The Health Foundation
Inspiring Improvement

Summit report:

Leading the way to shared decision making

The critical steps for the NHS Commissioning Board to make 'no decision about me, without me' a reality

February 2012

Identify Innovate Demonstrate Encourage

Acknowledgements

We would like to thank all those that took part in the summit for their time and commitment.

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Introduction

The case for 'no decision about me, without me' is clear in ethics and in policy and is supported by a growing evidence base.

To make 'no decision about me, without me' an everyday experience for patients requires a significant change in philosophy, in culture and in the roles of patients and professionals. This fundamental shift must be modelled and led by every part of the system to drive change in government and in the consulting room.

As champion of patient and carer involvement, the NHS Commissioning Board has a critical role to play in making shared decision making the norm.[1]

The summit

In December 2011 the Health Foundation convened patient representatives, clinicians, academics, commissioners, policy makers and health service managers to consider what must be done to make a reality of 'no decision about me, without me'. This report is a distillation of that summit.

A consistent message at the summit was that, while the involvement and leadership of all players in the system is essential, there is a critical role for the NHS Commissioning Board in convening, facilitating and modelling change so that shared decision making is adopted across the NHS.

To make this happen, the Board must:

- engage in the development of a strong narrative for shared decision making
- inspire others to play their part
- invest in the development of robust and meaningful measures of patients' involvement in their own care
- pro-actively encourage the changes in service provision necessary to meet different expectations.

In this report, we briefly introduce the concept of shared decision making and then look at each of these four areas of action for the NHS Commissioning Board, identified at December's summit. A full list of participants is available at the end of this report.

1 Department of Health, 2010. *Equity and excellence: Liberating the NHS.*

What is shared decision making and why is it important?

The case for embedding shared decision making throughout NHS practice has already been made. Not only is there a strong ethical imperative driving the case for patients to be partners in their care, but the evidence shows that involving patients in making important decisions about their lifestyle or their healthcare improves their experience of healthcare and the quality of their lives. Where there are concerns about this direction of travel, they tend to be about implementation rather than the principles.

Delivering evidence-based care is an essential foundation for effective care and, more broadly, the effective use of a limited healthcare resource. However, the uncomfortable truth is that as more people are living longer, developing multiple long term conditions, and thus facing more complex choices between a growing number of treatment or support options, the evidence from single-focus randomised controlled trials is becoming less helpful. In this context patients' goals and preferences need to be given even greater weight, especially where the traditional evidence base may have less relevance to what the patient thinks is important.

What is shared decision making?

Shared decision making is defined by the Foundation for Informed Medical Decision Making[2] as a process in which clinicians and patients work together to choose test, treatment, management or support packages, based on clinical evidence and the patient's informed preferences.

In the context of discussions about 'no decision about me, without me' the term 'shared decision making' is being used more broadly to describe all aspects of people's involvement in their own health and care. This includes access to personal health records, supported self management, personal health budgets, care planning and decision aids.

For the purposes of this document the Health Foundation is using shared decision making in its broadest sense.

What are the benefits?

Research shows strong proven benefits from shared decision making, including:

- better treatment adherence, creating greater effectiveness and value
- improved confidence and coping skills for patients
- fewer patients choosing major surgery, creating cost savings
- improved health behaviours such as greater exercise and reduced smoking
- more appropriate service use, particularly fewer emergency admissions.[3, 4, 5]

2 Further information is available online at: www.informedmedicaldecisions.org/

3 Murray, E., Burns, J., See, T. S., Lai, R., & Nazareth, I. 2005, 'Interactive Health Communication Applications for people with chronic disease', *Cochrane Database Syst Rev* no. 4, p. CD004274.

4 Picker Institute Europe (2010). *Invest in engagement*. London: Department of Health.

5 O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, et al. 'Decision aids for people facing health treatment or screening decisions'. *Cochrane Database Syst Rev* 2009 Jan 1;(3):CD001431.

Patients place even greater value on choice of treatment than location of treatment.[6] Many people want to exercise greater control over many aspects of their care. However, it is still the case that most of the policy on choice is restricted to decisions about where treatment is to be delivered and who will carry it out, as opposed to the more fundamental decision of what treatment to have. Questions about how patients can get involved in deciding which course of treatment is most appropriate to them, given their preferences and values, have received insufficient attention from policy makers and practitioners.

It is a truism that we measure what we value and value what we measure. The NHS Outcomes Framework 2011/12[7] includes measures of patient experience under the domain 'ensuring that people have a positive experience of care' but gives insufficient attention to patients' participation in decision making.

Those who create the policy that shapes the way healthcare is delivered could influence the extent to which shared decision making is practised. For example, they could:

- create materials that identify decision points in patient pathways and provide information and decision support
- ensure that relevant training is available for health professionals
- incentivise the practice of shared decision making through measurement, feedback and contracting.

However, the scope for policy makers to directly influence the extent to which shared decision making is taking place shouldn't be over-estimated.

Fundamentally, shared decision making is something that largely takes place in the private space between a patient and a health professional. The attitude and behaviour change required on behalf of clinicians and patients, the need for approaches to be adapted to each patient and the diverse nature of the issues that arise during clinical consultations means that this area is very different from many of those for which policy is designed.

Successful implementation of shared decision making requires both patients and clinicians to interact in new and challenging ways. This cannot be mandated, specified in a contract or designed into a pay-for-performance system: the participants need to have internalised the ideas and so change their behaviour because they believe it is the right thing to do, not because they have been directed. This type of change requires radically different techniques from those usually employed by policy makers.

As the new operating model for the NHS in England is designed and introduced, there is an opportunity for the NHS Commissioning Board to play a critical part in making shared decision making the norm, fulfilling its role as champion of patient and carer involvement.

6 Coulter, A. 'Do patients want a choice and does it work?' *BMJ* 2010; 341:c4989

7 Department of Health, 2011. *The NHS Outcomes Framework 2011/12.*

Critical steps for the NHS Commissioning Board

1. The Board must engage in the development of a strong narrative for shared decision making

While the case for shared decision making is strong, some are still sceptical about its value, some believe that shared decision making is already commonly practised and others face considerable anxieties in making the change. Many people don't know what shared decision making is. More needs to be done to ensure that:

- the perspectives of clinicians and patients are understood
- the ideas and the strong case supporting shared decision making are considered by patients, commissioners, professionals and providers
- shared decision making is embedded in everyday practice.

Successful change processes often start with a deep understanding of the views of those involved and development of meaningful narratives about why there is a need for change, what it means for people, how it will be an improvement and what healthcare could be like. The NHS Commissioning Board must support all those with influence over the design and delivery of healthcare to work collaboratively to develop an impactful narrative for shared decision making.

The narrative must explore different behaviours and the underlying change in thinking. There are myths around shared decision making and genuine concerns which need to be unpacked and carefully considered. These include:

- the concern that shared decision making is incompatible with evidence-based practice
- the anxiety that professionals may have about this change in practice
- the view that shared decision making is not what patients want
- the concern that shared decision making poses a threat to the traditional way that doctors relate to patients: Does it damage the standing of the doctor? Could it reduce the effectiveness of the consultation as a form of therapeutic intervention?

Understanding these issues and supporting clinicians to change their practice styles is a job for professionals, peers and their leaders, not the NHS Commissioning Board. However, the Board could do much to support and encourage the Royal Colleges and other medical and nursing organisations to pick up the leadership baton.

One important point to note is that, although there is some evidence that shared decision making can reduce the use of expensive treatments, this may not be a helpful way of making the case to professionals.[8] Not only is it not always true but it obscures much more compelling arguments.

2. The Board must inspire others to play their part

Other parts of the system have critical contributions to make to foster shared decision making. The NHS Commissioning Board needs to encourage all those who have influence over the commissioning and delivery of healthcare to demonstrate how they are advancing shared decision making and patient participation, and what they are doing to promote this amongst their own stakeholders.

8 The Health Foundation, due to be published in 2012. *Helping People Share Decision Making.*

The NHS Commissioning Board will need to inspire professional bodies, regulators and patient organisations to:

- collaborate in the creation of a shared and strong narrative for shared decision making
- contribute to raising awareness of shared decision making
- lead change and deploy their powers or influence to make 'no decision about me, without me' real
- collaborate with others in developing measures to assess the extent to which shared decision making is being practised.

The NHS Commissioning Board needs to work together with the National Institute for Health and Clinical Excellence (NICE), the Care Quality Commission (CQC), Public Health England and Healthwatch England. NICE could greatly assist in making 'no decision about me, without me' a reality by ensuring its guidance is presented in a patient centred way and making more evident and accessible the choice of treatment options available. The CQC could equally assist by placing greater weight on the standards that relate to shared decision making.

The Board will directly influence clinical commissioning groups through the commissioning outcomes and indictors that it will set and the guidance and tools it will develop. These should inspire a process of challenge, encouragement and measurement but avoid attempts to specify in detail how providers and professionals should behave. There is a high risk that a performance based approach would be counter-productive – changes to clinicians' behaviour must develop from within the professions themselves.

Professional bodies have a key role in creating a culture among healthcare professionals that supports shared decision making. The NHS Commissioning Board could work more closely with professional bodies and regulators to support them in promoting changes in the style of clinical consultations and in embedding shared decision making in training and continuing professional development.

Non-judgemental observations of patient consultations and individual quality measurements, including patient experience as well as feedback from peers, should become an important component of training, selection, appraisal and revalidation.

The systematic gathering of feedback about patients' experience of consultations and supporting professionals to reflect and learn from this is absent from our current system. Yet it is one of the most effective changes that could be introduced.

Over the next two years, as the new operating model for the NHS in England is designed and introduced, there is a critical window of opportunity for the NHS Commissioning Board. To fulfil its role as champion of patient and carer involvement, the Board must take action as soon as possible to:

- provide practical support to help develop a community of practice of people who are leading change in this area
- bring together and support a leadership coalition of nationally influential people and organisations
- create awareness of shared decision making and supported self-management among patients, ensuring the availability of high quality decision support materials and fostering the development of organisations supporting patients to share in decision making
- build capability and capacity for shared decision making among commissioners, patient representatives, providers and professionals
- stimulate third party providers that could support shared decision making through methods such as providing information and pre and post consultation coaching
- review the mechanisms that could be used to ensure clinical commissioning groups commission for the involvement of each patient and at the very least ensure these mechanisms do not hinder shared decision making. These mechanisms might include the standard contract, CQUIN schemes, the GMS contract and choose and book.
- formally request NICE to develop standards and guidelines on support for self management, shared decision making and patient information. It must ensure these standards are supported by an implementation strategy.

3. The Board must invest in the development of robust and meaningful measures of patients' involvement in their own care

It is essential that robust and meaningful measures of patient involvement are developed to track progress in implementing 'no decision about me, without me' and improving the practice of shared decision making. The NHS Commissioning Board and other bodies will need measures of patient experience, decision quality and patients' confidence to self-manage to be able to demonstrate how they are creating an improved service. These measures should be given prominence in data collection throughout the NHS.

The NHS Commissioning Board should work with the National Institute for Health Research, academic researchers and other stakeholders to review existing measures and to assess what others are required.

A number of validated tools of patient activation and decision quality are already available but they are not used consistently or widely across the NHS. Capturing decision quality is a vital way of measuring progress in implementing shared decision making. The key questions to assess decision quality are:

- Was the patient informed about key options?
- Did the clinician involve the patient in the decision?
- Did the treatment selected match the patient's preferences?
- Does the patient have sufficient confidence and motivation to follow agreed care plans?

Investment is needed to build upon existing measures and develop those that are both tailored for specific conditions and that can support comparison across the health service. In particular, measures must be comparable between subgroups of the population, between patients with different conditions and between areas. For example, do different groups of patients have different expectations to the population generally about shared decision making or the level of patient activation required?

There is a trade-off between developing measures that will give a general measure of progress and an overall picture, and having measures that are considered specific and sensitive enough to reflect the concerns of patients faced with different decisions. Combining measures of shared decision making with PROMS, other patient experience data and data on practice variations has the potential to provide a powerful analytic tool which providers and commissioners could use to monitor changes in service design and quality. Ensuring a coordinated approach to the development and use of measures will be crucial.

4. The Board must pro-actively encourage the changes in service provision necessary to meet different expectations

As a major commissioner itself, the NHS Commissioning Board is well placed to encourage innovation and early adoption. While shared decision making starts with a change in mindset, it needs to be coupled with a change in system design and delivery. The Board should create demonstration sites for new techniques, advanced approaches, training and development, patient education and capacity building as well as the development of measurement systems.

The development of new approaches, such as experiments using social media and other innovative methods need to be nurtured and rigorously evaluated. New providers of health services may need to be encouraged to try innovative approaches – particularly as the introduction of new providers may be the only way to make rapid shifts in practice in some areas.

Conclusion

In the face of significant financial pressure and immense structural change, it is vital that the NHS Commissioning Board remains focused upon its role to champion patient and carer involvement.

Over the next two years, as the new operating model for the NHS in England is designed and introduced, there is a critical window of opportunity for the NHS Commissioning Board.

The Board has a key role to play in convening, facilitating and modelling change so that shared decision making is adopted across the NHS and the principle of 'no decision about me, without me' becomes part of people's everyday experience.

Ensuring that patients have the opportunity and support to be involved in their care will be crucial for ensuring that the social contract that underpins the NHS survives what may be its stiffest test yet.

Participants in the Health Foundation's summit of 5-6 December 2011

The views expressed by those participating in the Health Foundation's summit contributed to this report. However *Leading the way to shared decision making* does not necessarily represent their views.

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We want the UK to have a healthcare system of the highest possible quality – safe, effective, person-centred, timely, efficient and equitable. We believe that in order to achieve this, health services need to continually improve the way they work.

We are here to inspire and create the space for people, teams, organisations and systems to make lasting improvements to health services.

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