Everyone who provides or receives healthcare services needs to play a role in greater decision-making. It is an essential factor in the NHS becoming a truly patient-centred service and will undoubtedly help it both face today’s enormous challenges and manage its finite resources.

Involving and engaging patients and the public in decisions about their health and care improves outcomes, strengthens individual well-being and contributes towards more cohesive and healthier communities. And collectively involving patients and the public in the design and delivery of health services improves services and care and engages citizens as taxpayers to contribute to decisions about how resources are used.

This paper explores what it really means to put people first when commissioning and providing services, and sets out what we know about the benefits. It ends with a selection of useful case studies that demonstrate where shared decision-making has already made an impact.

Intended to stimulate discussion, this paper is the second in a series looking at interactions between the NHS, individuals and communities. The first, *Personal experiences, public value: changing relationships in the NHS*, explored what these changes might mean for the future leadership and sustainability of the NHS. A further three papers in the run up to the *2012 NHS Confederation annual conference and exhibition* will explore:

- information and the power paradigm
- micro-enterprises and building community assets
- building social value within the system and society.

*Key points*

- Greater shared decision-making is required for the NHS to become a truly patient-centred service.
- Behaviour change is required by both professionals and individuals to make this a reality.
- Shared decision-making is particularly helpful in situations where there is no clinical evidence in favour of one single best option.
- Shared decision-making and collective involvement may contribute to reducing health inequalities, if interventions and resources are tailored to the needs of disadvantaged groups.
- Collective involvement of patients and communities in the design and delivery of services strengthens communities’ sense of ownership and moderates demand for healthcare.
Putting people first through shared decision-making and collective involvement

**An uneasy consensus series**

These papers are intended to stimulate debate with members and others, culminating in a panel discussion with the authors during the NHS Confederation’s annual conference and exhibition in June 2012. To find out more, go to www.nhsconfed.org/2012

Introduction

The concepts of patients jointly making decisions with professionals about their care, and patients and the public being involved in the design and delivery of health services, are not new but are becoming increasingly important tenets of today’s NHS. Through its Health and Social Care Bill 2011, the Government aims to strengthen democratic accountability and patient voice within the NHS – both at the individual level where patients should be involved in decisions about their care and treatment, and collectively. The bill reforms the existing patient and public engagement structures by establishing HealthWatch to engage both adults and children locally and HealthWatch England nationally. HealthWatch representatives will be statutory members of health and well-being boards, where joint decisions will be made regarding local health and well-being priorities.

The Government’s focus on localism aims to move us towards a system where decisions about public services are being made more locally than ever. We discussed in the first paper of this series how people are taking more control over their own health and the services they use and therefore increasingly using less costly services. This means they are empowered to both improve their own well-being and contribute towards the sustainability of public services and of the NHS in particular.

This paper discusses what shared decision-making and collective involvement mean in the NHS today. The phrase ‘shared decision-making’ is mainly used when describing individual level interactions between patients and professionals about their health and care. We use the phrase ‘collective involvement’ when describing public and patient involvement in designing and delivering health services at a population level.

What do we mean by ‘shared decision-making’ and ‘collective involvement’?

**Shared decision-making**

Shared decision-making (SDM) is a process in which individual patients are involved as active partners with their clinicians to clarify acceptable options and choose their preferred course of care, one that is ideally aligned with their values and preferences. For SDM to happen effectively, it requires patients who are informed, empowered and have the skills, knowledge and confidence to discuss their options with health professionals, and subsequently influence their care and clinical outcomes.

Patients can be supported, using tools such as patient decision aids, and coaching and information materials, to develop the knowledge and confidence they need to communicate their preferences, voice their concerns and make the right choices for them and their families.

Vulnerable patients, from lower socio-economic backgrounds, and those with lower literacy levels, are likely to benefit the most from improved communication and involvement in healthcare. Provided more vulnerable patients receive adequate support and information that they can understand, SDM may also contribute to reducing health inequalities. However, healthcare inequalities will only decrease if interventions and resources can be specifically tailored and targeted to meet the needs of disadvantaged populations.

**Collective involvement**

The phrase ‘collective involvement’ is used when describing the engagement of people, patients and communities in the design, commissioning and delivery of services. This can mean involving patients and the public in the commissioning cycle which splits into three broad activities: strategic planning, procurement and management.

Collective involvement has an important role to play in the decisions NHS commissioners make at each of these points. Further detail about the contribution of engagement at all stages in commissioning, including information on the ‘engagement cycle,’ is available in the Department of Health’s Better health, better experience, better engagement.
Why shared decision-making and collective involvement are so important

Shared decision-making (SDM) is essential if the challenges that face the NHS are to be overcome and it is to become a truly patient-centred service that effectively manages its finite resources.

For patients, SDM is a process where all patients, with appropriate support, can become active partners in decision-making, identifying and choosing the option best tailored to their individual needs, values and preferences. To ensure patients get the care they need and want, it is about making the dialogue between health professionals and patients more equal, where patients and their carers play an active role in their care and decide with their clinicians when, where and how to be treated. The ethos of shared decision-making is simple and intuitive: we should all have the opportunity to be involved in decisions that affect our minds and bodies. By empowering and supporting patients to make informed healthcare decisions, patient satisfaction can be increased, experience improved and the quality of care strengthened.

Collective involvement enables patients and communities to be involved in designing, commissioning and delivering their own local services. It strengthens their sense of ownership, enables people to think about their own use and demand for healthcare resources and results in more personalised and cost-effective services – the sort of services and care that users value.

The NHS Confederation’s October 2011 paper, Patient and public engagement in the new commissioning system,\(^3\) discusses collective involvement and provides different models and approaches. An example of one model is ‘experience-based design’ which focuses on capturing service users’ and carers’ experiences through their stories and involving them alongside clinicians in redesigning experiences rather than just systems and processes.

When is shared decision-making and collective involvement appropriate?

Shared decision-making (SDM) is relevant across the entire care pathway, from lay care/self care right through to highly specialist care, and is not confined to a particular condition, treatment or diagnostic procedure. However, SDM comes into its own in clinical situations that are not clear cut and where there is no clinical evidence in favour of one single best option. Approximately half of all healthcare decisions\(^4\) fall into this category, meaning that discussion with the individual and SDM is appropriate at least half the time. However, many commentators suggest that no single best treatment option applies to the majority of healthcare decisions.

SDM in its truest sense requires both patients and clinicians to share information where each party makes distinctive contributions to the decision-making process. So, patients, incontestable experts about themselves, will typically share their lifestyle, circumstances, medical history and attitudes to risks and values. Clinicians will share their clinical expertise, including the diagnosis, cause of disease, prognosis, treatment options and outcome probabilities.

The principles for collective involvement are similar to that of SDM. A useful handbook, Publicly involved GP leadership,\(^5\) sets out principles for GPs leading programmes of commissioning change by working with their local population.

The benefits

For patients, evidence shows that SDM can increase knowledge, lead to realistic expectations and reduce decisional conflict and indecision.\(^6\) Other likely benefits include reducing the uptake of some elective surgical procedures, where there is over-utilisation,\(^7\) reduced unwarranted practice variation and lower litigation costs.

The Department of Health’s Better health, better experience, better engagement\(^8\) sets out the following benefits of collective involvement:

- bringing patients and public with you from the outset about proposed service change can increase your ability to manage risk and deliver difficult change successfully
- understanding patient experience of services can help you identify areas of waste and inefficiency and how to make services better
- understanding patient experience of services allows you to define the outcomes of service...
reconfigurations from the patient perspective as a ‘measurable’ patient experience

- patients and the public can help you redesign care pathways so that they are more patient-friendly and efficient
- engaging people can help manage demand for services such as inappropriate use of emergency care services.

Progress to date
Patients often feel they are insufficiently involved in decisions about their own care.9 Not being told about their illness and the options for treatment is the most common cause of patient dissatisfaction.

In the last comprehensive patient survey, in 2009, when asked whether they had been sufficiently involved in decisions about their care, nearly half of hospital inpatients and 30 per cent of outpatients said they were not involved as much as they wanted to be.10 A survey about patient involvement specifically found that over 50 per cent of people wanted a model where doctors and patients made joint decisions about treatment decision.11 It also found that a higher proportion of younger people preferred this model, suggesting greater demand in the future for joint decision-making.12 The idea of shared decision-making attracts broad support from patients, professionals and policy makers.13

There is no doubt that the NHS is working towards developing collective involvement models and work has started on shared decision-making and increasing control for people. However, evidence shows a culture of medical paternalism could preclude citizens and patients from being involved in decisions about services. As information becomes more readily available to patients and citizens and we are able to share opinions or good practice with thousands of others at a touch of a button, this type of paternalism will need to change.

What is happening in the NHS already?
The Government’s ambition is for collective involvement and shared decision-making (SDM) to become the norm in the NHS, and for its ‘no decision about me without me’ ethos to become a reality. The principles of both collective involvement and SDM offer a new paradigm to improving patient care and experience, while managing growing demand for healthcare by involving patients and the public in healthcare decisions.

The Health and Social Care Bill places a duty on both the NHS Commissioning Board and clinical commissioning groups (CCGs) to promote involvement of:

- patients and their carers in decisions about their care and treatment
- the public in planning and developing services.

CCGs will need to consult patients and the public on their commissioning plans and report this involvement in annual reports. The NHS Future Forum public health report in January 2012 emphasised the importance of shared decision-making and the need for it to permeate the culture at all levels of the healthcare system, while ensuring that ‘every contact counts’.15

Citizen participation and personalisation
As the NHS moves towards increasing personalisation, putting power into the hands of patients regarding the commissioning of

Patient and public involvement is already a requirement
It is worth reflecting that shared decision-making is not a new phenomenon. As part of their registration with the Care Quality Commission, health service providers are already required to enable “service users to make, or participate in making, decisions relating to their care or treatment” (Regulation 17 of Health and Social Care Act 2008 (Regulated Activities)). Since December 2010, shared decision-making has been included specifically in the NHS operating framework: “PCTs should develop and implement plans for shared decision-making and should include these areas in contracts.” It also features in guidance from health professional bodies such as the GMC’s Good medical practice.

The Commissioning for Quality and Innovation (CQUIN) payment framework, intended for commissioners who want to reward excellence by linking some of the contractor’s income to the achievement of local quality improvement goals, recently included the following goal for CQUIN scheme for acute hospitals: “Improve responsiveness to personal needs of patients.” The composite measure used for this goal includes a survey question which offers one indicator of shared decision-making: “Were you involved as much as you wanted to be in decisions about your care and treatment?”
their care, collective involvement in health services is an extension of this at a population level. In social care, and increasingly in the NHS, self-directed support is seen as a core part of the wider transformation process that aims to promote independence, extend choice and offer cost-effective solutions for citizens needing ongoing support. In social care huge opportunities are being created to give people the freedom and control they want to shape services around their own personal circumstances.

Read the acute service reconfiguration case study on page 6 of this paper to find out about the Office for Public Management’s work to support the Better Services, Better Value and Healthier Together teams.

Increasing opportunities for collective involvement

With the advent of clinical commissioning groups and health and wellbeing boards, now is the time for the new structures to engage communities in the design of their new services. For the first time, locally elected councillors will sit alongside clinicians on the health and wellbeing boards. Together, they will assess the needs of the local population by producing a Joint Strategic Needs Assessment and jointly agree the priorities for commissioning through the joint health and wellbeing strategy.

Bringing the local democratic process together with setting priorities for health commissioning is a significant opportunity. However, collective involvement is about involving all groups within communities, including those that do not hold a vote such as children and young people under 18. Quality mechanisms will be required to ensure diverse and groups representative of local communities are involved and engaged.

The work and learning from the clinical commissioning group pathfinders and engagement front-runners demonstrates how and why emerging commissioning organisations are building new relationships with local people and communities and finding innovative and effective ways of involving people and responding to what really matters to them. For example, in Brighton and Vale Royal, Cheshire, new technology has been shown to reach parts of their local populations that have not responded to traditional engagement approaches. More information and resources are available at NHS Networks Commissioning Zone and Pathfinder Learning Network www.networks.nhs.uk/nhs-networks/clinical-commissioning-community/commissioning-networks

Drawing on the early learning from CCGs, a series of short, practical mini guides bringing the best of good engagement practice to clinical commissioners will be published on the Department of Health website (www.dh.gov.uk/en/index.htm) later in spring 2012. The guides will cover topics such as working with Local Involvement Networks (LINks), patient participation groups (PPGs) and lay members, using new technology and building public support for service change.

Conclusion

To see the real improvements in patient outcomes and achieve the culture change that is fundamental to the success of improved patient care and good long-term conditions management, the principles of shared decision-making and collective involvement must be incorporated throughout the NHS.

It is clear that embedding shared decision-making and collective involvement means significant changes to the patient-clinician relationship and the way care is organised, and draws attention to the required skills, capabilities and expertise of clinicians and commissioners to effectively engage with these ways of working. Our work on personal health budgets shows that service users are sceptical about the possibilities for making personal health budgets work in the NHS as they do not consider current services to be sufficiently person-centred. A paradigm shift in organisational and professional culture towards partnership and supported risk taking is needed to make shared decision-making more of a reality.

There are challenges in ascertaining patients’ and the public’s preferences for involvement and information formats, remaining flexible for different individuals and groups, and in maintaining familiarity and confidence with the data and information produced. However, the case studies we show here demonstrate what can be achieved.

Ultimately, behaviour change is required from both professionals and individuals within communities to shift towards more
Putting people first through shared decision-making and collective involvement

Case study. Acute service reconfiguration: collective involvement

Reconfiguring services is a sensitive and difficult process. One of the four Department of Health tests that any reconfiguration proposal needs to demonstrate is strengthened patient and public engagement (PPE). The Office for Public Management (OPM) has been supporting the Better Services, Better Value (SW London) and Healthier Together (SE Midlands) teams to ensure their reviews are doing everything they can to ensure all stages of their work are informed by the views of patients, the public and other stakeholders.

The Better Services, Better Value (BSBV) review is now entering its final stages. In terms of collective involvement, it started with high-profile, large-scale deliberative events for members. They were asked whether they agreed there was a case for change and how they felt about the future vision. They were also asked to look at a set of draft criteria which would be used to assess reconfiguration options further down the line. Similar deliberative events were then held with a range of stakeholders from across the borough. Between July and December 2011 the BSBV team held hundreds of meetings with stakeholders to tell them about the review and gather their views.

Another deliberative event was also held with 79 GPs. As well as raising awareness of the review, it also aimed to explore the evidence supporting the case for change and provide them with the opportunity to influence future service models in five specific service areas. The following stage involved people who had participated in some of the earlier stages in reviewing proposals for how the service reconfiguration options would be assessed and deciding which should be put forward to formal public consultation.

For the final stage, the review team is designing an appraisal event for a broad range of stakeholders, including patients and the public, to give them the opportunity to review and score the shortlisted options.

For more information, contact rclarke@opm.co.uk

Shared decision-making in the future

With the aim of making shared decision-making a reality nationwide, various national and local initiatives have, or are about to, commence. Below is a snapshot. Patient Decision Aids (PDA), designed to help patients choose the appropriate course of care when there is uncertainty about the best option, are already available on the NHS Direct website (www.nhsdirect.nhs.uk/en/DecisionAids). All nine online PDAs (with a telephone back-up) are evidence-based and easy to use, so patients can weigh up the pros and cons of all available options, watch patient stories and videos of health professionals, input their personal preferences and have an informed discussion with their clinician about the preferred option for them.

Jean Hardiman Smith, who suffers from osteoarthritis of the knee, said:

“[using PDA] was like having a long, unhurried session with a top knowledgeable specialist, with the extra benefit of additional advice from the videos.”

The Health Foundation MAGIC (Making Good Decisions in Collaboration) Programme is currently underway. This project is exploring how SDM can be embedded into clinical practice as a core part of mainstream health services. A report is expected later in 2012. See www.health.org.uk/areas-of-work/programmes/shared-decision-making for more information.

More information on the Department of Health’s Right Care SDM Programme can be found at www.rightcare.nhs.uk/index.php/shared-decision-making/about-the-sdm-programme

What does this mean for your organisation?

• How are the key the issues raised in this paper relevant to you?
• How can we embed shared decision-making and collective involvement more in the NHS?
• How does your organisation need to behave differently to make shared decision-making and collective involvement a reality?
People Powered Health is a new programme from NESTA to support the design and delivery of innovative services for people living with long-term health conditions. The programme focuses on co-production and the idea that people's needs are better met when they are involved in an equal and reciprocal relationship with professionals. It is working with six health and community organisations across the country. For more information, see www.nesta.org.uk/areas_of_work/public_services_lab/people_powered_health for more information.

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