



National Voices

People shaping health
and social care

National Voices

HEALTH AND SOCIAL CARE BILL 2011

Briefing for House of Lords Second Reading, 11th October

Summary of improvements sought

National Voices has welcomed the government's vision of Putting Patients First, and relevant amendments made since the 'pause', but seeks further improvements and clarifications as follows:

- 1. Key issue: clarify the duty to commission for individual patient involvement in care and treatment**
Sections 20(13H) and 23(14T)
- 2. Recognise expert patients and patient organisations as people from whom commissioners should 'obtain advice'**
Sections 20(13H) and 23(14V)
- 3. Establish a Duty of Candour so patients must be informed when things go wrong with their care and treatment**
New Section 5
- 4. Ensure HealthWatch England has strength and independence to be an effective patient champion**
Sections 178(2)(1B) and 178(45A)
- 5. Provide for elections to HealthWatch England from local HealthWatch organisations**
Section 178

Notes:

On issue 1, individual patient involvement, National Voices has produced a detailed joint briefing with the Health Foundation. This is available by email from don.redding@nationalvoices.org.uk

On issues 1 and 2, National Voices has been campaigning with ten other national charities since February 2011 (see below).

About National Voices

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.

National Voices has been working since February 2011 to improve the Bill, together with a coalition of ten other charities: Rethink Mental Illness, Macmillan Cancer Support, Diabetes UK, Breakthrough Breast Cancer, Age UK, the British Heart Foundation, the Neurological Alliance, the Stroke Association and Asthma UK.

1. Key issue: defining patient involvement

WHAT WE ARE ASKING PEERS TO DO

- ask questions of Ministers that draw out the Department's full expectations with regard to: Sections 20(13H) and 23(14T) [duties to promote the involvement of each patient] – what does the duty mean and what specific aspects of 'involvement' should commissioners promote?
- ask through questions to Ministers for a commitment that statutory guidance and/or regulations relating to these duties 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 to improve outcomes in relation to individual involvement and choice

The single most important aspect of 'no decision about me, without me' is still at risk of failure. This relates to commissioners' duty to ensure the involvement of individual patients in decisions on managing their own care and treatment.

Such individual engagement is a potential 'win-win'. It improves the quality of patient care and leads to better, more efficient use of limited NHS resources.

The evidence base¹ for the effectiveness of involving patients in shared decision making is well developed and referenced by the government in its White Paper as a key justification for its adoption of the 'no decision' approach:

"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."²

Thus, individual involvement results in higher quality and better value – and therefore this section is one of the most relevant in the Bill for meeting the 'Nicholson challenge'.

¹ See www.pickereurope.org/investinengagement which contains a DH-funded review and analysis of 280 high level and systematic research reviews on the effectiveness of interventions to involve patients in health services

² Equity and Excellence: Liberating the NHS, DH, 2010

National Voices strongly believes that this duty will not have an impact unless it sends a very clear signal to commissioners about the meaning of 'patient involvement' and what is involved in commissioning for it.

This duty is not about commissioners themselves engaging with patients (which is properly part of the 'public involvement' duty). It is about commissioning care and treatment services in such a way that those services engage patients as fully as possible in managing and controlling their health and care.

To provide a clear signal to the system, the relevant Sections should offer a definition of patient involvement. This should include those interventions proven to be effective – where services provide patients with:

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

National Voices has pressed for such a definition to be on the face of the Bill, with appropriate wording to ensure it does not exclude other forms of involvement.

The government has resisted putting a definition in primary legislation. Yet the aspects mentioned above are *already* in statute – in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010³, which applies to providers, and which the CQC uses as its 'outcomes' for regulating provider performance.

Department of Health officials have verbally assured us that the Department wants the same meaning and same outcomes for 'patient involvement' as we do, but that this can be done through guidance under this section.

On behalf of patients, service users and carers, National Voices requests peers to test the government's intentions with regard to this section; to seek Ministerial statements on the record to clarify the meaning and scope of the duty; and to explain which guidance or regulations will provide system-wide clarity for it.

2. Patients providing advice to commissioners

WHAT WE ARE ASKING PEERS TO DO

- Seek amendment to the duties on commissioners to obtain advice -- Sections 20(13H) and 23(14V) -- so that they include expert patients and patient organisations among those who provide the advice.

³ Note in particular Regulations 17, 18 and 19: <http://www.legislation.gov.uk/uksi/2010/781/part/4/made>

National Voices and its charity coalition partners welcome multi-disciplinary commissioning, for which we campaigned, which the Future Forum picked up, and to which the government responded.

However, we also campaigned for commissioning similarly to involve expert patients and their organisations. Although the clinical workstream of the Future Forum backed the inclusion of lay people and patient groups in, for example, networks and senates, the government did not pick this issue up.

Simply, patients with experience of a condition and its treatment become, over time, experts, particularly in the way in which care and treatment are experienced by users, and how they could be improved from the user viewpoint. This is especially true of chronic conditions, where the patient's journey with the condition can last years and decades.

Patient organisations can aggregate these experiences. They may also, often, be more knowledgeable in the pathways, standards and quality indicators for their particular condition than local commissioners are.

The best existing clinical networks involve patient representatives and patient organisations as equal partners in advising on commissioning and provision, and this should be the model for new networks and senates under the Bill's revised provisions.

A simple amendment to the duty would help to give effect to this, as well as to local consultations by commissioners, and we believe it would not be opposed by government.

Proposed amendments:

In Section 20(13H) and Section 23(14V) –

Insert new sub-clause (c) –

'patients' experience of illness and of relevant healthcare services'

3. Establish a Duty of Candour so patients must be informed when things go wrong with their care and treatment

WHAT WE WANT PEERS TO DO

- Insert a new clause to require any organisation providing NHS services to inform a patient and their family or carer as soon as it is known that any adverse incident that may have caused them harm, or may cause them harm in the future, has occurred during their treatment or care

There is currently no statutory requirement that forces disclosure to the patient when something has gone wrong during their care and treatment.

This has allowed cases to occur where NHS organisations have withheld such information from patients or, worse, actively covered it up.

Organisations concerned with patient safety, including National Voices, have campaigned for a statutory Duty of Candour to rectify this situation.

In its response to the NHS Future Forum, the government promised to introduce a 'duty of candour', but without using the word 'statutory'.

In its subsequent report on complaints and litigation the House of Commons Health Select Committee recognised the force of the arguments for a statutory duty. Its own recommendations, however, were that:

- a) "service agreements between NHS commissioners and their providers should include a contractual duty of candour to the commissioner", and
- b) "a duty of candour to patients from providers should also be part of the terms of authorisation from Monitor, and of licence by the Care Quality Commission".⁴

We understand the committee's opinion that this would provide a route to openness.

Putting such a requirement into the licence terms of the CQC would, de facto, create a statutory duty as it would require a change to the secondary legislation (regulations) under the Health and Social Care Act 2008.

In its response to the committee the government's rejected the second recommendation precisely because it would be a statutory change:

"The Government has already committed to implement a contractual duty of candour requiring hospitals to be open with patients when things go wrong... Making a Duty of Candour to patients part of the terms of authorisation for providers would represent a further statutory duty. For this reason, the Government does not currently intend to introduce a statutory duty of candour into the CQC registration requirements."⁵

National Voices is concerned that this approach will create only a weak contractual arrangement, since commissioners are yet to prove they have the strength to take on powerful providers on behalf of patients.

We are also concerned that the government seems to envisage this would only apply to 'hospitals', not to all providers of NHS services. Some of the most egregious cases of non-disclosure have been where, for instance, general practitioners have made mistakes or caused harm.

National Voices does not understand why patients' basic right to disclosure of information about care that may cause or have caused them harm cannot be included in statute.

We believe a probing amendment to put such a duty on the face of the Health and Social Care Bill will press Ministers further to justify their continuing resistance.

Proposed amendments:

Page 2, line 29:

Insert new Section 3: The Secretary of State's duty to secure openness and transparency with patients when things go wrong

⁴ House of Commons Health Select Committee Sixth Report of Session 2010-11: Complaints and Litigation, HMSO, July 2011

⁵ Government Response to the House of Commons Health Select Committee Sixth Report of Session 2010-11: Complaints and Litigation, HMSO, September 2011

“After section 1A of the National Health Service Act 2006 insert—

“1 B **Duty of Candour when things go wrong**

“The Secretary of State must act with a view to securing -

- (a) that any persons providing health services should provide, within as short a period as possible, full information to patients, their carers or representative about any incident or omission in or affecting their care which may have caused harm, or may in the future cause harm

- (b) that regulations are introduced to enable the Care Quality Commission to take action against a registered person or body who fail to disclose details of such incidents as set out in those regulations”

4. Ensure HealthWatch England has strength and independence to be an effective patient champion

WHAT WE WANT PEERS TO DO

- amend the Bill so that HealthWatch England has the function of making recommendations – not just providing advice – to the Secretary of State, the Care Quality Commission, the NHS Commissioning Board, Monitor and local authorities

HealthWatch England is a government innovation to provide a powerful consumer champion for the views and experiences of patients, their families and carers.

Members of the current Local Involvement Networks, which will make the transition to local HealthWatch organisations, are already concerned that, by being created as a ‘committee’ of the CQC, the national HealthWatch may have its independence and authority compromised.

As a further bulwark to its independence, therefore, National Voices proposes that HealthWatch England should be able to make recommendations to the Secretary of State and the various arms-length bodies to which it relates. They in turn should be required to respond publicly.

Proposed amendments:

p175, Section 178(2)(1B), line 24:

after ‘assistance’, insert ‘and make recommendations’

p176, Section 178(45A)(3), line 9:

after ‘information’ insert ‘, recommendations’

p176, Section 178(45A)(6), line 26:

after ‘information’ insert ‘, recommendations’

5. Provide for elections to HealthWatch England from local HealthWatch organisations

WHAT WE WANT PEERS TO DO

- amend the Bill so that the committee known as HealthWatch England shall substantially be appointed through election from local HealthWatch organisations

In the mid-2000s, local patient and public involvement was the responsibility of PPI Forums. These local bodies were given a national lead organisation called the Commission for Patient and Public Involvement in Health (CPPIH).

CPPIH was unanimously felt to have been a failure in leading local organisations because there were no mechanisms requiring it to act in accordance with local Forums' wishes, or to be accountable to them.

In order to help ensure that HealthWatch England does not become 'captured' by the CQC or by its own appointed members, LINK members want a substantial proportion of the committee's members, preferably a majority, to be appointed by election from the local HealthWatch bodies.

Proposed amendment:

Page 175, Section 178, line 22:

insert new clause 1(B):

“a majority of the members of the committee shall be appointed by election from local HealthWatch organisations”

For further information:

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See also: <http://www.nationalvoices.org.uk/health-and-social-care-bill-2011-0>