



National Voices

People shaping health
and social care

National Voices

HEALTH AND SOCIAL CARE BILL 2011

Memorandum to the Commons Public Bill Committee

4th July 2011

Summary

1. National Voices has welcomed the government's vision of Putting Patients First, and wants to see it implemented through the Bill as effectively as possible.
2. National Voices participated fully in dialogues during the 'pause' in the Bill and welcomed both the report of the NHS Future Forum, and the government's response. The amendments subsequently proposed by the government will take us a further step towards achieving the vision.
3. However, we also argue that it is necessary to strengthen some of the provisions of the Bill still further, including:
 - a. commissioners' duties to individual patient involvement
 - b. commissioners' duties to obtain expert advice, and
 - c. commissioners' duties to collective public involvement
4. We also wish to signal to the committee some areas in which the new or amended clauses give rise to further questions or concerns with regard to the operation of the new structures, and the secondary legislation and guidance that may follow. These include:
 - a. the date for the establishment of HealthWatch
 - b. how the clinical networks and senates will operate
 - c. the nature of the mandate to the NHS Commissioning Board
 - d. the regulations for governance of clinical commissioning groups (CCGs)

About National Voices

5. National Voices is the national charity coalition for health and social care. It strengthens the voice of people who come into contact with the NHS and care services, and of the voluntary organisations that work for them. Our broad membership, rooted in people's experience, represents millions of people, and covers a diverse range of health conditions and communities.
6. 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).
7. To date National Voices has had the following engagement with the Health and Social Care Bill 2011:
 - a. together with ten other national charities, calling for changes to the original Bill to strengthen PPI, accountability and transparency
 - b. providing the Committee with written and oral evidence on the original Bill
 - c. providing its chief executive, Jeremy Taylor, to be a member of the NHS Future Forum panel and to help to draft its recommendations
 - d. participating, and securing the participation of its members and of patients, service users and carers, in listening events during the 'pause'
 - e. providing the Committee with oral evidence in the second sitting on 28th June 2011

Defining patient involvement

National Voices recommends:

8. **Amend Clause 19 paragraph 13N and Clause 22 paragraph 14N to include an additional sub-clause defining 'patient involvement' for the purpose of that section**, drawing on wording from the regulations for registered providers under the Health and Social Care Act 2008¹.
9. This definition should include ensuring that patients, carers and patient representatives (if any) can, in particular:
 - i. give their views and experience of care and treatment they receive, to which commissioners must have regard
 - ii. be provided with appropriate information, and support to use it, in relation to their condition and to available services
 - iii. be provided with appropriate information, and support to use it, about all available treatment choices, including risks
 - iv. participate in decisions about care and treatment, and in planning their care,
 - v. have opportunities and support to manage their condition and their chosen care, and
 - vi. be involved in such other ways as commissioners deem appropriate and as may be specified in guidance issued by the Commissioning Board.

¹ <http://www.legislation.gov.uk/ukxi/2010/781/part/4/made>

Justification

10. The government amendments for the twin patient involvement duties on commissioners in Clause 19(13FA) and Clause 22(14NA) are a response to the NHS Future Forum's call to strengthen and clarify these duties.
11. National Voices welcomes the changes proposed. The duties are separated from surrounding duties; made to apply to 'each patient', thereby clarifying that they operate at the right level; and applied to 'all functions' of the commissioners, thereby 'wiring' patient involvement into the system.
12. However, the government has not accepted the need to define the meaning of 'patient involvement' in statute. Instead it will be elaborated in national guidance. We continue to argue that this is an historic mistake.
13. 'Patient involvement' is an evidence-based practice which can lead to benefits including increased patient knowledge and confidence to self-manage; increased satisfaction and a better experience of services; greater likelihood of treatment being 'appropriate' to the patient's circumstances, values and preferences; and increased treatment adherence and use of appropriate screening and other preventive measures². The practice of sharing decisions about treatment can reduce unwarranted geographical and demographic variation in treatment. These benefits are recognised by the government in its White paper vision.
14. In short, this is a win-win proposition which can achieve better outcomes in the domains of effectiveness and patient experience, while also getting the maximum public value from limited healthcare resources. As such, these clauses are among the most important in the Bill for their relevance to the 'Nicholson challenge'.
15. Unfortunately, despite the evidence base, and despite professional regulation placing duties on doctors, nurses and midwives to work in partnership with their patients in these ways³, patient involvement is still not mainstream practice in the NHS.
16. 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 which have not changed since the surveys began in 2002⁴.
17. Likewise, the practice of participative, personalised care planning for people with long term conditions is still marginal. For asthma, one of the most prevalent chronic conditions, only 10% of people with asthma in England have a written personal asthma action plan⁵. For epilepsy, a 2009 survey suggested the figure is 13%⁶.

² 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

³ Good Medical Practice (duties of all doctors), General Medical Council, 2006; the Nursing and Midwifery Code, NMC

⁴ 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

⁵ Asthma UK/Ipsos-Mori survey 2010

⁶ Time for change, Epilepsy Action, 2009

18. One reason that patient involvement has not become widespread is that commissioners have not demanded changed models of care and treatment from their providers. Hence the mechanisms provided through this Bill are extremely important.
19. A second reason is that throughout the NHS, professionals and organisations have a poor understanding of what ‘patient involvement’ is, and what it includes.
20. It is frequently taken to mean ‘better customer care’, as when NHS organisations and general practices focus on involving patients in improving reception facilities and booking systems, while ignoring the need to change consultation styles.
21. Many professionals believe it is something which ‘we already do’, and are reluctant to re-examine their practice⁷.
22. ‘Patient involvement’ is also frequently confused with collective involvement, as the most recent parliamentary Inquiry on the subject concluded⁸:

“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.”
23. Without clear definition, the government’s vision of Putting Patients First is likely to go the way of every previous intention to create a ‘patient-centred’ NHS – an aspiration which already dates back a decade to the NHS Plan 2001, and which is still unrealised.
24. We disagree with the government that such a definition should be elaborated through guidance from the Commissioning Board. Such guidance, whether from the Department of Health or from professional bodies, has had weak impact throughout the last decade. Commissioners are much more likely to take note of and to fulfil their duties as laid down in legislation.
25. It may be possible to provide the definition through secondary legislation, as with the regulations for providers under the Health and Social Care Act 2008. However, we note that there is no specific set of regulations currently mentioned in the Bill (including the new amendments) to which it would be appropriate to attach this definition.
26. For these reasons, National Voices and its members, and the charities with which we are working in coalition on this legislation, continue to argue that for the new structures of commissioning to have real impact, **there is a requirement for a clear, statutory, system-wide definition of ‘patient involvement’**.
27. There is already legal wording approved by Parliament in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010⁹. These are binding on all providers, and there would be powerful advantage in ensuring that both commissioners and providers are working to a common specification.

⁷ See, for example, the findings of the ‘Point of Care’ programme, King’s Fund, 2009

⁸ House of Commons Health Select Committee, Third Report, Session 2006-07, Inquiry into patient and Public Involvement in the NHS

⁹ <http://www.legislation.gov.uk/ukxi/2010/781/part/4/made>

Involving patients and patient groups as experts

National Voices recommends

28. **Amend the government’s revised clauses 19(13G) and 22(14O).** These currently state:

“The [Board/consortium] must obtain advice appropriate for enabling it effectively to discharge its functions from persons who (taken together) have a broad range of professional expertise in—

- (a) the prevention, diagnosis or treatment of illness, and
- (b) the protection or improvement of public health.”

29. The word ‘professional’ should be removed and an additional sub-clause added along the following lines:

- (c) the experience of people who have accessed or been in receipt of relevant services, as well as those who do not or cannot access relevant services

30. **Amend clauses 19(13L) and 22(14P) in such a way as to provide for the involvement of expert patients, carers and their organisations in monitoring, reviewing and redesigning services and pathways.**

31. This amendment should remove the reference to ‘informing or consulting’ and provide a form of words which encompasses meaningful and continuous involvement, including with targeted patient and population groups, in all stages of the commissioning process.

Justification

32. In this section we wish to focus on two areas of the Bill: the twin duties on commissioners to obtain advice from experts [Clause 19(13G) and Clause 22(14O)]; and the twin duties to involve the public [Clause 19(13L) and Clause 22(14P)].

33. The government has proposed amendments to the duty to obtain advice which we warmly welcome. National Voices and its charity coalition partners have argued strongly that all relevant professionals with expertise on our conditions should be involved in commissioning for those conditions, and we believe the amended clauses meet that demand.

34. However, we have argued that *all* people with expertise should be involved – and that this includes patients and carers, and their organisations, whose experience relates to:

- a. the experience of people accessing and using services, and those who are unable to achieve access
- b. the entitlements of people accessing and using services, and
- c. the optimum design of services in order to meet people’s needs and deliver best practice

35. Individual patients and carers, and peer groups of patients and carers, who have lived through an illness or are continuing to live with a chronic condition will have views and experiences to offer about where services have gaps or failures, and how they could be better designed and commissioned.
36. Patient and carer organisations have an aggregated knowledge of these matters gained from their everyday and continuing contacts with patients and carers, including through providing help, support and information to them.
37. In addition, patient and carer organisations often have a well developed knowledge of NICE guidelines and standards, the indicators of best practice and effectiveness, and the entitlements of patients and carers to receive these. This expertise may often be greater than that of local commissioners, especially in the case of less common conditions.
38. This individual and collective experience and expertise offers considerable additional value to the NHS for quality improvement. However, that value is too often untapped.
39. The value of this experience and expertise lies in a domain of 'involvement' that is not currently recognised in the Bill's formulations. It is not part of 'patient involvement' – the involvement of an individual in his or her own care and treatment. Nor is it part of 'public involvement', which is usually understood as being collective public involvement in consultations about service change.
40. More specifically, it lies in the domain of 'co-design' and 'co-commissioning' of services. This means the involvement of specific groups of experienced service users in the process of monitoring, reviewing, redesigning and recommissioning services that are relevant to those groups.
41. This type of involvement is proactive, continuous and targeted, with a direct influence on commissioning decisions, and therefore much more likely to produce meaningful change and benefits than population-wide consultation.
42. Services which have been co-designed by their user group are more likely to be used effectively, to be safer, and to create a better patient experience – the three domains of quality improvement, to which commissioners have a duty.
43. At national level, strategies in which patient organisations have been closely involved as co-designers, such as the cancer strategy, have been demonstrably successful in improving outcomes and experience, and in identifying innovations such as the development of new service models for cancer survivors.
44. At local level, an example of bringing this kind of experience and expertise to bear is Neurological Commissioning Support (NCS), which works alongside health and social care commissioners, to ensure that people affected by long-term neurological conditions are at the heart of commissioning, producing clear recommendations to deliver better outcomes for services in neurology¹⁰.
45. A joint initiative from the MS Society, the MND Association and Parkinson's UK, NCS works with commissioners to audit and redesign services by involving people with relevant conditions. In Gloucestershire, 2009-10, NCS helped commissioners from the NHS and local authority to audit their existing services, to decommission those

¹⁰ <http://www.csupport.org.uk/>

which people with the conditions said were ineffective or poor, and to design new services that deliver a better experience as well as meeting the standards set in the national framework. Service users whom NCS engaged as a reference group have continued to work with the PCT to ensure recommendations are followed through, and indeed have formed their own regional alliance to continue to press for improvements and innovations.

46. National Voices believes it is essential that this kind of co-design and co-commissioning of services becomes widespread under the new structures, to improve quality and to help meet the 'Nicholson challenge'. The Bill is a key opportunity to open the way for this to happen.
47. *National Voices therefore recommends* amending the government's revised clauses 19(13G) and 22(14O). These currently state:
- “The [Board/consortium] must obtain advice appropriate for enabling it effectively to discharge its functions from persons who (taken together) have a broad range of professional expertise in—
- (a) the prevention, diagnosis or treatment of illness, and
- (b) the protection or improvement of public health.”
48. The word 'professional' should be removed and an additional sub-clause added along the following lines:
- (c) the experience of people who have accessed or been in receipt of relevant services.
49. *National Voices further recommends* amending clauses 19(13L) and 22(14P) in such a way as to provide for the involvement of expert patients, carers and their organisations in monitoring, reviewing and redesigning services and pathways.

Additional matters

50. In this section we wish to inform the Committee with regard to the questions and concerns that have arisen during the pause or as a result of the government's new amendments, and which follow from the primary legislation itself.

HealthWatch England

51. As noted by National Voices in its oral evidence to the Committee on 28th June 2011, we believe there is a case to reconsider the date for establishment of the HealthWatch England committee of the Care Quality Commission.
52. During the transition period, emerging clinical commissioning groups, including the pathfinders, will be supported by the National Commissioning Board, which begins its establishment in shadow form in October 2011. There is a lack of parallel provision for emerging HealthWatch organisations, where the establishment of HealthWatch England is planned for October 2012.

Operation of clinical networks and senates

53. National Voices, its members and charity coalition partners strongly welcome the government's decision, in response to the NHS Future Forum, to preserve, support and develop clinical networks. No further detail has been provided on how these, and the associated clinical 'senates', will be organised and funded. Nor is it clear how they will be used to advise and influence commissioning decisions at national, regional and local level.
54. The government's intention is that these will not be 'organisations' and will be hosted by the Commissioning Board, hence they are not included in the Bill itself.
55. However, without further information and direction from the government as to how they will operate, it is difficult to assess the extent to which the intentions of the revised clauses 19(13G) and 22(14O) are likely to be achieved in practice.
56. In particular we are interested to know:
- what the 'senates' consist of and how they relate to the networks
 - whether networks are likely to be banded together for similar areas of care – such as the maternity and neonatal networks that are currently separate
 - whether, being hosted by the national Board, networks and senates will operate only from the national level – noting that for many conditions the more relevant contribution would be at regional or local levels
 - whether, as the NHS Future Forum recognised may be desirable, patients and patient groups are to be involved in the senates

Lay people on the governing bodies of clinical commissioning groups

57. The government's new clauses state that regulations will describe how CCGs should select lay members, and will be able to stipulate a minimum and a maximum number of such members.
58. National Voices strongly believes that these regulations should *not* set a maximum number. It should be open to the CCG to have as many lay members as it chooses on its governing body, including deciding to have a lay majority. Principia Partners in

Health, a pathfinder CCG in Nottingham, has a lay majority on its board, and is a strong advocate for the benefits of so operating.

59. National Voices also believes that lay members should not be drawn from out of the commissioning area of the CCG, but from within the population for which it commissions. They should not repeat the 'non-executive director' role that has been used for PCTs; but act as representatives of the concerns and priorities of local stakeholders, in a similar way to parent or foundation governors in schools.

60. National Voices further believes that, as the NHS Future Forum recognised, there will be a need to train and support these individuals in the fulfilment of their roles.

For enquiries or further information about this Memorandum please contact:

Don Redding, Director of Policy, National Voices

don.redding@nationalvoices.org.uk