



# Health & Social Care Bill

## Second Reading Briefing

### No decision about me without me: completing the agenda

5 October 2011

#### OVERVIEW

There is a crucial piece of unfinished business in the Health and Social Care Bill's attempts to entrench the principle of 'no decision about me, without me' in the reformed NHS.

Government amendments to the Bill in Commons committee have strengthened the accountability and transparency of new organisations to patients and the public. However, we remain concerned that the Bill does not go far enough to ensure that individual patients are involved in decisions about managing *their own care and treatment*.

Involving patients in their care improves the quality of patient care *and* leads to better, more efficient use of limited NHS resources.

There are some duties for commissioners which *could* be used to promote individual involvement. But, they do not represent a clear enough signal to the system, and are unlikely to be interpreted or acted upon to improve and increase the involvement of patients in decisions about their care.

The Health Foundation and National Voices are therefore seeking reassurances from the Government about how it expects the NHS Commissioning Board and Clinical Commissioning Groups (CCGs) to commission services that promote those modes of *individual patient involvement* that are proven to be effective in improving quality.

#### WHAT WE ARE ASKING PEERS TO DO

The Health Foundation and National Voices are respectfully asking peers to:

- Question Ministers at Second Reading to get clarification of the Government's intention behind clauses 20(13H) and 23(14T) [duties to promote the involvement of each patient] and clauses 20(13I) and 23(14U) [duties as to patient choice].

This would provide an opportunity for the Minister to set out, on the record, the scope of the duties, and to set out broad definitions of involvement and choice, which reflect the recommendations made by the Future Forum.

We would ideally like to see the definitions of both involvement and choice separately probed.

*Identify Innovate Demonstrate Encourage*

- Seek a commitment from Ministers that statutory guidance and/or regulation will a) reflect the full range of modes of individual involvement and choice, and b) require commissioners to demonstrate through evidence that they are commissioning services that enable patients to be involved and have choice over their care and treatment.

Below are listed examples of places in the Health and Social Care Bill where there is a commitment to developing guidance or regulations. Issues (a) and (b) could be clarified in these regulations and guidance when it is developed:

- regulations under clause 17(1)(6E) whereby the Secretary of State may require the Board or CCGs to commission specified services, or to commission them in specified ways, and may require certain matters, terms and conditions to be specified in commissioning contracts
  - guidance developed under clause 23(14T)(2) ["The Board may publish guidance for clinical commissioning groups on the discharge of their duties under this section"]
  - regulations developed under clause 22(14C)(3) on the Board's authorisation of CCGs ["Regulations may make provision - (a) as to factors which the Board must or may take into account in deciding whether it is satisfied as to the matters mentioned in subsection (2); (b) as to the procedure for the making and determination of applications under section 14B"].
- Ask Ministers at Second Reading how the NHS Commissioning Board and the CCGs will be held to account for promoting involvement of each patient and patient choice and how this will be measured.

This would provide an opportunity for the Minister to set out how the NHS Commissioning Board will be held to account for meeting these duties, and how in turn the Board will hold CCGs to account for meeting their duties. It will also be an opportunity for the Minister to provide clarity about what evidence will be collected on the fulfilment of the duties and how any failures to fulfil them will be rectified.

## RELEVANT CLAUSES IN THE BILL

### 13H Duty to promote involvement of each patient

The Board must, in the exercise of its functions, promote the involvement of patients, and their carers and representatives (if any), in decisions about the provision of health services to the patients.

*Explanatory Note:*

*195. Duty to promote involvement of each patient.*

*New section 13H requires the NHS Commissioning Board, in exercising its functions, to promote the involvement of individual patients and their carers and other representatives in decisions about their own care (shared decision-making) including the management of their own care. This could be achieved through effective involvement and engagement in dialogue with CCGs, through commissioning and contract guidelines, and outcomes frameworks. This duty is intended to address the commitment outlined in the White Paper Equity and Excellence: Liberating the NHS to the policy of "no decision about me without me".*

### 13I Duty as to patient choice

The Board must, in the exercise of its functions, act with a view to enabling patients to make choices with respect to aspects of health services provided to them.

*Explanatory note:*

*196. Duty as to patient choice.*

*New section 13I requires the NHS Commissioning Board to act with a view to enabling patients to make choices with respect to aspects of health services provided to them. The NHS Commissioning Board will be responsible for championing effective involvement and engagement in decisions about healthcare by working with CCGs, local authorities, voluntary sector groups, patient-led support groups and Healthwatch, for example. The intention is that the Board would also develop and agree with the Secretary of State the guarantees for patients about the choices they can make. In addition, the Board will be responsible for commissioning, promoting and extending information to support meaningful choice over the care and treatment that people receive, where it is provided and who provides it (including personal health budgets). This information should include patient-reported experience and outcome measures.*

#### **14T Duty to promote involvement of each patient**

(1) Each clinical commissioning group must, in the exercise of its functions, promote the involvement of patients, and their carers and representatives (if any), in decisions about the provision of health services to the patients.

(2) The Board may publish guidance for clinical commissioning groups on the discharge of their duties under this section.

(3) A clinical commissioning group must have regard to any guidance published by the Board under subsection (2).

*Explanatory note:*

*294. Duty to promote involvement of each patient.*

*Section 14T requires that CCGs must, in the exercise of their functions, promote the involvement of patients and their carers and representatives in decisions about the provision of health services to patients. The Board may publish guidance on how to discharge this duty, to which CCGs must have regard*

#### **14U Duty as to patient choice**

Each clinical commissioning group must, in the exercise of its functions, act with a view to enabling patients to make choices with respect to aspects of health services provided to them.

*Explanatory Note:*

*295. Duty as to patient choice.*

*Section 14V imposes a duty on CCGs, in the exercise of their functions, to act with a view to enabling patient choice (for example, by commissioning so as to allow patients a choice of treatments, or a choice of providers, for a particular treatment).*

## **OUR CONCERNS**

### **Duties to promote involvement of each patient**

We are concerned that the Bill's Explanatory Notes imply that a dialogue between local patients and their CCGs would be an acceptable mechanism for delivering the duty to promote patient involvement. This would not promote patients' involvement in their own care and treatment.

Rather than commissioners themselves engaging directly with 'each patient' for whom they secure the provision of services, we want the Bill and guidance to CCGs to require them to 'commission for involvement'. That is, they must ensure that all the care and treatment they plan and purchase for 'each patient', engages as fully as possible the individual patient in that care and treatment.

### **Duties as to patient choice**

The Bill's Explanatory Notes on the choice duties refer to patients having choices about both treatment and the provider of their treatment. However we are concerned that the greater focus is on 'system' choices, such as choices of providers, since these are the easiest to develop and 'guarantee' through national policy and the 'choice mandate'.

## Accountability

We want clarity about how the NHS Commissioning Board, and in turn the CCGs, will be held to account for performing all these duties and what evidence will be used to demonstrate that they are fulfilling them.

## WHAT WE ARE SEEKING FROM THE GOVERNMENT

We need clear statements from Ministers of their intent for these duties and a tangible commitment to statutory definitions that will ensure proper interpretation. Otherwise a key opportunity to capitalise on the strong evidence base for patient engagement is going to slip away. We would also like there to be accountability on the NHS Commissioning Board for the duties of patient involvement and patient choice.

Ideally, we would like the following definition of 'patient involvement' and 'patient choice' to be spelt out clearly in guidance or regulations in relation to clauses 13H, 13 I, 14T and 14U:

- ability to comment and give views about the quality of their care and treatment
- ability to choose the means by which healthcare is provided (eg telephone, e-mail, web-consultation, as well as traditional 1-1 face-to-face visit)
- provision of appropriate information, and support to use it, in relation to care and treatment
- being enabled to understand all available treatment options, including their risks and benefits
- being enabled to make, or to participate in making, decisions about care and treatment
- being actively supported and encouraged to manage one's own health, care and treatment
- giving consent to care and treatment

Some people (civil servants, clinicians, patients, policy-makers) use the terms choice and involvement interchangeably. In this context, we have drafted the definition above so that it can be used as the definition *either* of choice, *or* of involvement, *or both*. We would ideally want the Department to set out a definition of each, both separately encompassing the full range of types of involvement/choice given above. This would overcome problems that may arise from people using the terms interchangeably.

With regard to providers, statute already exists requiring them to enable these modes of involvement or choice<sup>1</sup>. What is missing is the expectation that commissioners will plan and buy services that enable patients to be involved in their own care treatment.

## ABOUT US

The Health Foundation is an independent charity working to continuously improve the quality of healthcare in the UK. We are here to inspire and create the space for people to make lasting improvements to health services. Working at every level of the system, we aim to develop the technical skills, leadership, capacity and knowledge, and build the will for change, to secure lasting improvements to healthcare

National Voices is the coalition of health and social care charities working to strengthen the voice of patients. Our broad membership, rooted in people's experience, represents millions of people, and covers a diverse range of health conditions and communities.

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<sup>1</sup> Health and Social Care Act 2008 (Regulated Activities) Regulations 2010, especially Regulation 17, 'respecting and involving service users', Regulation 18 (giving consent) and Regulation 19 (complaints).

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