Quality Commission (2011). *Survey of Adult Inpatients 2010: Full national results with historical comparisons*. Available at: www.cqc.org.uk/sites/default/files/media/documents/ip10_historical_comparisons_tables_final.doc (accessed on 8 February 2012).
- Challis D, Hughes J, Berzins K, Reilly S, Abell J, Stewart K (2010). *Self-care and Case Management in Long-term Conditions: The effective management of critical interfaces*. London: HMSO. Available at: www.sdo.nihr.ac.uk/files/project/SDO_FR_08-1715-201_V01.pdf (accessed on 23 February 2012).
- Commission on Funding of Care and Support (2011). *Fairer Care Funding: The Report of the Commission on Funding of Care and Support*. London: Department of Health. Available at: www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf (accessed on 10 February 2012).
- Corke CF, Stow PJ, Green DT, Agar JW, Henry MJ (2005). 'How doctors discuss major interventions with high risk patients: an observational study'. *British Medical Journal*, vol 330, pp 182–4.
- Côté J, Bowie DM, Robichaud P, Parent JG, Battisti L, Boulet LP (2001). 'Evaluation of two different educational interventions for adult patients consulting with an acute asthma exacerbation'. *American Journal of Respiratory and Critical Care Medicine*, vol 163, no 6, pp 1415–19.
- Coulter A (2007). *Evidence on the Effectiveness of Strategies to Improve Patients' Experience of Cancer Care*. Oxford: Picker Institute Europe. Available at: www.pickereurope.org/Filestore/PIE_reports/project_reports/Cancer_reform_strategy_Macmillan.pdf (accessed on 16 February 2012).
- Coulter A, Collins A (2011). *Making Shared Decision-making a Reality: No decision about me, without me*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/nhs_decisionmaking.html (accessed on 23 February 2012).
- Curry N, Ham C (2010). *Clinical and Service Integration: The route to improved outcomes*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/clinical_and_service.html (accessed on 24 February 2012).
- Da Silva D (2011). *Helping People Help Themselves: A review of the evidence considering whether it is worthwhile to support self-management*. London: Health Foundation. Available at: www.health.org.uk/publications/evidence-helping-people-help-themselves/ (accessed on 8 February 2012).
- Department of Health (2009). 'Care Planning'. Department of Health website. Available at: www.dh.gov.uk/en/Healthcare/Longtermconditions/DH_093359 (accessed on 8 February 2012).
- Department of Health/Ipsos MORI (2011). *Long Term Health Conditions 2011 Research Study Conducted for the Department of Health*. London: Department of Health.
- Egede LE, Zheng D, Simpson K (2002). 'Comorbid depression is associated with increased health care use and expenditures in individuals with diabetes'. *Diabetes Care*, vol 25, no 3, pp 464–70.
- Goodwin N, Smith J (2011). *The Evidence Base for Integrated Care*. Slidepack. Available at: www.kingsfund.org.uk/current_projects/integrated_care/integrated_care_work.html (accessed on 13 December 2011).
- Goodwin N, Smith J, Davies A, Perry C, Rosen R, Dixon A, Dixon J, Ham C (2012). *Integrated Care for Patients and Populations: Improving outcomes by working together*. London: The King's Fund and the Nuffield Trust. Available at: www.kingsfund.org.uk/publications/future_forum_report.html (accessed on 9 February 2012).
- Healthcare Commission (2007). *Managing Diabetes: improving services for people with diabetes*. Available at: http://archive.cqc.org.uk/_db/_documents/Managing_diabetes.pdf (accessed on 9 February 2012).
- Health England (2009). *Prioritising Investments in Preventative Health*. Matrix Insight. Available at: http://help.matrixknowledge.com/file.axd?file=HE_final_report.pdf (accessed on 24 February 2012).
- House of Commons Health Committee (2012). *Public Expenditure: Thirteenth Report of Session 2010–12 – Volume I: Report, together with formal minutes, oral and written evidence*. London: Stationery Office. Available at: www.publications.parliament.uk/pa/cm201012/cmselect/cmhealth/1499/1499.pdf (accessed on 10 February 2012).
- Imison C, Naylor C, Goodwin N, Buck D, Curry N, Addicott R, Zollinger-Read P (2011). *Transforming our Health Care System: Ten priorities for commissioners*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/articles/transforming_our.html (accessed on 24 February 2012).
- Jenkins R, McCulloch A, Friedli L, Parker C (2002). *Developing a National Mental Health Policy*. Maudsley monograph 43. Hove: Psychology Press.
- Moore R, Groves D, Bridson J, Grayson A, Wong H, Leach A, Lewin R, Chester M (2007). 'A brief cognitive-behavioral intervention reduces hospital admissions in refractory angina patients'. *Journal of Pain and Symptom Management*, vol 33, no 3, pp 310–16.
- Murray E, Burns J, See TS, Lai R, Nazareth I (2005). 'Interactive health communication applications for people with chronic disease (Cochrane Review)'. *Cochrane Database of Systemic Reviews*, issue 4, article CD004274.
- National Voices (2011). *Principles for Integrated Care*. London: National Voices. Available at: www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/principles_for_integrated_care_final_20111021.pdf (accessed on 13 December 2011).
- Naylor C, Bell A (2010). *Mental Health and the Productivity Challenge. Improving quality and value for money*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/mental_health_and.html (accessed on 24 February 2012).

- Naylor C, Parsonage M, McDaid D, Knapp M, Fossey M, Galea A (2012). *Long-term Conditions and Mental Health: The costs of comorbidities*. London: The King's Fund. Available at: [Document4www.kingsfund.org.uk/publications/mental_health_ltc.html](http://www.kingsfund.org.uk/publications/mental_health_ltc.html) (accessed on 24 February 2012).
- Netten A, Darton R, Bäumer T, Callaghan L (2011). *Improving Housing with Care Choices for Older People: An evaluation of extra care housing*. London: Personnel Social Service Research Unit (PSSRU) and Housing Learning and Improvement Network (Housing LIN). Available at: www.housinglin.org.uk/_library/Resources/Housing/Research_evaluation/PSSRUsummary.pdf (accessed on 17 February 2012).
- NHS Future Forum (2012). *Information: A report from the NHS Future Forum*. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_132086.pdf (accessed on 8 February 2012).
- NHS Institute for Innovation and Improvement (2011). 'NHS Better Care, Better Value Indicators (incorporating Opportunity Locator)'. NHS Institute website. Available at: www.productivity.nhs.uk/Indicator/608/For/National/And/25th/Percentile (accessed on 24 February 2012).
- NHS Wales (2010). 'Chronic Conditions Management Demonstrators'. NHS Wales website. Available at: <http://www.ccmdemonstrators.com/ResearchAndEvaluation.aspx> (accessed on 13 December 2011).
- O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, Entwistle VA, Fiset V, Holmes-Rovner M, Khangura S, Llewellyn-Thomas H, Rovner D (2009). 'Decision aids for people facing health treatment or screening decisions (Cochrane Review)'. *Cochrane Database of Systemic Reviews*, issue 3, article CD001431.
- Picker Institute Europe (2010). 'Invest in Engagement: Outcomes and effectiveness'. Picker Institute website. Available at: www.investinengagement.info/91 (accessed on 24 February 2012).
- Purdy S (2010). *Avoiding Hospital Admissions: What does the research say?* London: The King's Fund. Available at: www.kingsfund.org.uk/publications/avoiding_hospital.html (accessed on 9 January 2012).
- Richmond Group of Charities and the The King's Fund (2010). *How to Deliver High-quality, Patient-centred, Cost-effective Care: Consensus solutions from the voluntary sector*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/articles/how_to_deliver.html (accessed on 24 February 2012).
- Rosen R, Mountford J, Lewis G, Lewis R, Shand J, Shaw S (2011). *Integration in Action: Four international case studies*. London: Nuffield Trust.
- Ross S, Curry N, Goodwin N (2011). *Case Management: What it is and how it can best be implemented*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/case_management.html (accessed on 24 February 2012).
- Singh D, Ham C (2005). *Transforming Chronic Care: Evidence about improving care for people with long-term conditions*. Birmingham: University of Birmingham, Health Services Management Centre.
- Stevenson FA, Cox K, Britten N, Dundar Y (2004). 'A systematic review of the research on communication between patients and health care professionals about medicines: the consequences for concordance'. *Health Expectations*, vol 7, no 3, pp 235–45.
- The King's Fund (2011). *Improving the Quality of Care in English General Practice: A report of an independent inquiry commissioned by The King's Fund*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/gp_inquiry_report.html (accessed on 24 February 2012).
- Wagner W, Austin B, Von Korff M (1996). 'Organizing care for patients with chronic illness'. *The Millbank Quarterly*, vol 74, no 4, pp 511–4.
- Windle K, Wagland R, Forder J, D'Amico F, Janssen D, Wistow G (2009). *National Evaluation of Partnerships for Older People Projects: Final report*. Canterbury: Personal Social Services Research Unit, University of Kent. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_111353.pdf (accessed on 17 February 2012).

TheKingsFund>

This paper is the collective effort of ten of the leading health and social care organisations in the voluntary sector. The organisations worked with The King's Fund to establish a common position.

The King's Fund team comprised Catherine Foot, Nick Goodwin and Lara Sonola