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National Voices
People shaping health and social care

People in control of their own health and care

The state of involvement

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Foreword

As a person and a patient, I care deeply about involvement, because I know it helps me as a patient to live more sustainably with my health conditions, and because I know that that, in turn, can help the National Health Service to exist more sustainably, too.

At first glance, this report may feel like we've been standing still for a decade when it comes to involving people. But what it really shows is the dedication and determination of those who 'get it' and have been pushing this in such challenging environments and cultures for years.

The eight different areas of involvement discussed in this report form the basis of a continuum of involvement that extends to the collective level and beyond. These areas are the foundations of the 'person-centred' health care system we hear so much about, and can help us turn the rhetoric into tangible experiences for people accessing our services. However, these eight areas are not a list of 'either/ors'; they cannot be employed in isolation from each other and for that to be considered to have 'ticked' the 'involvement box'. They are not single 'interventions' but collectively represent a fundamental cultural shift.

This report acknowledges that despite progress, barriers still remain. Discussing these barriers is necessary, but not sufficient. The next step is action. I hope that having read this report, the importance of involvement at the individual level is clear. Having established that, what is your goal to start to make a difference?

Although I *am* a patient, it doesn't mean that we can afford to *be* patient about the involvement agenda any longer.

Anya de Iongh
Patient leader and self-management coach

① Introduction

'Putting patients first' has become the favoured mantra of politicians and senior policy-makers in health. For 20 years or longer it has been an explicit policy goal. The aim has been that people should have a stronger voice in decisions about health and care, and that services should better reflect their needs and preferences. Several factors have contributed to this shift – the march of consumerism, the retreat of traditional paternalism, and the persistence and assertiveness of health charities, patient advocates and rights campaigners, for example. And the evidence is clear: overall, people are not as involved as they want to be in decisions about health and care, yet when they are involved, decisions are better, health and health outcomes improve, and resources are allocated more efficiently.

Despite this history, in 2014 it still feels to many that 'putting patients first' is more of an aspiration than a programme of action; that the reality lags behind the rhetoric. As this report demonstrates, on a number of fronts, despite pockets of good practice, there has been a lack of systematic progress. Why is this? I see three broad reasons.

First, we lack clarity about the business of involving people in health. What is it? Why do it? What does the evidence say? What are the benefits? How do I start? As we show in this report, involving people is not one 'thing', and there is not a single lever that policy-makers, service designers and citizens can pull to make it happen. Rather, there is a range of approaches, with different philosophies, histories, perspectives and terminologies. At worst this can lead to confusion and paralysis, with decision-makers unsure what to make of the exhortations to 'engage', 'involve', 'share decisions', 'empower', 'personalise' and so forth. And there has been a tendency for the professional community to focus more on the 'public' bit of 'patient and public involvement', so that anxiety about the public handling of hospital closures, for example, crowds out thinking about models of care and the involvement of individuals in these.

The desire to bring clarity to this potential muddle was the inspiration behind this report. The good news is that the different approaches do broadly cohere; there is a

strong evidence base about the benefits; and there are practical things that people can and should do that will make a difference.

The second reason for slow progress is that involvement is challenging. It challenges orthodoxies, vested interests and established ways of doing things. It requires professional communities to do things differently and to let go. It requires unwieldy administrative systems to become more responsive and human. It requires some patients and citizens themselves to think about their health and their care in different ways. In short, it poses a fundamental cultural and behavioural challenge to our systems of health and social care. Technocratic responses to this challenge – for example, the introduction of patient decision aids and feedback questionnaires – are not in themselves sufficient. There must also be a will to do things differently.

That is why this report calls for consistent national leadership of the involvement agenda, and meaningful support in areas such as measurement, training and tools for care and support planning. The reality is that, although it is a policy goal, the business of involvement has never been a priority, and this is the third main barrier to progress. The history of policy-driven change and reform in the National Health Service (NHS) is a story of other priorities. It is a story of a preoccupation with activity, capacity, professions and organisations, and is denominated in the currencies of pounds, doctors, nurses and beds. And when things go spectacularly and publicly wrong, as they did in the cases of general practitioner (GP) Harold Shipman, Mid Staffordshire NHS Foundation Trust and Winterbourne View private hospital, the instinctive policy and political response – for understandable reasons – has been to regulate and protect, rather than to liberate and empower. Creating the conditions in which people have more say has not been the dominating narrative.

Our ambition is that this report will contribute to a new narrative about the involvement of citizens in health. We hope it will illuminate the way forward, both conceptually and practically, that it will build confidence and inspire action. As the health and social care charity coalition National Voices has argued elsewhere, it is time for person-centred care to become the central ambition for health and care reform, and for the fundamental design principle to be seen as 'what matters to people'.

Jeremy Taylor
Chief Executive, National Voices

2 Background

A brief history

The aspiration to involve people and give them more control over their health and care has a long history of initiatives and campaigns from policy-makers, professionals and patients and carers.

Patient involvement can be traced back to the roots of the NHS. The first considerations of involvement were to provide individuals with the ability to choose a general practitioner, and subsequently to offer a choice of services according to need, including accessing treatment privately. The involvement of patients through making active choices formed a core component of policy in Margaret Thatcher's government, as outlined in the White Paper *Working for Patients* (Department of Health 1989). The Patient's Charter (Department of Health 1991) then took this further and set out a number of rights for patients, including maximum waiting times and the right to have a complaint investigated. Alongside the provision of increased rights to treatment and care were new rights to involvement for those already in receipt of treatment.

Studies of the extent of unwarranted variation in clinical practice and abuses of power led to increasing interest in ensuring that patients' values and preferences are taken into account (Wennberg 2010; Coulter 2011). The General Medical Council's 1995 guide *Good Medical Practice* included a duty to 'respect the right of patients to be fully involved in decisions about their care' (General Medical Council 1995, p 4), and the Mental Health Act 1983 provided a specific legal framework that restricted the circumstances in which patients could be treated without their consent.

With the election of the Labour government in 1997 came an increasing interest in personalisation, in which patients' individual needs and preferences shaped provision (Department of Health 1997). In 2000, *The NHS Plan* boldly stated: 'Step by step over the next ten years the NHS must be redesigned to be patient centred – to offer a personalised service… by 2010 it will be commonplace' (Department of Health 2000, p 17).

Enabling patient choice continued to constitute the main mechanism for achieving this vision, but now the implementation of patient surveys offered new ways in which patients could take an active role in contributing to health service improvement. In terms of public health and health improvement, the 1999 White Paper *Saving lives: our healthier nation* aspired to achieve a new partnership with patients to help them lead healthier lives (Department of Health 1999). The Wanless Report in 2002 further extended the role of patients as independent agents of their own health, arguing that only by people becoming 'fully engaged' in their own health and health care can we hope to limit the escalating costs of health and social care provision associated with the growing burden of disease (Wanless 2002).

Recent years have seen the increasing involvement of individuals at all levels of provision, from prevention and health promotion, through individual decision-making to self-management for individuals with long-term conditions. The instigation of a legal duty for NHS bodies to involve people in the planning, consideration of proposals for changes, and in decisions regarding services came in the National Health Service Act 2006. The Health and Social Care Act 2008 outlined the Care Quality Commission's duty to set out how it would promote and engage service users and carers in its work, and Regulation 17 (Health and Social Care Act (Regulated Activities) Regulations 2010) made clear that providers needed to support people to participate in decision-making and self-management. In 2009, an interest in patients' rights returned with the NHS Constitution, this time also including a set of responsibilities for patients when both managing their health and interacting with health services (Department of Health 2009). For the first time, the Health and Social Care Act 2012 separated patient and public involvement and included separate duties for each, and NHS England has issued guidance on meeting these statutory duties (NHS England 2013).

In social care, born out of provision for public participation in local authority planning, involvement has been a key element of policy and practice for many years. As with health care, it has had a number of driving forces behind it, including concerns for citizenship, meeting individuals' needs, equal rights and enabling social inclusion. The National Health Service and Community Care Act 1990 provided a framework for involvement, with care tailored, responsive and flexible to individual need, and saw the introduction of individualised care-planning. Often seen as a means of supporting people to maintain their independence, this evolved to provide

individuals with their own budget through the Independent Living Fund, and subsequently direct payments to purchase care according to need. These budgets promoted choice and control for people using social care services, and in doing so were conceived as supporting the delivery of more efficient and accessible services.

These changes in involvement have not occurred in isolation. Patient and disability groups have played a key role, challenging power differentials and highlighting instances of poor care and neglect. Prioritising inclusion, autonomy and independence, they have sought to have more of a say in the agencies, organisations and institutions that have an impact on them, as well as to be able to exert greater control over their lives, an area in which their key success has been the development of personal budgets. Alongside the development of the social model of disability, patient and disability groups have been integral in changing beliefs about the roles and capabilities of individuals and their potential for involvement.

History has also highlighted the impact of not involving people. A successive number of reports commissioned as a result of adverse events in health and social care have concluded that in the majority of cases significant harm could have been prevented and financial cost saved if organisations had listened to those in their care (Department of Health 2012e; Francis 2013).

Today, political and policy rhetoric abounds with aspirations that patients are 'at the centre' and 'in control'. *The NHS five year forward view* puts giving people far greater control of their own care among its top priorities for the health system (NHS England 2014e) and elsewhere NHS England Chief Executive Simon Stevens has stressed the 'renewable energy' that patients, carers and communities can offer (Stevens 2014, para 35). Health care quality experts agree that truly safe and effective care can only be achieved when patients are 'present, powerful and involved at all levels' (Berwick 2013, p 18).

Different perspectives on involvement

One thing evident from this brief and partial history of individual involvement is the range of different motivations that have contributed to it. These perspectives include the following inter-related approaches.

- A consumerist approach: health and health care is seen as a marketplace in which patients (consumers) are involved by making choices about services, and the health care market responds to their preferences. Patient involvement is then a means to improve quality.

- A democratic approach: people have political, social and economic rights as citizens, and those who use or are affected by a public service should be involved in how it is run, and have certain rights regarding what they receive from that service.

- An ethical and outcomes-based approach: involvement is seen as the ethical thing to do, and the best approach to improve outcomes. This means recognising that good care comprises the application to individual circumstances of evidence-based medicine along with knowledge and experience. Patient involvement is essential to the judgement of relative risk and benefit associated with decision-making.

- A value-based approach: to achieve truly the best value for money from our health and care system, we must know and respond to what people need and want. In this way, we can deliver care that meets their preferences and patients receive 'the care they need (and no less), and the care they want (and no more)' (**Mulley** *et al* **2012**).

- An approach based on sustainability: it is increasingly difficult for health systems to provide the best possible care to everyone as the prevalence of long-term conditions increases and the population ages. By involving people in managing their own health and care, and keeping well and independent, we can minimise our use of services.

- A person-centred care approach: our health and care system should be focused on its users, promoting independence and co-ordinated around people's full needs rather than being fragmented and siloed. Patient involvement is an essential component of delivering a more person-centred service that is tailored and responsive to individual needs and values.

The current state of involvement has arisen from different initiatives led by different groups, at a number of different points in time, influenced by different ideologies and serving different goals. It is not a neat, single concept but encompasses multiple perspectives, which is important to understand when considering how and why people support or resist different forms of involvement.

A focus on rights and responsibilities

Policy has tended mainly to focus on or articulate patient involvement in the form of rights, but inherent in this are associated responsibilities. This was first acknowledged in Wanless's 'fully engaged' scenario, but was taken further in the 2009 NHS Constitution (Department of Health 2009). Most recently, Healthwatch England has been consulting on rights and responsibilities for health and social care in order to provide a framework for its work of ensuring that the voice of patients and the public are heard in the health and care system.

People's responsibilities in relation to health and care reflect expectations of how patients can help the services to work effectively and ensure that finite resources are used fairly (Department of Health 2013b). These responsibilities can take a number of different forms:

- responsibilities that are conditional for access to treatment (such as abstaining from alcohol before a liver transplant)

- responsibility to do something as part of your own health care (such as taking your prescribed medicines)

- responsibility in your wider life to behave in certain ways for your own health, often in the long term (such as not smoking, or eating healthily)

- responsibility to meet agreements or good standards of social behaviour in your contact with services (such as not abusing staff and not missing your appointments without reason)

- responsibility to do something that might have a small real or perceived cost to you but has wider population-level benefits (such as not visiting the accident and emergency department for minor problems, or not demanding antibiotics for viral infections).

Fundamental to the discussion of rights and responsibilities is an acknowledgement that both involve a transfer of power. Many of the rights allocated to patients seek to empower them, challenging the balance of power and control held by providers and health professionals. At the same time, it is recognised that as patients are allocated greater powers and control, the balance of responsibility also shifts, and patients must increasingly play a role in maintaining and managing their own health.

There are also issues of motivation and capability – as the five different forms of responsibility above demonstrate, this could mean taking on greater responsibility for areas that impact directly on one's health, either now or in the future, on the health of others, or even on the health of society as a whole. Evidence from some areas of medicine suggest that patients are responsive to taking responsibility when the reasoning is clearly explained, and the value of taking action (such as losing weight as a requirement for bariatric surgery) can be seen as of direct benefit to themselves. But in some cases, 'responsible' use of services may offer little personal benefit and, indeed, 'irresponsible' use may be rewarded with prompt treatment, as in the case of choosing to attend the emergency department with a minor problem.

Involvement provides opportunities to achieve a balance between rights and responsibilities, but the challenge to dominant hierarchies and new roles that it requires individuals to adopt presents a significant hurdle to be overcome.

About this paper

This paper concentrates on individuals' involvement in their own health and care, and the involvement of an individual's family or other carers. It doesn't look at collective forms of involvement, where people get involved with services to help improve them for others, through, for example, taking positions of authority on governing bodies or engaging with consultations about the future direction of services.

We set out eight key forms of individual involvement, ranging from being involved in keeping healthy and well, to taking part in research and evaluating the services you receive:

- engaging people in keeping healthy

- shared decision-making

- supported self-management

- having a personal health or social care budget

- involving families and carers

- choosing a provider

- taking part in research as part of your care and treatment

- evaluating services through feedback.

The paper is aimed at those who are less familiar with the day-to-day concepts and practice of individual forms of involvement, and who would benefit from a strategic overview to inform practice, strategy and policy. It offers some ways of making sense of this complex agenda, appraises the different approaches, the impact that involvement can have when done well, and makes recommendations for how our health system can achieve the transformation required in the relationship between people and services.

Figure 1 **Eight priorities to transform individual involvement in health and care**

1 Engaging people in keeping healthy

2 Shared decision-making

3 Supported self-management

MY CARE PLAN

8 Evaluating services through feedback

not joined-up

poor information

staff were kind

Eight priorities to transform individual involvement in health and care

4 Personal health and social care budgets

7 Participation in research

CLINICAL RESEARCH

6 Choice of provider

?

?

?

5 Involving families and carers
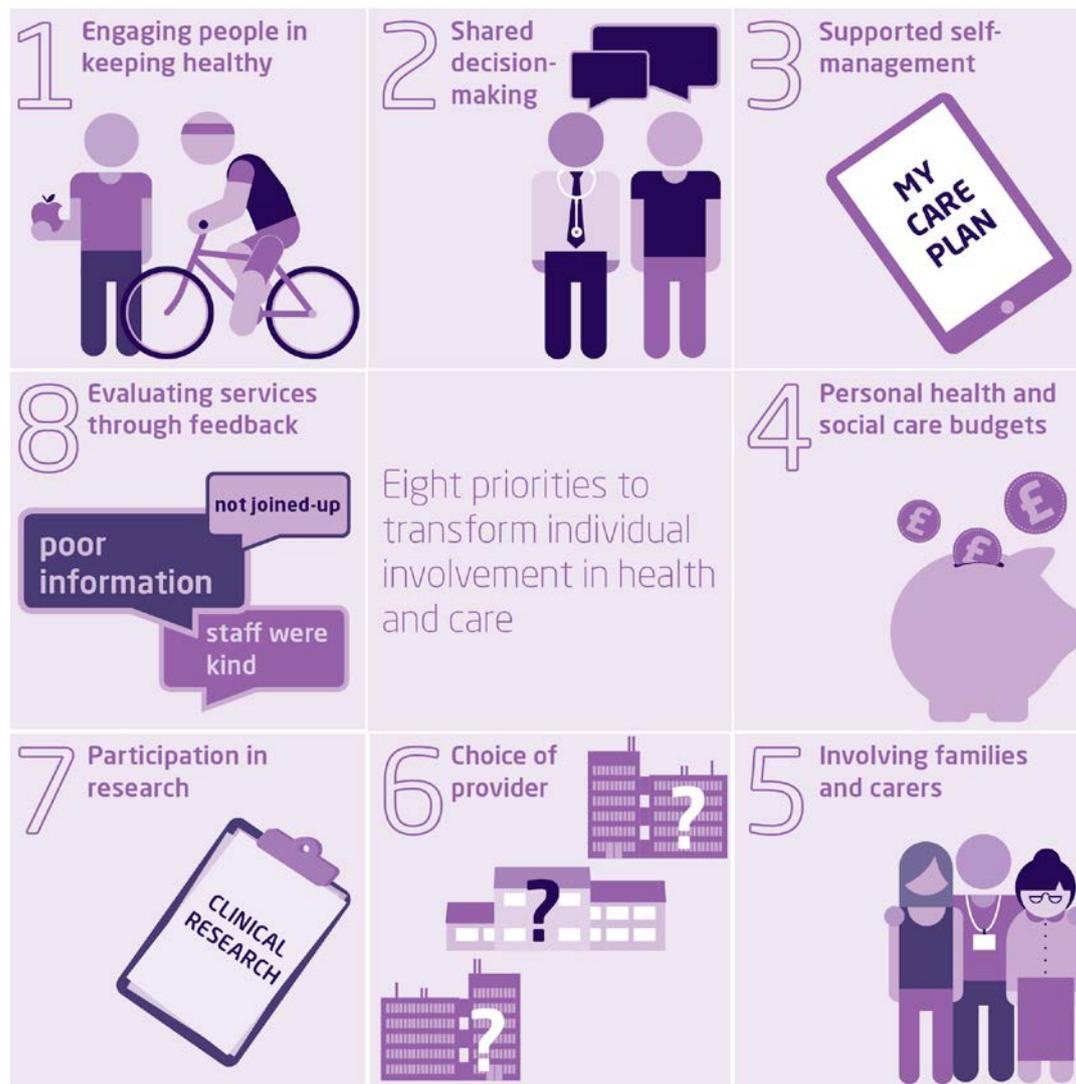
③ Engaging people in keeping healthy

What is it?

Our lifestyles play an important role in determining our health. Smoking, high blood pressure and overweight and obesity together accounted for about 30 per cent of all years of life lost to disability in the United Kingdom in 2010, followed by physical inactivity, alcohol use and a diet low in fruits (Murray *et al* 2013). Much, if not all, of this burden is potentially preventable.

This section focuses on interventions that aim consciously and actively to involve people in keeping healthy. Other important and effective interventions to improve people's health behaviours that do not actively involve the people themselves – for example, tackling the wider determinants of health, regulating unhealthy products, and influencing people's subconscious behaviours through 'nudge' tactics (such as those available at The Cabinet Office/Behavioural Insights Team website 2014) – are not covered in this paper.

Who is it relevant to?

Everyone.

How to do it

- Local areas need to develop and implement comprehensive behaviour change strategies in a partnership of public health, the NHS, social care, wider local authority services and the local community. The strategy should ensure that:
  - high-quality, evidence-based behaviour change initiatives are commissioned or innovative approaches are evaluated
  - all relevant staff have the appropriate training and support to help people change their behaviours
  - interventions are sustained, monitored and evaluated.

- Approaches need to take account of individuals' capabilities and motivations. A concept called 'patient activation' has been helpful in understanding why some people are active in managing their health and others are passive (**Hibbard and Gilburt 2014**). People with high levels of activation and health literacy may only require an initial conversation, signposting them to relevant information or guided support. For those with low levels of activation, tailored coaching approaches have proved most effective at supporting behaviour change. In addition, it is important for those with low levels of health literacy to be provided with information in different formats and the support necessary for them to understand and use that information.

- Brief advice and intervention from GPs and other professionals – with information or decision aids – is one of the most effective and cost-effective ways to change behaviour. The Making Every Contact Count initiative (**Local Government Association 2014**) is attempting to systematise this across health care in a more consistent way, and more and more health care staff are being trained. Local authorities are also increasingly supporting and implementing Making Every Contact Count as part of their new public health roles.

- Lay and peer support, of which there are many forms, including one-to-one, group-based and virtual or 'actual' formats, offers considerable potential for tackling multiple lifestyle risks. Many areas have extensive health trainer programmes and networks offering tailored advice, motivation and practical support to people wanting to adopt healthier lifestyles delivered by staff who are representative of their local communities. There is also emerging evidence that, like health trainers, community health champions – lay people who are involved in supporting their peers – can be successful and cost-effective (**South et al 2010**; **Hex and Tatlock 2011**; **Altogether Better 2014**).

- Incentives and disincentives can also be used to encourage people to change their behaviours. There is, however, debate about whether incentives work and the moral and ethical implications of being paid, or penalised, according to health behaviours (Marteau *et al* 2009). Recent review evidence does suggest that this can be more effective than usual care and standard information, and therefore, used appropriately, offers an effective approach (Giles *et al* 2014).

- Finally, it is important to recognise that people's wider environment affects their ability to engage actively in their own health. For example, factors such as poverty impact on our cognitive reasoning and the ability to engage in health-related improvement activities (Mani *et al* 2013). Efforts to tackle the wider determinants of health therefore not only improve health outcomes directly, but can also improve people's capacity to be actively involved in their own health.

What impact can it have?

There is good evidence that interventions to support individuals in changing their behaviour can be successful and cost-effective. For example, an analysis of the behaviour change interventions reviewed by the National Institute for Health and Care Excellence (NICE) suggests that of the 200 interventions assessed, 15 per cent saved costs, and the great majority were judged to be cost-effective on NICE's criteria of £20,000 per quality-adjusted life-year gained (Owen *et al* 2011). Supporting people to be more involved in behaviour change is therefore likely to be successful in many cases, and a good use of scarce resources.

Current progress

- As of 2012, many adults were still not meeting government recommendations on healthy lifestyles (Table 1; Health and Social Care Information Centre 2013).

Table 1 Lifestyle choices in adults (aged 16+ years) in England

Behaviour	Men (% of all men)	Women (% of all women)
Not meeting government recommendations for physical activity	34	45
Overweight or obese	68	59
Smokers	22	18
Drinking more than four (or three for women) units of alcohol on heaviest drinking day in the week	37	28

Source: Analysis by The King's Fund, adapted from Health and Social Care Information Centre 2013

- In 2008, 70 per cent of adults were not meeting at least two of the current government guidelines on smoking, alcohol use, diet or physical activity. Furthermore, those with lower education and from lower socio-economic groups are more likely to fail to meet three or four of these guidelines (**Buck and Frosini 2012**).

- Some recent trends in lifestyles offer some encouragement, particularly for children. The proportion of children having ever smoked or taken alcohol or drugs has been falling consistently since the mid-2000s (**Fuller and Hawkins 2013**).

Useful resources

- NICE Behaviour change: Individual approaches. Public Health Guidance 49 (2014): **www.nice.org.uk/guidance/ph49**

- National Voices have produced a review of 308 systematic reviews of preventative interventions: **www.nationalvoices.org.uk/sites/www.nationalvoices. org.uk/files/promoting_prevention.pdf**

④ Shared decision-making

What is it?

Shared decision-making is a process in which clinicians and patients work together to make decisions about care and treatment based on both clinical evidence and the patient's informed preferences. A central part of shared decision-making is the recognition that patients and clinicians bring different, but equally important, knowledge and expertise to the process (*see* box).

Clinician's expertise	Patient's expertise
• Diagnosis	• Experience of illness
• Disease aetiology	• Social circumstances
• Prognosis	• Attitude to risk
• Treatment options	• Values
• Outcome probabilities	• Preferences

Source: Coulter and Collins 2011

Essentially, shared decision-making involves the following stages:

- information exchange, in which the clinician provides reliable, evidence-based information, outlines the options, their likely outcomes, and uncertainties and risks, and the patient shares his or her own knowledge of the condition, and the beliefs, values and preferences that may impact on his or her decision

- deliberation, during which the options are discussed and preferences are clarified

- implementation, when the clinician and patient work together to achieve consensus, and the patient's decisions are then recorded and implemented (Elwyn and Charles 2009).

Who is it relevant to?

Everyone. It is appropriate in every clinical conversation where there is more than one possible course of action (as long as the situation is not an emergency), ranging from major treatment decisions to decisions about tests, medication and lifestyle.

Another important form of shared decision-making is advance care-planning, in which decisions are made about future care and treatment towards the end of life. Similarly, people with serious mental health conditions that might involve admission to hospital may wish to specify how they would like to be treated should this occur.

Although not everyone says they want an active role in their care and treatment, most surveys suggest that a majority do (Flynn *et al* 2006). The important principle behind shared decision-making is that the clinician should not make assumptions about the level of involvement a person wants to have without checking with him or her first.

How to do it

Shared decision-making requires particular attitudes, skills, techniques and tools.

- Clinicians need skills in decision-support counselling and a curious, supportive consulting style.

- Coaching and counselling can also be provided outside of the consultation in order to help patients prepare for shared decision-making.

- Decision aids (such as leaflets and online resources) can supplement the information a clinician gives verbally and help patients think about what different options might mean for them.

- The outcomes of shared decision-making conversations should be recorded in care plans or the patient's records.

- Depending on the type of decision being taken, responsibility for implementation could fall to a clinical team (such as a decision to have surgery) or to the patient (such as choosing to take a medication).

- Although numerous measures of decision quality and shared decision-making have been developed, none are used widely across the NHS as yet (Right Care Shared Decision Making Programme 2012). One example of a measurement tool that is currently in use in several clinical settings in the United Kingdom and the United States is shown in the box.

The CollaboRATE measure

1. How much effort was made to help you understand your health issues?

0	1	2	3	4	5	6	7	8	9
No effort made									Every effort made

2. How much effort was made to listen to the things that matter most to you about your health issues?

0	1	2	3	4	5	6	7	8	9
No effort made									Every effort made

3. How much effort was made to include what matters most to you in choosing what to do next?

0	1	2	3	4	5	6	7	8	9
No effort made									Every effort made

Sources: Elwyn *et al* 2013; CollaboRATE 2014

What impact can it have?

- It is only through shared decision-making that we can achieve and respond to a fully accurate picture of what patients want. Mulley and colleagues, writing for The King's Fund in 2012, termed this inability of the health care system fully to understand and respond to patients' preferences 'the silent misdiagnosis' (**Mulley** *et al* **2012**).

- Shared decision-making leads to better adherence to treatment and medication (**Nunes** *et al* **2009**).

- When patients use decision aids they: improve their knowledge of the options; feel more informed and clearer about what matters most to them; have more accurate expectations of the possible benefits and harms associated with their options; and participate more in decision-making (Stacey *et al* 2011).

- Patients using decision aids are less likely to choose major surgery for a range of conditions, and less likely to choose tests that are often deemed unnecessary (Hawker *et al* 2001; Kennedy *et al* 2002; **O'Connor and Stacey 2005**; Stacey *et al* 2011).

- Decision coaching, in which people are given one-to-one coaching in preparation for shared decision-making, has been found to improve knowledge and participation in decision-making (**Stacey** *et al* **2013**).

Current progress

- National patient surveys show that around half of hospital inpatients and one in three people using GP services said that they were not as involved in decisions about their care as much as they wanted to be. These figures have remained broadly static for a decade or more, suggesting that no systematic progress has been made.

- The most common cause for dissatisfaction is not being properly told about one's illness and the options for treatment (Grol *et al* 2000).

- Doctors, nurses and other clinicians often think they are sharing decisions more than their patients do (Stevenson *et al* 2000).

1 2 3 **4** 5 6 7 8 9 10 11

- There is considerable scope to increase the proportion of patients involved in decisions about their future end-of-life care through advance care-planning (Dening *et al* 2013). A primary care audit in 2009 showed that only 25 per cent of people who had died had been previously identified on the palliative care register (Thomas *et al* 2011).

Useful resources

- Coulter and Collins (2011). *Making shared-decision-making a reality*. London: The King's Fund. Available at: **www.kingsfund.org.uk/publications/making-shared-decision-making-reality**

- The suite of patient decision aids from the Right Care Shared Decision Making Programme is available at: **http://sdm.rightcare.nhs.uk/pda/**.

- The Health Foundation (2014b) shared decision-making resources: **http://personcentredcare.health.org.uk/person-centred-care/shared-decision-making**

- National Voices review of 48 systematic reviews on shared decision-making: **www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/supporting_shared_decision-making.pdf**

5 Supported self-management

What is it?

People make choices and decisions every day about how to manage their lives and their health conditions. Supported self-management means giving people with long-term conditions the support they need to increase the control they have over their own lives and to minimise the constraints imposed on them by their state of health or disability. It requires seeing patients not as passive recipients of care but as active partners (Bodenheimer *et al* 2005).

The main elements of successful supported self-management include:

- personalised care-planning

- structured education and information, including peer support

- 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 (Wagner *et al* 1996).

  I need support because self-management is hard work. Maintaining positive behaviours and lifestyle changes, and keeping on top of it all, is not easy. Motivation waxes and wanes, as does my ability to cope.
  Anya de Iongh, patient and self-management coach (de Iongh 2014)

Who is it relevant to?

Self-care is relevant to everyone. Most people cope and manage minor illnesses without recourse to professional help because they know what to do and are confident in taking action. Supported self-management is particularly relevant to people who are living with a chronic disease or long-term health condition, when taking an active role is key to good quality care, improving outcomes and quality of life, and preventing deterioration.

How to do it

- Individuals need to understand the role they play in managing their health and how this impacts on their outcomes. Health professionals play an important role in meeting patients 'where they are' and supporting them to gain the requisite skills, knowledge and confidence to take an active role (**Hibbard and Gilburt 2014**, p 16).

- Evidence-based information and decision support is required for both professionals and patients to guide shared decision-making.

- Personalised care-planning is an essential component of effective supported self-management. People need to be supported to express their own needs and decide on their own priorities through a process of information-sharing, shared decision-making, goal-setting and action-planning.

- Care plans need to be holistic, covering the full range of health and social care needs within a single care plan. The emphasis in care-planning should be on proactive interventions to keep people as healthy as possible.

- The care-planning process may involve referral to non-traditional sources of support outside professional NHS services, for example, those provided by voluntary organisations or community groups.

- Education programmes can support people to gain the necessary skills to self-manage, but providers need to encourage participation by those who can benefit the most, in particular younger people, and those who lack confidence or are finding it hard to cope.

- Supported self-management needs to take account of the capabilities and needs of each individual. Individuals who find it harder to engage with health issues or have complex problems are likely to need more intensive support, although many others might manage on their own, with appropriate support when necessary.

- Giving patients access to their primary care medical records can help people to manage their own health care and access to services (*see* box).

Patient access to records at Haughton Thornley Medical Centres

- For the past eight years, Haughton Thornley Medical Centres have involved patients and their families in transforming primary care by providing access to their GP electronic health record. As well as allowing registered patients to book appointments, update contact details, request repeat prescriptions and send messages to their GP, the website and app allow people to view their medical records, access information about current medication, test results, health screens, read clinical letters and complete questionnaires before seeing a clinician.

- At the latest count, 1,411 males and 1,834 females had access to their GP electronic health record, constituting 28 per cent of the total patient population and representing patients of all ages and those with a range of conditions (Haughton Thornley Medical Centres 2014).

  Many calls to reception are from patients chasing up test results. Those who have access to their record can view their results and can make an informed judgment as to whether or not they need to speak to their GP… one example of how access to their records results in a reduced number of unnecessary calls to reception and more importantly reduce stress on the patient.
  Deborah Smith, receptionist (Hannan 2014, p 25)

Source: Hannan 2014

What impact can it have?

As synthesised in the National Voices substantive evidence review (**National Voices 2014c**).

- Integrating self-management education and support into routine care with active involvement from health professionals can improve patient knowledge, understanding, confidence and coping ability, as well as improving health behaviours.

- Lay-led generic self-management education courses can improve patient knowledge, understanding, confidence, coping ability and social support, but may have only a limited impact on outcomes.

- Interactive online self-management programmes can improve patient knowledge, understanding, social support, health outcomes and health behaviours.

- Self-management programmes appear to be most effective when they are disease-specific.

- Tailored coaching approaches that take account of an individual's knowledge, skills and confidence can improve self-management behaviours and clinical outcomes.

- Proactive telephone support including health coaching, motivational interviewing and psychosocial support can improve confidence and self-management behaviours.

- Disease-specific group education, psychosocial interventions, tailored coaching for activation, self-monitoring and simplified dosing strategies have achieved reduced service use and costs as a result of appropriate use of medications, and fewer hospital admissions and unscheduled visits.

Current progress

- There are a number of well-established self-management programmes that aim to empower patients to improve their health. The Stanford model of self-management education has been widely used and adapted over the past decade in particular (Lorig and Holman 2003), and certain education programmes for people with particular conditions are increasingly widely available, such as the DESMOND programme for people with diabetes (DESMOND project 2014). Overall, however, access to self-management support and education remains patchy.

- A survey of primary care patients found that 84 per cent of those with a long-term condition had had a care-planning discussion and reported some benefit (Burt *et al* 2012), although only 12 per cent of them also reported being told they had a care plan. London and the South East and other urban areas tend to have lower rates of care-planning discussions than elsewhere in the country (Department of Health 2012b).

- Care-planning is part of a national policy for chronic disease management and clinical commissioning groups are expected to have a 'roadmap' for developing a responsive, whole-person delivery system, which includes supported self-management for people with long-term conditions.

- Models such as the Year of Care and the House of Care provide clear guidance on implementing self-management (Department of Health 2012d; Coulter *et al* 2013). More than 3,000 practitioners and 60 trainers working in 26 communities around England are now involved in the House of Care model (Coulter *et al* 2013).

- The Coalition for Collaborative Care (2014) is a cross-sector coalition that is using the House of Care approach to support local communities to deliver more person-centred care for people with long-term conditions.

Useful resources

- National Voices (2014a). 'Care and support planning guide'. National Voices website. Available at: www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/guide_to_care_and_support_planning_final.pdf

- The Health Foundation (2014a). 'Person-centred care resource centre: self-management support'. The Health Foundation website. Available at: http://personcentredcare.health.org.uk/person-centred-care/self-management-support

- Coulter A, Roberts S, Dixon A (2013). *Delivering better services for people with long-term conditions: building the house of care*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications/delivering-better-services-people-long-term-conditions

- The Coalition for Collaborative Care (2014). The Coalition for Collaborative Care website. Available at: http://coalitionforcollaborativecare.org.uk

- QISMET provides quality accreditation for providers of self-management education: http://qismet.org.uk

6 Having a personal health or social care budget

What is it?

Personal budgets in social care and personal health budgets in health care are allocations of funding that allow individuals to choose and purchase services in order to meet and support their needs. The main stages of implementing a personal budget are:

- an assessment of the person's needs

- working out the amount of money available

- making a personalised care plan

- organising and managing care

- monitoring and review.

Who is it relevant to?

Personal budgets are only available to those who are eligible and who meet a needs assessment. In social care, they are available to people with disabilities, older people, those with mental health problems, carers and parents of children with disabilities, and are subject to a financial means test. In October 2014, people with complex health care needs under NHS Continuing Healthcare (approximately 60,000 people) have a formal right to a personal health budget.

How to do it

- Good information is essential. Frontline staff and patients need access to the necessary information to help them know about and understand personal budgets in order that they may be offered to everyone eligible.

- Without effective personalised care-planning (*see* previous sections), personal health budgets will never be useful or effective.

- Care-planning needs to reflect the person's whole life and needs, and enable some flexibility in what sort of services can be purchased, with clear guidance about how the money can be spent.

- Resources need to be adequate to meet the person's needs, including the costs of arranging care, and budget holders need to have an indication of the amount of money available before starting to plan and arrange support.

- The necessary support services infrastructure needs to be in place. This includes access to independent brokers, voluntary organisations and peer networks.

- Partnerships involving user-led support schemes and a designated full-time post to champion policy development offer the strongest basis for effective implementation.

- People need to be offered a choice in how to manage the money (whether by receiving a direct payment, devolving control of the money to a third party support service, or by receiving a notional or virtual budget with the money managed by the commissioner). There needs to be sufficient separation from those allocating the money and those obtaining the care.

- Regular reviews are important to ensure that the care plan is being followed and needs are being met.

- Direct payments' prices need to reflect the number of people needing services and the impact of price on the supply of provision.

What impact can it have?

- Having a personal social care budget has been shown to be associated with improvements in people's self-determination, direction, support, choice and control, financial position, quality of life, social care outcomes, and participation in community life (**Poll** *et al* **2006**; **Glendinning** *et al* **2008**; **Hatton** *et al* **2008**).

- Having a personal health budget has been shown to be associated with care-related quality of life and psychological wellbeing, although no improvement has been found in clinical outcomes (Forder *et al* 2012).

- Personal budgets have the potential to be most cost-effective in people with mental health problems and young disabled people (**Glendinning** *et al* **2008**).

- Personal health budgets have been found to be cost-effective in relation to care-related quality of life when they offer greater choice and control and budget value is high (Forder *et al* 2012).

Current progress

- The number of eligible users of social services who had been offered a budget rose from 43 per cent in 2011/12 to 55.5 per cent in 2012/13. This trend masks regional variations, however, with some local authorities experiencing a decrease (**Department of Health 2013a**). Black and minority ethnic people have especially low levels of engagement with personal budget payment schemes (**Carr and Robbins 2009**).

- The take-up of direct payments across the United Kingdom has been slow, patchy and sometimes inequitable (**Carr and Robbins 2009**). Most direct payments are provided to people with a physical disability or sensory impairment compared with other groups, and least commonly to people with mental health problems (**Davey** *et al* **2007**). There is a range of factors that help to explain this patchy implementation to date. These include: lack of training and information for frontline staff; lack of support services infrastructure; and problems with lack of resources and supply of services (**Carr and Robbins 2009**).

- Use of direct payments has largely been limited to purchasing care or equipment, with little availability for one-off payments for responsive support, or to promote social inclusion and prevention (**Davey *et al* 2007**). Personal budgets are often not offered as a routine mainstream option (Williams 2006; Ellis 2007).

- Personal health budgets are in the early stages of roll-out after pilots between 2009 and 2012. Personal health budgets form part of NHS England's Integrated Personal Commissioning Programme, which is going to commence in a number of locations from April 2015, and which will pool health and social budgets for certain population groups and support patients/service users to have control over how the money is spent (**NHS England 2014a**).

Useful resources

- Social Care Institute for Excellence (2014). 'Personalisation: personal budgets'. Social Care Institute for Excellence website: **www.scie.org.uk/topic/keyissues/personalisation/personalbudgets**

- NHS England (2014b) Information about the integrated personal commissioning programme: **www.england.nhs.uk/ourwork/commissioning/ipc**

- NHS England (2014d). 'Personal health budgets toolkit'. NHS England website. Available at: **www.personalhealthbudgets.england.nhs.uk/Topics/Toolkit/**

7 Involving families and carers

What is it?

Involving families and carers is an essential part of good patient care (**Cross-Government Publication 2010**; **Francis 2013**). Families and carers play a diverse number of roles, including:

- providing emotional, social and financial support

- domestic assistance

- monitoring health and wellbeing

- providing basic health and personal care

- helping to provide professionals with information about the individual

- advocating for individuals

- proactively seeking out care and treatment options.

Who is it relevant to?

There are 1.4 million people providing care round the clock in the United Kingdom (over 50 hours of unpaid care per week) and around six and half million people provide some level of care helping to look after friends and family with life-limiting conditions and disabilities (**Carers UK 2014**). Carers can be any age and may themselves have care needs. They could be providing long-term care, or helping someone through a temporary set of circumstances.

How to do it

In this paper, we have chosen to address the involvement of families and carers in this separate section, as there are particular issues involved. However, the essential principle should be that the involvement of families and carers should be considered at all stages of care-planning, decision-making and delivery, with the same thought and attention as for the patient.

- The **Care Act 2014** has afforded carers the legal right to needs assessment and support. It requires local authorities to assess carers' need for support wherever they appear to have such needs.

- Health professionals need to identify carers, and then keep this information up to date in medical records. The Royal College of General Practitioners recommends that all services play a role in identifying carers, for example, at GP registration, through list searches, at diagnosis, on hospital admission or discharge, when there is a concern and via carers' organisations (**Royal College of General Practitioners 2014**).

- Organisations should have a carer policy that is well communicated to staff, with training programmes and specific remits for staff around involving carers.

- The involvement of carers is subject to the agreement of the individual who they are caring for. Slade *et al* (**2007**) provide a useful framework for navigating issues of consent with individual service users, including discussing the role of the carer.

- Subject to consent, information around the care of an individual should be shared with the carer, including details of services, diagnosis, treatment options and support mechanisms.

- Carers should be involved in care-planning as team members. In some situations, it might be appropriate to assess the needs and assets of the patient and carer together, or as a family unit (**The Princess Royal Trust for Carers/ Crossroads – Caring for Carers 2009**).

- Carers should be identified and involved in discharge plans from hospital.

- Carers can be important co-workers in what is traditionally deemed delivery of professional care (Twigg 1989). This has been happening in, for example, intensive care units (Hammond 1995), children's care (Mottaghipour and Bickerton 2005) and care homes (Woods *et al* 2007).

- Finally, it is important to ensure that carers receive adequate support and help with their own needs. This can range from arranging appointments at times of the day when carers can get cover, through to providing formal periods of respite care.

The Triangle of Care

The Triangle of Care is a holistic methodology that brings together carers, service users and health professionals. It aims to promote safety and recovery for people with mental health issues and to encourage their wellbeing by including and supporting carers.

The approach identifies six key standards required to achieve better collaboration and partnership as service users and their carers progress through mental health services.

Initially developed by carers and staff seeking to improve carer engagement in acute inpatient services, this approach has now been extended to cover all mental health services and for people with dementia while in hospital.

There is a regional group of trusts who want to share best practice in working towards the Triangle of Care, and a membership group to recognise those who have achieved its standards.

Sources: Carers Trust 2014; Worthington *et al* 2014

What impact can it have?

- The involvement of families and carers has been found to increase patients' knowledge, confidence and understanding in dealing with their health problems, reducing rates of relapse and admissions to hospital, and aiding the recovery of the service users (Pilling *et al* 2002; Kuipers 2006; Pharoah *et al* 2006). An inquest conducted in 2007 found that failure to inform a family that their family member had discharged himself could have contributed to his subsequent death (INQUEST 2007).

- Involvement can also bring benefits to carers, by enhancing self-confidence and giving opportunities to learn new skills (Orr *et al* 2013). Survey research by Rethink found that carers who reported having sufficient information to support their caring role rated significantly fewer adverse impacts on their lives (Pinfold and Corry 2003).

- Staff can feel more confident and informed about their practice, and complaints to the organisation can be reduced (Carers Trust 2013).

- The involvement of families in ward rounds in the United States has demonstrated improvements in perception of parental satisfaction, communication, co-ordination of care, discharge planning, teamwork, quality improvement and improved trainee education (Mittal 2014).

Current progress

- NHS England (2014c) recently published its 'commitment to carers' setting out the actions it intends to take to improve how the NHS involves families and carers.

- Data about carers' contacts with services is not routinely collected. A number of studies indicate that carers want and are open to more support from services, but it is clear that that involvement is limited (Larkin and Dickinson 2011; Orr *et al* 2013; Ridley *et al* 2014).

- Carers report difficulties in getting access to information (Ridley *et al* 2014), not being given opportunities to discuss information with professionals, feeling staff do not listen to their concerns (Pinfold *et al* 2004; Ridley *et al* 2014) and feeling that they are not involved in decisions about care as much as they would like to be (Alzheimer's Society 2009). Carers often need to be proactive to develop effective relationships with professionals (Pinfold *et al* 2004).

- A 2010 review of carer involvement in discharge planning revealed 'a continuing gap between what national policy said should happen and what people experienced' (Association of Directors of Adult Social Services 2010, p 14).

Useful resources

- Cross-Government Publication (2010). *Recognised, valued and supported: next steps for the Carers Strategy*. London: Department of Health. Available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf

- NHS England Commitment to Carers is available at: www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf

- More detail about the Care Act 2014 is available at: http://careandsupportregs.dh.gov.uk/careact/

- The Carers Trust has a specific website to signpost anyone working professionally with carers to the best information available (Carers Trust Professionals 2014): http://professionals.carers.org

- Royal College of General Practitioners (2014). *Involving and supporting carers and families: an educational framework and learning resource for GPs and primary care teams*. London: Royal College of General Practitioners. Available at: www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx

8 Choosing a provider

What is it?

We have included choosing where to go for care or treatment as a specific section in this paper because this particular choice has been, and continues to be, a specific policy priority of successive governments since the 1970s. The Labour governments of 1997–2010, in particular, used the introduction of choice of provider for elective surgery as part of a policy that established independent sector treatment centres and delivered drastic reductions in waiting times.

Who is it relevant to?

The *2014/15 Choice Framework* (Department of Health 2014) outlines the occasions on which patients can choose who provides their care, including:

- GP and GP practice

- where to go for first appointment as an outpatient with physical or mental health conditions

- asking to change hospital if the waiting time exceeds the maximum (18 weeks, or two weeks to see a specialist for cancer)

- choosing who carries out a specialist test

- maternity services

- services provided in the community.

How to do it

- Few patients as yet make use of performance measures to inform their choice of provider, relying instead on their own or others' experience, or the advice of health professionals (**Dixon *et al* 2010**). Nevertheless, a fundamental element in enabling fully informed choice is the ready availability of high-quality, transparent information.

- A second element is the ability to compare provider information about a number of different factors, for example, using the My NHS comparison website tool (**NHS Choices 2014a**).

- Raising awareness is also key if more people are to be able to choose. Information and support for both patients and health professionals, particularly GPs, is necessary in order to encourage people to discuss where to go for care and treatment.

- Referral processes and technology need to support implementation of the choice made. People can currently choose the time, date and place of their hospital or clinic appointment via Choose and Book. This is being replaced by a new NHS e-referral service in spring 2015 (**Health and Social Care Information Centre 2014**).

What impact can it have?

- Evidence shows that the ability to choose hospital services is intrinsically valued by people (**Dixon *et al* 2010**). Three-quarters of respondents in the 2009 British Social Attitudes Survey thought they should have some choice over which hospital they went to (Appleby and Phillips 2009).

- There is some evidence that increasing choice does increase providers' focus on quality of care (**Dixon *et al* 2010**), although the evidence suggests that this is a function of the public reporting of performance information (and providers' response to the associated reputational risk of poor performance) rather than a direct consequence of patients making choices about where to go (Hibbard *et al* 2003).

- Those that took part in the GP Practice Choice pilot (and had increased choice and flexibility) had a superior experience compared with similar patients not on the pilot, and with only modest costs to the system (**Mays** *et al* **2014**).

- Some think that choice has the potential to exacerbate inequalities through, for example, the more educated choosing higher quality services, or the less affluent not being able to travel, and therefore being prevented from exercising their choices. One study also found that providers were competing most actively on the fringes of their catchment area, suggesting that those outside of urban centres may be more likely to be offered choices (**Dixon** *et al* **2010**).

- Enabling people with long-term conditions to choose and buy the package of services and providers that best meets their needs has potential to lead to radical change in the types of services that are commissioned. For example, personal budgets in social care are often used to directly employ personal assistants.

Current progress

- A 2010 survey found that 45 per cent of patients were aware of their right to choose a hospital; awareness was higher among older patients and those looking after their family at home, and among men and those holding a degree. Older respondents, people with no qualifications and those from mixed and non-white backgrounds were more likely to value choice (**Dixon** *et al* **2010**).

- A survey of outpatients in 2014 found that:
  - only 53 per cent of those referred by their GP had had a discussion about where they might go for their first outpatient appointment
  - only 38 per cent had been offered a choice, of which 92 per cent were able to attend their chosen place
  - just over half were aware that they could choose before going to see their GP (**Populus 2014**).

Useful resources

- The NHS Choices website provides an information and support tool that aims to improve the flow of data to the public and is governed by a number of core principles which aim to ensure data quality, accessibility, accountability and impartiality (NHS Choices 2014a): www.nhs.uk/Service-Search/performance/search

- My NHS is a comparison tool, launched in September 2014 (NHS Choices 2014a): www.nhs.uk/Service-Search/performance/search

- Other sites that allow comparison of providers include Dr Foster Intelligence (2014), My Health London (2014), Which? Birth Choice (2014) and the Good Care Guide (2014).

- The *2014/15 Choice Framework* (Department of Health 2014) outlines the choices people have and when, where to find information and how to complain if choices are not offered.

9 Taking part in research as part of your care and treatment

What is it?

The United Kingdom carries out world-leading medical research. Clinical research is carried out by the NHS, universities, research institutes, social care services and the private sector, funded mostly by the National Institute for Health Research, the Medical Research Council, charities and pharmaceutical organisations. Clinical trials, in which the effectiveness of a treatment or intervention is tested, are probably the most well-known type of research, but research is also conducted for a wide range of other purposes, including studies that look at how to organise and provide services, or investigations of long-term trends in health behaviours and disease.

People are involved in research as participants, but should also be involved in the wider designing, shaping and conducting of research (*see* Involve 2014). Since our paper focuses on people's involvement in their own health and care, we have not covered the latter important part of patient and public involvement in research.

Who is it relevant to?

Clinical research involves patients, family members, carers and members of the public. Most studies have specific eligibility criteria that applicants are assessed against before being given information and signing a consent form to participate in the study.

Individual participation in research is recognised in the NHS Constitution (Department of Health 2013b) with a pledge to keep people up to date and informed about relevant studies. In addition, NHS organisations were allocated a number of research-related duties under the Health and Social Care Act (2012).

How to do it

- People can take part in research by:
  - being invited to join a study by their health professional or via a patient organisation
  - finding information and applying online, using, for example, the UK Clinical Trials Gateway (2014) website, or that of People in Research (2014), through university sites advertising opportunities, and also via sites like PatientsLikeMe (2014), Cystic Fibrosis Unite (2014), and Cancer Research UK (2014). There is no single comprehensive database.

- Increasing public awareness of research is important. The Citizen Scientist project in Salford (*see* box) provides one example of how this can be done.

- Organisations need a research and development strategy, which should, among other things, focus on increasing staff awareness and engagement in research, and supporting staff with training in talking to patients about participating in research.

- Trusts need to engage effectively with their local National Institute for Health Research Clinical Research Network, which provides support and research infrastructure.

- The NHS Health Research Authority provides advice and resources on issues such as gaining consent and providing information to participants at the start and end of a research project.

The Citizen Scientist project

Struggling to recruit enough people for trials within tight timescales, Salford ran a series of focus groups and found that people often did not how to get involved or knew little about clinical research.

The Citizen Scientist project launched in September 2012 with the aim of promoting research opportunities, improving access, increasing participation and understanding, and raising awareness of local research. Opportunities are promoted via:

• a website

• Salford Royal open days and other local events

• a roadshow, visiting supermarkets, the university and individual groups

• local advertising.

As of March 2014, almost 1,000 people had signed up to receive information. Eventually researchers should be able to source healthy volunteers and patients with a particular condition from those already registered on the site.

Sources: Moore 2013; Citizen Scientist Salford 2014

What impact can it have?

• Participating in research can bring both benefits and potential drawbacks to the individual, even if the benefit to wider society is unequivocal.

• Benefits can include:
  – having access to new treatments or services
  – being more closely monitored
  – being paid (or at least having expenses paid)
  – learning more about research, a condition, or the topic being researched
  – developing practical skills
  – sharing experiences
  – feeling valued and satisfied to have contributed to improving a treatment or service
  – meeting people with the same condition
  – feeling empowered and confident.

- Potential drawbacks can include:
  - additional time commitments
  - additional tests and monitoring
  - a risk of distress or harm from some research
  - potentially not benefiting from the treatment being studied.

- Hanney *et al* (2013) found that for clinicians and health care organisations, engaging in research is likely to have a positive impact on health care performance. 'Research-active' organisations thus tend to outperform those where research is not a priority.

- Investment in clinical research yields returns not just in improved health, but also in national economic growth, and patient participation in research is essential to this (Health Economics Research Group *et al* 2008).

Current progress

- The United Kingdom has seen a fivefold increase in recruitment to clinical studies in the past 10 years. UK patient participation in clinical research is the highest in the developed world (National Cancer Research Institute 2012). In 2013/14, the National Institute for Health Research Clinical Research Network recruited more than 600,000 patients, bringing that total to more than three million within the past six years (National Institute for Health Research 2014).

- Older people, people with rarer diseases, and people from black and minority ethnic groups are less likely to be involved (Crome *et al* 2011; Hussain-Gambles 2003).

- In a national survey of cancer patients, 95 per cent of those who were given the opportunity to take part in research said they were glad to have been asked, but only around one-third of patients reported having actually been asked (Department of Health 2012a).

- More than 99 per cent of NHS trusts are now research-active and recruit on to National Institute for Health Research studies (National Institute for Health Research 2014). Data from the national cancer patient experience survey, however, show that there is significant variation in the proportion of patients

who say that taking part in research was discussed with them, ranging from 10–61 per cent between trusts (Quality Health 2014).

- A 'mystery shopper' study reported that 91 per cent of the hospitals studied did not have any research information on display in public notice areas, and that 46 per cent of receptionists said that research was not something the organisation got involved in (National Institute for Health Research Clinical Research Network 2013).

Useful resources

- National Cancer Research Institute (2012). *Action on access: widening patient participation in clinical trials*. Available at: www.ncri.org.uk/wp-content/uploads/2013/07/2012-NCRI-Action-on-access-report.pdf

- Further resources are available from the NHS Health Research Authority website: www.hra.nhs.uk/resources/

10 Evaluating services through feedback

What is it?

The individual patient is the only witness to all his or her care experiences, making him or her an essential source for information across services and care settings (**O'Hara and Isden 2013**). Feedback from individuals (patients, carers, family members) about services can take a number of forms – in real-time or in retrospect, formally or informally, at a national or local level, prompted or unprompted, in-depth or high-level, in person, on paper, on a mobile device or online – and serves varying purposes (**Coulter** *et al* **2009**).

Who is it relevant to?

Everyone using health and care services can provide feedback, and all services should work to gather feedback from patients to evaluate and understand their performance.

How to do it

- Patient experience surveys and feedback aim systematically to gather the views of patients and carers about the care recently received. There is a number of regular national surveys, but organisations also need to encourage feedback in other ways and to conduct their own surveys to get more timely and service-specific feedback (*see* box).

- The Friends and Family Test is a single-question national survey (with free text) carried out by providers of NHS-funded services that aims to enable patients to give quick feedback on the quality of care they receive. It asks 'How likely are you to recommend <our service> to friends and family if they needed similar care or treatment?'

Real-time feedback at Northumbria Health Care NHS Trust

'Two minutes of your time' is a trust-wide, real-time, short survey covering seven core domains of experience (incorporating the friends and family test). Data are fed back to staff within a week and shared publicly. Consultant-level feedback is included in appraisals.

The trust also carries out a patient perspective survey (20,000 patients per year) with commissioner-set targets, and real-time surveys involving more than 600 patient interviews every month. Results are fed back to staff within 24–48 hours so that they can be acted upon while the patient is still in their care.

Source: Laverty 2012

- Patient stories provide a descriptive narrative of an individual's treatment or care and their journey as a patient through a care pathway or organisation. They can be used to encourage discussion in team or board meetings, particularly with regard to patient safety issues.

- Experience-based co-design (EBCD) is an approach where individual patients tell the story of their experience of care, then patients and staff together identify areas for improvement, and form co-design groups that work to implement changes to services. Patients and staff monitor and oversee changes and improvements as they happen throughout this time.

- Patients can play an individual role in reporting patient safety incidents through the National Reporting and Learning System. Patient reports are analysed to help identify common hazards and to understand why things go wrong and how to stop them happening again. Two new patient safety measures – the patient measure of safety and the patient incident reporting tool – are being developed with the aim of better use of patient input to improve the safety of care (Ward *et al* 2011).

- Patient-reported outcome measures (PROMs) are questionnaires that are completed by the patient and capture a robust measure of symptoms and care as perceived by patients themselves. PROMs focus on symptoms, functional status and quality of life. There is a wide range of available measures, many of which are condition-specific and are used in practice.

- Complaints form the primary mechanism for individuals to provide feedback when an experience of care or treatment has been unsatisfactory. By law, all organisations providing NHS and local authority social care must have a complaints procedure.

- Patients can also give feedback via a third party, such as online feedback platforms like **Patient Opinion** (2014), **iWantGreatCare** (2014), the NHS Choices website (**NHS Choices 2014b**), and the local **Healthwatch** (2014). With the continued growth in digital communication, patients are increasingly turning to social media sites as a forum for giving feedback. Although proactive organisations engage with these sites, there is no formal responsibility to use or respond to information posted on them.

- Particular attention needs to be given to gathering feedback from people who might find traditional methods difficult to participate in, such as very elderly or housebound people who find it difficult to post back a questionnaire, or people with learning disabilities or those who do not read or write well.

- Importantly, organisations need the staff or support services with the skills and time to analyse and interpret patient feedback data (**de Silva 2013**).

- Finally, patient feedback needs to be acted upon. From individual appraisal through to teams, service lines and organisations, patient feedback needs to be used as a central source of insight into performance and how it can be improved. Organisations are increasingly trying to show patients the impact that feedback has on their services, for example, through 'You Said…We Did…' posters.

What impact can it have?

- Audit and feedback data usually have small to moderate effects on health professionals' practice (Jamtvedt *et al* 2003).

- Although the impact is hard to quantify, surveys of health care leaders report that trusts do make positive changes following patient surveys and feedback (**YouGov 2005**).

- In oncology, clinicians were most likely to discuss symptoms with their patients in response to PROMs feedback (Takeuchi *et al* 2011).

- Not acting on feedback given by patients can have a damaging impact. The Mid Staffordshire NHS Foundation Trust Inquiry noted: 'A poor complaints system has a negative impact on the patients and others who seek to use it. Inadequate responses cause distress and may exacerbate bereavement' (**Francis 2010**, para 60, p 20).

- Complaints and compliments have been shown to have an impact when providers analyse these systematically (**Simmons and Brennan 2013**). The formal compilation of compliments can change staff attitudes to receiving feedback by couching observations in positive terms (Ashton 2011).

- There is good evidence to show that EBCD has positive effects, including on service improvement. For example, a review of its use in cancer services reported: 'Interviewees highlighted four characteristics of the EBCD approach as being key to its successful implementation: patient involvement, patient responsibility and empowerment, a sense of community, and a close connection between their experiences and the subsequent improvement priorities' (**Tsianakas *et al* 2012**, abstract).

Current progress

- Fundamentally, patient feedback is effective only if it leads to action. A common finding in studies continues to be that the impact is often minimal because, in the main, patient feedback data is insufficiently used or acted on to improve clinical practice. Coulter and colleagues argued recently in the *British Medical Journal*: 'It is unethical to ask patients to comment on their experiences if these comments are going to be ignored' (Coulter *et al* 2014).

- Sixty per cent of those who want to complain about a public service do not do so because they believe the complaints process would be complex, would involve them having to chase for a response, and because they fear that nothing would change as a result of their complaint (**The Parliamentary and Health Service Ombudsman 2013**).

- The annual health and social care rights survey found that three in five do not feel that they have a clear way of providing feedback on a service (**Healthwatch England 2013**).

- The routine use of PROMs in practice has been slow and difficult to implement (Antunes *et al* 2014).

- In its first annual report, Healthwatch England raised major concerns about the extent to which professionals seek and listen to feedback. The report highlighted systematic failures to listen to and act upon the concerns of patients, carers and families that resulted in neglect, poor quality care and even death, and called for these instances to serve as a mandate for change (**Healthwatch England 2013**).

Useful resources

- Patient experience reviews are available on the Picker Institute Europe website. Available at: **www.pickereurope.org/patient-experience-reviews/**

- Picker Institute Europe (2009). *Using patient feedback*. Oxford: Picker Institute Europe. Available at: **www.nhssurveys.org/Filestore/documents/QIFull.pdf**

- The Patient Experience Portal (2014). 'Excellence framework for patient experience'. The Patient Experience Portal website. Available at: **http://patientexperienceportal.org/**

- De Silva (2013). *Measuring patient experience*. Evidence Scan no 18. London: The Health Foundation. Available at: **www.health.org.uk/public/ cms/75/76/313/4300/Measuring%20patient%20experience.pdf?realName=7qM8Wm.pdf**

- The King's Fund (2013). *Experience-based co-design toolkit*. Available at: **www.kingsfund.org.uk/projects/ebcd**

11 Conclusions and recommendations

What is so striking in this brief overview of the main types of individual involvement in health and care is how broadly similar the conclusions are that can be drawn about progress to date in all of them:

- there is good or reasonable evidence of its potential impact

- there is good or some evidence for how to do it well

- there is a clear, stated policy commitment, but with varying degrees of active national support at present

- there are examples of excellent local practice

- but there is a general continued lack of systematic progress or improvement.

Why, then, despite increasingly having all the essential tools and knowledge available to empower patients to have greater control over their own health and care, have we failed to make significant progress? In preparing this paper, a number of elements have emerged that would seem to be key to facilitating that change.

Providing consistent and meaningful national support

One-off initiatives, although well-intentioned and often hard-fought, are not enough to create the fundamental shifts in power and practice that are required (Coulter 2012). Furthermore, it is clear from our report that although involvement activities are often pursued as separate initiatives, there are strong interdependencies between them that require a more systemic approach to support. NHS England's programme of work on transforming participation provides a first step to achieving

this (NHS England 2013), but significantly more must be done to ensure that a framework is put in place to underpin the various initiatives with concrete and consistent support, and to make organisations accountable. In particular, national bodies need to take the following steps.

- **Reframe professional education and training:** professional education should enable health professionals to develop a model of professionalism based on working with users and citizens, rather than on an assumption of the superiority of expert knowledge (Barnes 1999). Large cohorts of clinicians need access to training in areas such as health coaching, motivational interviewing, risk communication and eliciting people's values and preferences.

- **Provide access to tools and support:** the techniques and approaches discussed in this paper require support to be implemented. Staff and patients need access to high-quality tools such as patient decision aids and tools for structuring and recording care-planning and shared decision-making conversations. National support for promoting and disseminating these tools will aid implementation.

- **Measure involvement and hold organisations to account:** we require a radical improvement and systematisation of how we measure both the quality and the outcomes of involvement (Collins 2014). A range of measures exist (in areas such as decision quality and involvement in care-planning), but consensus must be reached on which should be used, and national support must then be provided for data collection and analysis. Furthermore, the availability of data needs to be matched by accountability. Collecting data that are not used is inefficient, unethical and contravenes the whole purpose of involvement (Coulter *et al* 2014).

- **Enable local organisations to focus on patients not politicians:** a system that is still focused on 'top-down' approaches to reform and improvement is unlikely to find it easy to transform into a system that listens to and empowers patients. A national approach to reform that supports organisations to enable staff to lead change locally is urgently needed (Ham 2014).

Recognising and addressing the different perspectives on involvement

Involvement initiatives require trust and collaboration between different groups, each of which can be undermined when different or conflicting agendas are involved. A self-management initiative framed in terms of reducing costs rather than improving outcomes, for example, may be mistrusted by the people involved. Efforts to gather feedback that feel like a tick-box exercise for accountability purposes and in which the data are not analysed or acted on can similarly be rejected by the people it is seeking to involve. This not only undermines the case for involvement but can lead to distrust around motives or commitment between stakeholder groups. Involvement initiatives therefore need to ensure that the outcomes aimed for genuinely reflect what matters to people (Collins 2014; National Voices 2014b), and that a balance is achieved between the different values held by each group so as to support meaningful engagement.

Meeting the leadership challenge

Drawing lessons from leading providers of patient-centred care, the following core elements are required to create an effective organisation-wide approach to involvement (Coulter 2012):

- strong, committed, senior leadership

- dedicated champions at operational level

- active engagement of patients and families

- clarity of goals

- focus on the workforce

- building staff capacity

- adequate resourcing of care delivery redesign

- performance measurement and feedback.

This requires leadership at multiple levels – from patients and carers to professionals and providers – with 'the concerted effort of many people working together at different places in the system and at different levels, rather than of single leaders acting unilaterally' (**Ghate** *et al* **2013**, p 6).

Given the significant challenges to established roles and power dynamics that involvement presents, leaders will need to be capable of ensuring that multiple and disparate voices are heard and taken seriously, and the vested interests are noted, questioned and challenged. Understanding the different perspectives that underpin involvement, and having the skills and tools to support the culture change required and respond to 'counter resistance' (Caygill 2013) will be important. Although this paper has focused on individual rather than collective forms of involvement, the continuing work of patient leaders in advocating and leading change will be crucial.

A new compact between citizens and services

It is easy to be cynical about the NHS Constitution – evidence suggests that very few people have heard of it, let alone read it (**Department of Health 2012c**), and its rights and responsibilities can read as a mixture of the obvious and the unenforceable. With little evidence that the rights of patients are being upheld (**Redding 2013**) it is difficult to maintain the concept that patients should also share the responsibilities. Embarking on an honest conversation about rights and responsibilities requires consideration of people's motivation and the capability to engage.

However, the NHS Constitution is perhaps the first step in what needs to be a wider and more fundamental national conversation about a new relationship between citizens and services. This new relationship needs to address the imbalance of power in decision-making between professionals, patients and carers; between statutory and community-based partners; and between leaders across systems. It needs to recognise that all parties need support and tools to develop the confidence and skills to behave in new ways. This will require a radical realignment of the current power dynamic away from paternalistic, expert approaches in the consulting room, to a more collaborative, shared decision-making relationship between patients, carers, professionals and communities, along with a refocusing of resources towards a more integrated 'whole life' approach that recognises the complexity of the context in which patients lead their lives, and recognition that services can maximise their impact through access to other 'life' resources.

This is a cultural shift that is not simply about empowering patients, but empowering us all – citizens, patients, carers, clinicians, managers, and community workers – to be active and equal partners. Putting involvement truly at the forefront of policy and practice not only provides the opportunity to create an effective and sustainable health and care system, but also to contribute to a more equitable and healthier society.

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About the authors

Catherine Foot is assistant director of policy at The King's Fund and manages a programme of work on patient experience and quality. Catherine joined The King's Fund in March 2009, and her interests include how organisations gather and respond to feedback and information from patients, how patients can be meaningfully involved in and lead service design and improvement, the effectiveness of national structures and systems for assuring and improving quality and patient experience, and international comparisons.

Previously, she was programme director of the International Cancer Benchmarking Partnership, a Department of Health-led initiative to study why cancer survival rates vary among countries with similar health systems and expenditures on health, and before that was head of policy at Cancer Research UK, where she worked on cancer services reform, public health, health inequalities and medical science policy.

Helen Gilburt joined The King's Fund in 2013 as a fellow in health policy with a particular lead on mental health. Previously she worked at the Institute of Psychiatry at King's College London, where she remains a visiting researcher. Helen has expertise in health services research and a particular interest in service-user involvement, utilising her experience of using mental health services to inform the research she has undertaken.

This research includes a national study of alternatives to standard acute inpatient services, implementation of recovery-orientated care in community mental health, and a trial of assertive outreach treatment for alcohol dependence. Helen holds a PhD in zoology from the University of Birmingham.

Phoebe Dunn joined The King's Fund as a research assistant in the policy directorate in July 2014, and provides support on a range of health and care research projects within the team.

Before joining the Fund, Phoebe worked for a marketing and strategy agency called ZPB, and was involved in projects for small and large organisations from across the health care sector. These projects included contributing to the launch report for

the Point of Care Foundation, digital strategy for a large health charity, and a myth-busting campaign around outcomes-based approaches to health care.

Phoebe completed a Masters in demography and health at the London School of Hygiene and Tropical Medicine, and also holds a BSc in biology from University College London.

Joni Jabbal joined The King's Fund as a policy officer and researcher in July 2013. She contributes to the Fund's responsive policy work, focusing on models of care, quality regulation, and tracking the performance of the English health and social care system.

Previously, Joni worked at the Royal College of Physicians (RCP), focusing on the impact of the NHS reforms, developing new models of urgent and emergency care services, and leading the RCP's public health work streams. She has also worked as a senior policy executive at the British Medical Association. Joni has a particular interest in incentives and behavioural outcomes in health care settings, researching the intrinsic motivation of junior doctors in England. She has also published work on the commissioning structures in the new NHS, and on the development of urgent and emergency care services for the future. She has an MSc in comparative social policy from the University of Oxford.

Becky Seale is a programme manager in leadership development at The King's Fund, joining the Fund in June 2013. With a background in social research and participatory methods, she has more than seven years' experience of carrying out research and engagement for the public and private sector. She has a particular interest in the role that non-traditional voices can play in leadership, policy development and governance.

Becky works on several leadership programmes, including board leadership for foundation trust governors, shared leadership with patients, and leadership for public health trainees. Becky also established and managed the experts by experience group providing advice to the Commission on the Future of Health and Social Care in England.

Before joining The King's Fund, Becky was a senior associate director at TNS BMRB, one of the leading providers of social research to Whitehall, specialising in qualitative and deliberative research. Previously Becky worked at Opinion Leader

Research. She has a first-class honours degree in English literature and French from the University of Manchester, and is a board member of Healthwatch Hackney.

Joanna Goodrich is a fellow in the policy directorate. She joined The King's Fund in 2007 to work on the Point of Care programme, which aimed to improve the way that patients are cared for by examining the quality and humanity of care in acute hospitals.

Joanna came from the Multiple Sclerosis Society where she established a new research programme that aimed to improve health and social care services for people with multiple sclerosis. She has a background in public health and health promotion research, and after working for the Health Development Agency, was a freelance research consultant for a number of voluntary sector organisations and government departments.

David Buck joined The King's Fund in January 2011 to lead on public health and inequalities.

Before joining the Fund, David worked at the Department of Health as head of health inequalities. He managed the previous government's public service agreement target on health inequalities, the independent Marmot review of inequalities in health, and helped to shape the coalition's policies on health inequalities. While in the Department of Health, he worked on many policy areas including diabetes, long-term conditions, the pharmaceutical industry, childhood obesity and choice and competition.

Prior to working in the Department of Health, David worked at Guy's Hospital, King's College London and the Centre for Health Economics in York, where his focus was on the economics of public health and behaviours and incentives.

Jeremy Taylor is Chief Executive of National Voices, the national coalition of health and care charities for England. He joined National Voices in 2009 – a year after its launch – and has grown National Voices' reputation as a strong and independent champion for patients, carers and the voluntary sector.

Jeremy is regularly called on as a representative, expert adviser, writer, commentator and speaker on patient issues. He has featured for the past three years in the *Health Service Journal*'s annual list of the 100 people with the greatest influence in health,

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Among his current commitments he is a member of the BMJ advisory board and the London Health Commission under Lord Darzi.

Jeremy joined the voluntary sector in 2007 and was previously a senior official at HM Treasury.

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The King's Fund is an independent charity working to improve
health and health care in England. We help to shape policy and
practice through research and analysis; develop individuals,
teams and organisations; promote understanding of the health
and social care system; and bring people together to learn,
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possible care is available to all.

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The aspiration to involve people and give them more control over their health and care has a long history of initiatives and campaigns from policy-makers, professionals, and patients and carers dating back to the beginning of the NHS. But is 'putting patients first' still more of an aspiration than a programme of action?

People in control of their own health and care considers how involved individuals can be in their own health and care. The report concentrates on eight areas:

- engaging people in keeping healthy

- shared decision-making

- supported self-management

- having a personal health or social care budget

- involving families and carers

- choosing a provider

- taking part in research as part of your care and treatment

- evaluating services through feedback.

The authors demonstrate that in each area, despite pockets of good practice, there has been a lack of systematic progress: evidence shows that individuals are not as involved as they want to be in decisions about health and care, yet when they are involved, decisions are better, health and health outcomes improve, and resources are allocated more efficiently.

Given the strength of current evidence, the report recommends that there should be a more systemic approach to involving individuals in their own health and care. Involvement needs to become a genuine policy priority. This requires a transformation in power dynamics and in culture to empower everyone – citizens, patients, carers, clinicians, managers and community leaders – to be active and equal partners in health and care.