



# BACKGROUND BRIEFING

## No decision about me without me

5 October 2011

### CREATING AN NHS WITH THE PRINCIPLE OF 'NO DECISION ABOUT ME WITHOUT ME'

The slogan, 'No decision about me, without me', was originally a demand formulated by the emerging patient movement.

Patients' experience of health services had been that, while clinical care might be very good, patients were treated as 'units of disease' and not as people with rights to information and to participation in discussions and decisions about their care and treatment.

Moreover, a strong evidence base has been built up which shows that, where individual patients are involved in this way, outcomes improve. These outcomes include better patient experience (one of the three domains of quality), greater confidence and knowledge to manage one's health, and better use of health service resources, for example through take-up of appropriate screening and prevention.

In 2002 the independent Wanless report recommended that, in order to cope with rising demand and costs, the NHS should move to ensure that all patients were 'fully engaged' in managing their health status and healthcare.

The current government recognised the strength of this evidence when it adopted the 'no decision' slogan in its 2010 White Paper, *Equity and Excellence: Liberating the NHS*:

"International evidence shows that involving patients in their care and treatment improves their health outcomes, boosts their satisfaction with services received, and increases not just their knowledge and understanding of their health status but also their adherence to a chosen treatment. It can also bring significant reductions in cost, as highlighted in the Wanless Report, and in evidence from various programmes to improve the management of long-term conditions."

The Government therefore declared that:

"We want the principle of 'shared decision-making' to become the norm..."

Thus, for the NHS to be a first class health service, people need to be given the right support so that they can be in control of their own health and healthcare decisions.

The NHS needs to transform the way it helps people become involved in their own care and make choices about how they look after their health, what tests and treatments they have, and how their care is provided.

A system where people are supported to be involved as active partners in their own care needs to offer true choice. True choice encompasses supporting people to make good daily choices about their health. It includes supporting people with the choices about what sort of healthcare they need and what type of treatment would suit them, as well as who provides that treatment. They are all choices that matter and that people want.

## **HOW ARE PEOPLE CURRENTLY INVOLVED IN THEIR HEALTH AND HEALTHCARE?**

In the current NHS, shared decision-making is far from 'the norm'.

People who use the NHS, and patient organisations that are members of National Voices, consistently say that the choices and decisions that matter most to patients are choices about the treatment and care they receive. Examples of these sorts of decisions include whether to have surgery and what type of surgery to have, and which medication to take, where there are options.

Research shows that patients care more about being able to exercise choice in relation to these types of questions than they care about being able to choose between providers of healthcare, eg which hospital or GP to use.<sup>1</sup>

Currently in England, the NHS performs very poorly in involving people in treatment decisions, despite the degree of priority patients attach to such involvement.

The latest data from national patient surveys published by the Care Quality Commission shows that 48% of all inpatients, and around one third of outpatients, primary care patients and maternity service users say they were not as involved in decisions about their care and treatment as they wanted to be. These proportions have barely improved since 2002.<sup>2 3</sup>

## **WHAT ARE THE BENEFITS OF PEOPLE BEING SUPPORTED TO TAKE AN ACTIVE ROLE IN THEIR HEALTH AND HEALTHCARE?**

Shared decision making is the involvement of patients as equal partners in their healthcare. Tools to support shared decision making can include self-management support, access to personal health records, personal health budgets, care planning and decision aids.

Systematic and other high level research reviews show strong proven benefits from shared decision making, including:

- fewer patients choosing major surgery, creating cost savings
- better treatment adherence, creating greater effectiveness and value

---

<sup>1</sup> Coulter, A. 'Do patients want a choice and does it work?' BMJ 2010;341:c4989

<sup>2</sup> Care Quality Commission, National NHS patient survey programme: survey of adult inpatients 2010; survey of adult outpatients 2009; maternity survey 2010; survey of local health services 2008.

Available at [www.nhssurveys.org](http://www.nhssurveys.org).

<sup>3</sup> Richards, N and Coulter, A. 'Is the NHS becoming more patient-centred?' Picker Institute Europe 2007

- improved confidence and coping skills
- improved health behaviours such as greater exercise and reduced smoking
- more appropriate service use, particularly fewer emergency admissions.<sup>4 5 6</sup>

For clinicians, a lack of shared decision making can compromise their effectiveness: the impact of clinicians' interventions can fall short if patients do not have the understanding or motivation required to adhere to treatment options or desired lifestyle changes.

For commissioners, it means that the services provided may not deliver the best outcomes for patients or meet their individual preferences. This may hamper the achievement of other commissioning duties such as the duty to improve quality and the duty to reduce inequalities (since patients with lower health literacy need more intensive engagement and support in order to improve their health and behaviours).

For patients, it means that they may not receive the care that best meets their needs and they may remain as passive recipients of care rather than taking an active role in managing their own health.

Failing to see patients as partners compounds the problems that lead to them being treated without dignity or respect. We are a long way from 'No decision about me without me'.

The government and commissioners must transform what remains a very paternalistic health service and remove the enforced dependency that the current system and culture creates. There is good international evidence<sup>7 8</sup> and practical experience from within the UK that shows that this is possible.<sup>9</sup>

## HOW CAN CLINICAL COMMISSIONING GROUPS HELP?

For shared decision making to be made real there need to be big changes in the way the NHS relates to patients, for example, how clinics are organised needs to change and so to do the style of consultations patients have with professionals, as demonstrated by the Year of Care pilots in Diabetes<sup>10</sup>.

---

<sup>4</sup> 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.

<sup>5</sup> Picker Institute Europe (2010). *Invest in engagement*. London: Department of Health.

<sup>6</sup> 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.

<sup>7</sup> *ibid*

<sup>8</sup> The Health Foundation (2011). *Helping people help themselves: a review of the evidence considering whether it is worthwhile to support self-management*.

<sup>9</sup> The Health Foundation has worked with over 500 clinical staff and 1000 patients in eight health economies across the UK through our Co-creating Health programme; see <http://www.health.org.uk/areas-of-work/programmes/co-creating-health>. Our MAGIC programme is building shared decision making into primary and secondary care in Newcastle and Cardiff. See <http://www.health.org.uk/areas-of-work/programmes/shared-decision-making/>.

<sup>10</sup> NHS Diabetes, Diabetes UK, The Health Foundation, and Department of Health (2011), *Year of Care: Report of findings from the pilot programme*

Commissioners potentially hold the levers to require these changes from their providers. But the new commissioning organisations – both the NHS Commissioning Board and local Clinical Commissioning Groups (CCGs) – are starting from a low base of knowledge and awareness of good practice in shared decision making. They need to be supported through the Health and Social Care Bill and its guidance to 'commission for involvement'. That means ensuring that all the care and treatment they plan and purchase for 'each patient', involves as fully as possible the individual patient in that care and treatment.

In addition, the requirement for authorisation of CCGs should support 'commissioning for involvement'. A recent revision to draft guidance issued to emerging CCGs by the Chief Executive of the NHS<sup>11</sup> states that CCGs "need to promote shared decision making by patients, about their care". This is a welcome improvement on the previous version, which suggested that CCGs should directly engage with their local patient population in order to gain 'insights' that can inform commissioning. This initial step must be built upon with subsequent statutory guidance and regulations.

## CONCLUSIONS

There is the potential for the Government to make real "no decision about me without me". This will require changes to the Health and Social Care Bill and to the authorisation of CCGs. If these changes are made, commissioners will start to commission for engaged patients. This will enable patients and clinicians to change how they relate to each other and as a result improve health outcomes and transform the NHS.

For further information:

Liza Coffin, Senior Public Affairs Manager  
The Health Foundation  
020 7257 8051  
liza.coffin@health.org.uk  
[www.health.org.uk](http://www.health.org.uk)

Don Redding, Director of Policy  
National Voices  
077 8654 2615  
don.redding@nationalvoices.org.uk  
[www.nationalvoices.org.uk](http://www.nationalvoices.org.uk)

---

<sup>11</sup> Developing clinical commissioning groups – towards authorisation, DH, 30 September 2011