



National Voices

People shaping health
and social care

National Voices

HEALTH AND SOCIAL CARE BILL 2011

Written Evidence to the Commons Public Bill Committee

Monday 7th February 2011

Summary

1. National Voices has welcomed the government's vision of Putting Patients First, and wants to see it effectively implemented through the Bill.
2. The Bill's provisions for involvement and accountability could be further strengthened throughout, including:
 - i. more clarity on how patient and public involvement in commissioning are defined, and how patients and the public can influence commissioning decisions locally and nationally
 - ii. lay involvement in the governance of commissioning consortia
 - iii. HealthWatch nationally to be guaranteed the independence to be effective
 - iv. HealthWatch locally to have stronger influence on local bodies
 - v. all NHS (and NHS-funded) bodies to meet in public and be fully transparent
 - vi. stronger provision for multidisciplinary involvement in commissioning to help integrate services and to mitigate GPs' lack of specialist expertise
 - vii. the purpose of 'integrated working' to be specified as to produce integrated *services*
 - viii. the risks to patients of removing the private income cap on trusts must be mitigated.

About National Voices

3. National Voices is the national, independent voice of patients, service users and their representatives. As an umbrella for health and social care charities, National Voices represents millions of people across a wide and diverse range of health conditions and communities. National Voice' mission is to work with national decision makers to narrow the gap between the rhetoric about person-centred care and the reality.
4. Our particular interests in this Bill are with regard to 'Putting Patients First' (integrated services, shared decision making, participative care planning, self-management support, and the information, education and support to achieve these); and 'accountability' (transparency, accountability to patients and the public, democratic legitimacy, and citizen involvement in the wider decisions about health and social care services).

Defining patient involvement

5. The 'Putting Patients First' agenda is principally implemented in the Bill through giving commissioning bodies – the NHS Commissioning Board and GP commissioning consortia – parallel duties to 'patient involvement' in S19 paragraph 13F(1)(c) and S22 paragraph 14N(1)(c) respectively. These require commissioners to 'promote the involvement of patients and their carers in decisions about the provision of health services to them'.
6. The Explanatory Notes state that such involvement will be achieved through commissioning guidance, dialogue between the Board and consortia, commissioning contracts and the use of outcomes frameworks.
7. National Voices welcomes these duties. However, 'patient involvement' is a contentious and often misunderstood concept, to which clinicians, including GPs, have shown significant resistance.
8. It is now ten years since the then government first declared the policy goal of a 'patient-centred NHS'¹. However, patients' experiences of services have improved only slightly².
9. The evidence base³ for the effectiveness of involving patients is well developed. It shows that involving patients can lead to benefits including increased patient knowledge and confidence to self-manage; increased satisfaction and a better experience of services; greater likelihood of appropriate treatment; increased treatment adherence and use of appropriate screening and other preventive measures.
10. In general, successful interventions to involve patients are either cost neutral, or indeed – since involved patients often choose less interventionist treatment or are more confident to manage their own care – are cost-effective. As such, patient involvement is crucially significant to the 'Nicholson challenge'.
11. Principles of patient involvement have been built into legislation⁴, policy⁵, guidance and professional regulation⁶.
12. Yet patients, service users, their carers and families have seen minimal change in the paternalist models of healthcare they are offered. For example, in national patient surveys, between one third (primary care) and one half (inpatients) of all patients say they were not as involved as they wished to be in decisions about their care and treatment – proportions barely changed since the surveys began in 2002⁷.
13. Likewise, the practice of participative, personalised care planning for people with long term conditions is still marginal. For asthma, only 10% of people with asthma in England have a

¹ NHS Plan 2001, Department of Health, London

² Is the NHS Becoming more patient-centred?, Richards N and Coulter A, Picker Institute Europe, Oxford, 2007

³ 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

⁴ eg Health and Social Care Act 2008

⁵ The NHS Constitution, Department of Health, London, 2008

⁶ Good Medical Practice (duties of all doctors), General Medical Council, 2006

⁷ National patient survey programme, Care Quality Commission; see also 'Is the NHS becoming more patient-centred?', Richards N and Coulter A, Picker Institute Europe, Oxford, 2007

written personal asthma action plan⁸. For epilepsy, a 2009 survey suggested the figure is 13%⁹.

14. One reason that patient involvement is not widespread is that commissioners have not demanded changed models of care and treatment from their providers. Hence the new mechanisms are welcome.
15. A second reason – confusion -- was summarised in the most recent parliamentary Inquiry on the subject¹⁰:

“Patient involvement and public involvement are distinct and are achieved in different ways. The conflation of these distinct terms and the confusion about the purpose of involvement has led to muddled initiatives and uncertainty about what should be done to achieve effective patient and public involvement.”

16. Therefore if the new mechanisms are to have real impact it must be absolutely clear to *all* parties what ‘patient involvement’ means. A strong common *statutory* definition is required.
17. There is already legal wording approved by Parliament in regulations 10, 17 and 18 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010¹¹. These are binding on all providers, and if repeated in this Bill, would ensure that both commissioners and providers are working to a common definition.

18. *National Voices recommends:*

Amend the two duties to include an additional sub-clause defining ‘patient involvement’ for the purpose of that section, drawing on wording from the regulations mentioned above.

Such definition should include:

- i. giving feedback, to which commissioners must have regard
- ii. getting appropriate information and support to use it
- iii. knowing about all treatment choices and their risks
- iv. participating in decisions about care and treatment
- v. having opportunities to manage one’s own care and treatment

Defining public involvement in commissioning

19. As noted above, patient and public involvement has a long history of confusion and poor implementation in the NHS. In the last three years, however, that began to change. The World Class Commissioning Framework which governs PCTs (but *not* practice based commissioners) recognises that better commissioning includes ‘proactive, meaningful and continuous engagement’ with patients and the public¹².

⁸ Asthma UK/Ipsos-Mori survey 2010

⁹ Time for change, Epilepsy Action, 2009

¹⁰ House of Commons Health Select Committee, Third Report, Session 2006-07, Inquiry into patient and Public Involvement in the NHS

¹¹ <http://www.legislation.gov.uk/uksi/2010/781/part/4/made>

¹² WCC Competency 3, Department of Health, London, 2007

20. Likewise, statutory guidance¹³ to which all NHS bodies must have regard in relation to Section 242 of the NHS Act 2006 (consultation) emphasises these principles:

“The aim should be to develop relationships over a period of time with continuity on both a personal and organisation level... It is important to be proactive and comprehensive...”

21. Good practice guidance for commissioning from the Department of Health suggests that there is a ‘cycle’ of commissioning (needs assessment, strategy development, planning, service design, monitoring provider performance, recommissioning) and that patient and public engagement is necessary *throughout* that cycle¹⁴.
22. As a result of such instruments, PCT commissioners measurably moved in two years from token and ineffective approaches to consultation, to putting it at the centre of ‘everybody’s business’¹⁵.
23. National Voices wants this recent clarity around proactive, continuous and meaningfully to be transferred to the new, successor commissioners.
24. *National Voices therefore recommends:*

Amending the two duties to include a clear definition of public involvement in commissioning based on existing policy and guidance, specifying the points in the commissioning cycle where people should be involved.

Advice to commissioners

25. There are two outstanding questions about the parallel duties of the Commissioning Board and commissioning consortia to ‘obtain advice’.
26. The first is the lack of provision for multidisciplinary commissioning. National Voices’ member organisations are extremely concerned about the advent of GP commissioning. The daily experience of patients and service users with diagnosed conditions is that GPs, as generalists, do not have the expertise to know how best their care and treatment should be provided. How, then, will they know how to commission such services?
27. These patients and service users instead look to hospital consultants, clinical nurse specialists, and a variety of other professionals in primary, community and social care, to understand their conditions and their needs and wishes. They want this full range of expertise brought to bear on commissioning.
28. Multidisciplinary commissioning is much more likely to lead to the *integration* of services from different providers.

¹³ Real Involvement, Department of Health, London, 2008

¹⁴ See The Engagement Cycle, Department of Health, London, at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098658

¹⁵ Patient and public engagement - the early impact of World Class Commissioning, Picker Institute Europe, Oxford, 2009

29. Second, we also want to see the involvement of relevant patients and patient groups in the *design* of services. This form of involvement is among the most effective – and the most neglected.

30. Patients, especially those with long term conditions, may become ‘experts’ on what works and is appropriate for them; and the involvement of these ‘end users’ is more likely to produce services which are appropriate, patient-centred and provide a good experience.

31. *National Voices recommends:*

Amending Section 19 paragraph 13G and Section 22 paragraph 14O to provide a stronger *twin* duty to take advice from, a) the full range of health and social care professionals that are relevant to a specific disease, condition or groups of conditions for which services are being commissioned, and b) patients and service users experienced in receiving care and treatment for those conditions.

An advisory committee on PPI for the NHS Commissioning Board

32. National Voices has a concern about the capacity and expertise available at Board level to ensure it is fully equipped to discharge its duties to patient and public involvement.

33. We want the Board to *start* from the same principle that the NHS Chief Executive has successfully driven PCT commissioners to adopt: that involvement is championed from the top down¹⁶.

34. As the section on ‘leadership’ in the statutory advice to NHS bodies¹⁷ states:

“Executive teams, board members, senior managers and clinical leads are upfront with their support for involvement activity and consistently recognise the benefits of doing it well.”

35. The Board will have a small number of members, likely to be dominated by people with high level clinical and managerial credentials. They may not have relevant expertise in ‘PPI’.

36. Therefore they should have continuous access to a pool of such expertise, in the same way that statutory regulators are normally advised by statutory committees to represent consumer interests.

37. *National Voices recommends:*

Amending Schedule 1, section 10 to require the establishment of an advisory committee to the Commissioning Board on PPI.

¹⁶ Patient and public engagement - the early impact of World Class Commissioning, Picker Institute Europe, Oxford, 2009

¹⁷ Real Involvement, Department of Health, London, 2008

Lay representation on commissioning consortia

38. The biggest omission from the ‘accountability’ agenda is that, although GP commissioning consortia are to be entrusted with enormous amounts of public money, there is no provision for public involvement in the governance of their operations in the public interest.
39. We regard the other mechanisms for the public accountability of consortia in the Bill – local HealthWatch, the Health and Well Being Board, and the PPI duties, for instance – as important, necessary, but *not sufficient* to ensure that consortia are acting in the interests of patients and the public. Real influence on commissioning decisions comes from being part of the decision making process.
40. We note that statutory guidance¹⁸, to which NHS bodies must have regard, on the implementation of Section 242 of the NHS Act 2006 (consultation), which was signed off by the Chief Executive of the NHS, advises that:

“The NHS organisation thinks about building in user involvement to its governance structures so that there are mechanisms in place for user representatives to be part of the decision-making processes for the organisation’s commissioning decisions.”

41. The omission of lay involvement is surprising considering that:
- i. all other NHS bodies have lay involvement on their Boards
 - ii. all the health professional regulatory bodies must have a lay majority by law
 - iii. the Coalition Agreement said local health boards would be democratically elected
 - iv. the education system has long demonstrated the value of having hundreds of thousands of parent and community governors engaged in the governance of schools
42. Some practice based commissioning consortia have demonstrated that having strong representation from the practice population brings advantages to commissioners in relation to their ability to understand need and to prioritise the use of resources¹⁹.
43. Some of the pathfinder commissioning consortia will be testing this approach to governance.
44. Public legitimacy will be crucial as consortia are expected to produce the efficiency savings required by 2014 and therefore must rationalise and redesign local services.
45. National Voices members were vocal in raising this demand at our national conference in September 2010.
46. *National Voices recommends:*

Amending Schedule 2 Part 1 to require the constitution of each consortium to specify a governing board, to be composed of at least equal numbers of lay representatives drawn from the practice lists of the participating consortia. The governing board should meet in public, make relevant documents publicly available, and report its decisions publicly.

¹⁸ Real Involvement, Department of Health, London, 2008

¹⁹ See the description of decision-making structures at the Principia consortium, Nottingham, in The quality of patient engagement and involvement in primary care, Parsons S, Redding D et al, Kings Fund, 2010

Strengthening integrated working

47. One of the strongest demands of patients, service users, their families and carers is for 'joined-up' services. Patients want continuous care, integrated around the patient – not, as now, to get lost in the gaps, or to have to fight their way from one service to another.
48. Integrated services are the key to all models of care which are proven effective in managing people with long term conditions (who consume 70% of healthcare). The NHS' recommended model for long term conditions is built on this evidence²⁰.
49. Thus the government's promise in its White Paper to work towards fully integrated services could provide one of the strongest benefits to patients and service users of all the reforms.
50. However, we see at least a very strong risk, and at worst a contradiction, in simultaneous plans to open the NHS to competition and economic regulation.
51. Therefore it is important that those provisions in the Bill that are intended to drive integrated working are as strong and effective as possible. The duties on the Commissioning Board and the Health and Well Being Boards use the relatively weak word, 'encourage'.
52. More significantly, from the point of view of patients and service users, the extent to which commissioning consortia and local authorities 'work closely together', as the Bill puts it, is *in itself not meaningful*.
53. What matters to patients is whether the resulting *services* are integrated.
54. Studies of joint working show there are often no discernible benefits from the *process* of 'working closely together' – unless the desired outcomes are specified from the start. The Audit Commission²¹ found that:

“Organisations can usually describe how they now work better together but often not how they have jointly improved user experience. Partnership agreements often fail to include quantifiable outcome measures.”
55. Professor Chris Ham's review of integrated care²² concluded that:

“The journey towards integration needs to start from a focus on service users and from different agencies agreeing what they are trying to achieve, rather than from structures and organisational solutions.”

²⁰ The NHS and Social Care model for improving care for people with long term conditions, Department of Health, 2007:

<http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH4100317>

²¹ Means to an end: Joint financing across health and social care, Health national report, Audit Commission, 2009

²² Only Connect: policy options for integrating health and social care, Professor Chris Ham, Nuffield Trust, London, 2009

56. *National Voices recommends:*

The meaning of the word ‘encouraging’ in relation to integrated working needs testing and clarifying, and if necessary strengthening. Wherever the function of ‘working closely together’ is mentioned, the Bill should specify that the *purpose* of so working is to secure the provision of integrated services.

Commissioners’ annual reports and performance assessment

57. Currently the Bill only specifies that certain selected duties must form part of the annual reports of the NHS Commissioning Board and of each commissioning consortium; and of the way the Board assesses the performance of consortia.

58. This appears to exclude, for example, reporting on their duties to reduce inequalities and promote patient involvement.

59. *National Voices recommends:*

The Board and each consortium should report annually on the performance of *each* of their statutory duties, and be assessed on these.

Commissioning plans of GP consortia

60. The Bill does not require commissioning consortia to include in their published plans details of how they will discharge their duty to public involvement.

61. The Bill requires each consortium to submit its plan to the Health and Well Being Board for an opinion before publication; but not to consult with or involve patients and the public or local HealthWatch before the plan is published.

62. *National Voices recommends:*

These omissions should be remedied.

Foundation Trust transparency

63. In line with our view that all NHS bodies should be transparent and open, and in accordance with the general duties of FT councils of governors to hold directors *publicly accountable*, the Bill should remedy the longstanding deficit which allows FT boards to meet *in camera*.

64. *National Voices recommends:*

All meetings of the FT Boards should be open to members of the public, with relevant documents published in advance, and their decisions publicly reported.

HealthWatch England effectiveness

65. HealthWatch England as a voice for patients, service users, their carers and families needs sufficient independence both from the Secretary of State and from the Care Quality Commission itself to be able to produce robust reports and advice.
66. It will need to be provided with sufficient resources by the CQC to be able to undertake its own research into the experiences of patients and service users around England (as, for example, Ofcom provides its Consumer Panel with such resources).
67. The committee must include people with expertise and experience in the interests and experiences of health and social care service users, their families and carers; and of organisations that aim to hold service providers and commissioners to account.
68. Local HealthWatch organisations will want to know that they have the right and ability to elect or otherwise select members of the committee that represents them.
69. *National Voices recommends:*

Transparent arrangements for the appointment of the Committee -- not to be done by the Secretary of State. There should be statutory provision for the selection of some members by local HealthWatch; and for the resourcing of the Committee by the CQC.

Membership of Health and Well Being Boards

70. Membership of these Boards currently appears heavily weighted towards statutory/bureaucratic interests. Boards may use the current stipulations as a license to marginalise and exclude non-statutory voices.
71. Having only one representative from HealthWatch will, in our experience and that of all of our members who have served as lay representatives on statutory committees, very likely lead to the disempowerment and isolation of that representative.
72. Moreover there are other civil society interests in local areas who should legitimately be represented, including Third Sector organisations who may have interests in the commissioning or provision of services, or in support to people who are deprived, marginalised or underserved.
73. *National Voices recommends:*

There should be a stipulation for two HealthWatch representatives on each board; plus two representatives from recognised voluntary sector umbrella bodies in the area.