



National Voices

People shaping health
and social care

National Voices



9 big shouts

Patients and Service Users respond to the health reforms

A paper for the NHS Future Forum listening exercise

May 2011

Patients, service users and their organisations have welcomed the listening period announced by the government. This is a chance to have our voices heard. But it is not the first opportunity. For a year, from the White Paper onwards, we have been responding constructively to all government consultations, and arguing for changes to the Bill.

The aim of this paper, therefore, is to assist the Future Forum by summarising from those consultations the nine key demands made by the patient, service user and carer movement, and pointing the way to solutions. Our 'big shouts' are:

- ◆ **Integration, integration, integration**
- ◆ **Right care, right place, right time**
- ◆ **Information and communication that work for us, now**
- ◆ **End paternalism**
- ◆ **No new lotteries - tackle inequalities**
- ◆ **Patients among a range of expert commissioners**
- ◆ **Proper governance and transparency**
- ◆ **Real involvement, with genuine influence**
- ◆ **Tell us when things go wrong**

1. Introduction

The government has created a 'pause' in the progress of the Health and Social Care Bill 2011, while it listens to views from all stakeholders about the health service reforms.

Patient and service user organisations including National Voices and its members have, since early 2011, established a common platform of changes which we would like to see made to the Bill in order to:

- strengthen patient and public involvement in health
- increase accountability
- enable good monitoring and scrutiny, and
- give patients and the public real influence on commissioning decisions.

But the health reforms are wider than those implemented in the Bill. We have also taken a strong interest in the White Paper and all associated consultations on, for example, HealthWatch, the NHS outcomes framework, the information strategy, and patient choice and control.

For us, the listening period is an opportunity to **review and rebalance** the reforms, as well as to improve the way the Bill enacts them.

2. Headline message

The '9 big shouts' add up to a strong call from the patient, service user and carer movement for a significant change of emphasis.

The complex Bill, and the debate around it, have magnetised political attention towards the most contentious areas of policy.

The government needs to convince us that it has a single paramount priority – to tackle the NHS future funding challenge in ways that create better services and better value for their end users, and for the NHS and the citizen who pays the bills.

The reforms, and the way they are implemented by the Health and Social Care Bill, need clearly to serve this goal. And the goal will only be achieved (and publicly supported) if all roads to its delivery are travelled in partnership with patients, service users, carers and their organisations.

Before the general election, in its 'Share the Power' campaign, National Voice and its members committed to support radical changes to the way health and social care

services are delivered, *so long as* the involvement of patients and the public was made integral to the change process.

The government has included the *themes* of many of our '9 big shouts' in its policy documents – but has not always convinced us with its *solutions*. Our proposed solutions are included in Section 6, below.

3. About National Voices

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 conditions and communities.

4. About this paper

This paper was drafted by National Voices with its members. We draw upon and summarise a series of previously agreed statements, as follows:

- National Voices pre-general election campaign, 'Share the Power'
- NHS Alliance manifesto document, 'Whose NHS Is It Anyway', 2010, endorsed by National Voices
- National Voices response to the White Paper and related consultations, 2010
- National Voices written and oral evidence to the House of Commons health select committee, Inquiry into commissioning, 2010
- National Voices submission to the consultations on information, choice and control, 2011
- National Voices strategy and mission (reviewed 2011)
- Parliamentary briefings from the charity coalition on the Health and Social Care Bill, 2011
- National Voices written and oral evidence to the House of Commons Bill Committee, 2011
- Members' submissions to the NHS Future Forum

To check whether these positions resonate with those of our sector more widely, we also reviewed *all* memoranda of evidence submitted by charities and service user organisations to the House of Commons Bill Committee, 2011.

A first version of this paper was sent to all National Voices members for consultation and amendment. Members were also offered a live Web chat to discuss the issues.

Finally, as a further check that these '9 big shouts' fully represent the views of our sector, we noted and have factored in the key messages arising from a 'listening event' organised by charities for the Future Forum on Thursday 19th May 2011.

5. 9 big shouts: summary of what we want

Integration, integration, integration

Patients and service users want services that are organised around, and responsive to, our human needs. We are sick of falling through gaps. We are tired of organisational barriers and boundaries that delay or prevent our access to care. We do not accept being discharged from a service into a void.

We want services to be seamless and care to be continuous.

That means primary and community health services, social care services, and services from voluntary organisations should all mesh together to help us succeed in managing our lives and conditions.

We do not want to have to chase information about services – it should come to us. And we do not want to have to explain ourselves, and our choices and preferences, every time we use a new service or meet a new professional – information about us should follow us.

We know that getting services to work together for better outcomes is the biggest priority if we are to achieve better quality, better value and better experience in response to the 'Nicholson challenge'.

Right care, right place, right time

Patients and service users say we should be supported to:

- understand our conditions and medications

- learn how to use health information
- take achievable steps to improve our health
- prevent emergencies developing
- navigate the available services and support
- manage our own care and treatment, and
- take part in deciding our care plans and our treatment options

For many of us, especially those with one or more long term conditions, care should be based much closer to home.

The NHS seems to be making short-sighted cuts to services in the name of 'efficiency'. We want to see this balanced by real up-front investment in new and better services, designed with their end users, that deliver better public value.

Information and communication that work for us, now

Patients and services users want, as a high priority, the right types of information to support us in managing and participating in our care and treatment.

We want to be able to communicate with our service providers in easy, up to date ways that can be delivered now – via text and email, through online bookings, and in telephone consultations.

We want to see and amend our electronic records; and we want those to record what we want, not just what clinicians say.

End paternalism

Patients, service users and carers feel the model of care we receive is very often wrong, and we are impatient for change. We support the vision of 'putting patients first' and of 'no decisions about me, without me'.

We want to see this happen. The Bill and other reforms must not be allowed to disrupt momentum for this culture change.

No new lotteries – tackle inequalities

Patients, service users and carers do not want either cuts or reforms to result in new lotteries with regard to who gets what.

We want equal access to care and treatment based on evidence, mandated by national standards from NICE, and delivered under national strategies to which we have contributed.

We want existing inequalities to be identified and tackled vigorously. These include, for example, more treatment being given to people in better-off areas, and less to people in deprived areas; people missing out on care and treatment because of who they are; and neglect of vulnerable elderly people even when they are in the care of the NHS or local authorities.

People with rare conditions or who need specialised services should not lose out because the NHS fails to identify and count them, or because of poor links between specialised and local commissioners. They have the same entitlements to high quality, person-centred and seamless care.

Patients among a range of expert commissioners

Commissioning should not be done solely by generalists (Commissioning Board members and GPs).

Patients, service users and carers want people with relevant knowledge and expertise *always* to be involved.

These people include hospital consultants and other health professionals such as specialist and community nurses and allied professionals.

They *also* include **expert patients** (and service users and carers) with experience of the conditions and pathways for which commissioning decisions are being made; and patient, service user and carer organisations.

Proper governance and transparency

As patients and service users we want to know that our NHS is being properly run in our interests, and according to strategies and plans on which we have had a say.

Real involvement, with genuine influence

Patients and service users, and the public, want to be involved in making services better.

Involvement mechanisms need to be protected from disruption due to cuts and reforms, and vastly improved.

The whole NHS system must be crystal clear on what kind of involvement to create, and must be in no doubt that it is a 'must do'.

Tell us when things go wrong

Patients and service users do not want health and social care services to hide or cover up their mistakes. This makes them less safe for us to use. We want honest disclosure – and support to the service to put things right. We want the lessons from Mid Staffordshire to be learned and applied.

6. What are the solutions?

From the White Paper, 'Liberating the NHS', onwards, the government has proposed solutions to many of the issues raised in these nine points.

Its Vision of 'Putting Patients First' has been strongly welcomed by patient, service user and carer organisations. Likewise we acknowledge and welcome many of the specific measures to which the government is committed.

However, in the landscape of the reforms there are elements which seem to contradict or confuse each other. In the Health and Social Care Bill 2011 there is, as we have previously argued, greater scope to strengthen the provisions for Putting Patients First to be achieved.

This listening exercise therefore provides an opportunity for patients and service users to:

- Restate the solutions we have previously offered or requested
- Call for clarity on the emphasis of the reforms
- Ask for the Bill to be reviewed and amended

In this section, for each of the nine big shouts, we list some of the actions that government and others could now take to make sure the reforms really do put patients first.

<p>Big Shout 1</p> <p>Integration, integration, integration</p>	<p>Solutions</p>
<p>Services organised around, and responsive to, our human needs.</p> <p>No more gaps. Reduce organisational barriers and boundaries.</p> <p>Services to be seamless and care continuous.</p> <p>Information about services should come to us</p> <p>Information about us should follow us</p> <p>Get services to work together for better outcomes to meet the ‘Nicholson challenge’.</p>	<ul style="list-style-type: none"> • Integration to be clearly defined as bringing primary and community health services, social care services, and voluntary sector services and support together (not as ‘vertical integration’ - the takeover of other services by acute trusts) • Government switches reform emphasis from ‘competition’ to ‘integration’ – we can help to champion this • A rigorous review, with independent experts, of whether, and when, competition either aids or undermines service integration • A political undertaking to highlight the desired outcome of services integrated around patient needs in the first three annual ‘mandates’ for the new NHS • Strengthen the draft duty to ‘encourage integration’ – as applied to the NHS Commissioning Board and Health and Well Being Boards – to specify that the <i>purpose</i> of GP and local authority commissioners working together is to <i>secure integrated services</i> that improve quality for patients and service users • Give Monitor an equivalent duty to promote integrated services • Expand the number of Care Trusts, building on learning from the integrated care pilots

<p>Big Shout 2</p> <p>Right care, right place, right time</p>	<p>Solutions</p>
<p>Support us to:</p> <ul style="list-style-type: none"> - understand our conditions and medications - learn how to use health information - take achievable steps to improve our health - prevent emergencies developing - navigate services and support - manage our own care and treatment, and - take part in deciding our care plans and our treatment options <p>For many of us with chronic conditions, care should be closer to home.</p> <p>Invest in new and better services, don't just cut</p>	<ul style="list-style-type: none"> • A new deal for people with long term conditions - access to their electronic health records, a jointly prepared and annually reviewed care plan, a designated care co-ordinator able to deliver agreed packages of care, support for self-management, and support to navigate the system • NICE quality standards, NHS-CB guidance and the various outcomes frameworks must work together to ensure the right support services are commissioned – such as education for patients in how to manage their conditions themselves, and services offering emotional and psychological support • Take all necessary measures to ensure that the NHS efficiency programme delivers QIPP principles and programmes, and does not result in short term cuts that undermine the goal of <i>redesigning</i> services • Directly connect the best of QIPP thinking to the PCT clusters and commissioning consortia pathfinders – ensure that the work of the Right Care and long term conditions QIPP teams has real effect on commissioning and outcomes as soon as possible • Directly connect people's individual decisions about treatment and care plans to larger scale commissioning by capturing and aggregating the data • Reaffirm the role of agreed national strategies and service frameworks that emphasise these aspects of care, treatment and service design – e.g. declare the intention to include these strategies in the 'standing rules' described by the Health and Social Care Bill 2011 (Clause 16) • Follow the 'integration' agenda, above – integrated services are essential to provide this web of support

<p>Big Shout 3</p> <p>Information and communication that work for us, now</p>	<p>Solutions</p>
<p>Give us the right types of information to manage and participate in our care and treatment.</p> <p>Make it easy to communicate with our service providers in up to date ways [text, email, online bookings, telephone consultations].</p> <p>Let us see and amend our electronic records.</p>	<ul style="list-style-type: none"> • The DH information strategy to focus on getting information, education and support to people that helps them manage their care and treatment • Guidance to commissioners to emphasise the need to commission information provision for self-management and self-care; care planning; and patient participation in treatment decisions • Guidance to commissioners to emphasise the role of voluntary sector providers of information, education and support • Modernisation of service provider communications put into standard contracts, and GP contracts/incentives • Guidance to commissioners will emphasise the need for information to follow the patient, within the context of service integration • Roll out patient-centred telecare as an additional mainstream support

<p>Big Shout 4</p> <p>End paternalism</p>	<p>Solutions</p>
<p>We are impatient for old models of care to change.</p> <p>We want ‘putting patients first’ and ‘no decisions about me, without me’ to happen.</p> <p>No disruption to momentum for this culture change</p>	<ul style="list-style-type: none"> • The government to describe a set of concrete actions to drive the agenda of culture change among professionals and services, keeping momentum in the midst of reforms and efficiencies • The government to establish demonstrable programmes and ‘social marketing’ campaigns among professionals, to push for culture change, in partnership with clinical champions and patient organisations • Embed training in supporting health literacy, participative care planning and shared decision making within the education and continuing professional development of clinicians • Commissioners to demand evidence that their contracted providers are instituting these changes, and to re-commission accordingly • New outcomes and indicators to populate the ‘patient experience’ domain of the National Outcomes Framework to be capable of monitoring progress towards ending paternalism, for example by measuring responsiveness to patient feedback • Rapid roll out of an ambitious programme to research, develop and implement patient decision aids for shared decision making • Consider how to strengthen the legal rights for patients to be given appropriate, comprehensive information on their condition and treatment options at all key points on their journey with an illness or condition; and for patients to participate and decide on a care plan

<p>Big Shout 5</p> <p>No new lotteries – tackle inequalities</p>	<p>Solutions</p>
<p>Cuts or reforms should not create new unfairness with regard to who gets what.</p> <p>Equal access to care and treatment based on evidence, national standards, and national strategies.</p> <p>People with rare conditions or who need specialised services should not lose out because the NHS fails to identify and count them, or because of poor links between specialised and local commissioners</p> <p>We want existing inequalities to be identified and tackled vigorously</p>	<ul style="list-style-type: none"> • Make NICE quality standards mandatory for commissioners and providers • ‘Ramp up’ NICE resources to enable rapid production of the quality standards, and an expansion of their range, with priority to rapidly ‘translating’ existing NICE clinical guidelines • This expansion of range should include conditions which are rare or considered ‘low volume’ • Provide clarity on which conditions will be covered by local and national commissioning respectively • Ensure there is consultation with patients, carers and their organisations on which conditions are covered by local and national commissioning respectively, so no-one falls through the gap • The concept of ‘low volume’ conditions should be properly defined – or abandoned • The government and NHS-CB make it a priority to clarify: the definition of specialised services; the resource, structures and mechanisms for specialised commissioning within the NHS-CB • The NHS-CB has an adequate infrastructure to link with local commissioners and providers to ensure a seamless pathway for people requiring specialised services • Require local commissioners to co-ordinate and collaborate in commissioning services for any of the less common conditions that still fall outside the NHS-CB remit • Standard commissioning contracts amended – and national guidance issued – to require all

	<p>relevant providers to participate in national clinical audits, in order accurately to identify the population of people with each specific condition</p> <ul style="list-style-type: none"> • The government and NHS-CB to mitigate the risk that some commissioners may allow access to certain treatments that others may disallow • GP practices to be performance managed to reduce identified inequalities • Patient involvement in working with the NHS-CB and others to identify conditions for which there are few or no treatments, and in developing, funding and interpreting research on these
<p>Big Shout 6</p> <p>Patients among a range of expert commissioners</p>	<p>Solutions</p>
<p>People with relevant knowledge and expertise <i>always</i> be involved in commissioning, including:</p> <ul style="list-style-type: none"> - all relevant health professionals - expert patients with experience of the conditions/pathways for which commissioning decisions are made - patient and service user organisations. 	<ul style="list-style-type: none"> • The government reviews the Health and Social Care Bill, the secondary legislation and guidance, to strengthen the duties on commissioners to ‘take advice’, and to find additional mechanisms, to ensure those with expertise are always involved, including patients and their organisations • Existing clinical networks that can provide this advice, such as cancer networks, maternity networks, neonatal networks, and diabetes networks, should be preserved and funded • Encourage and support the formation of new clinical networks for rare conditions/condition groups to help both specialised and local commissioners • Incentivise and enable voluntary organisations to sub-contract commissioning on behalf of both the NHS-CB (for example, setting up centres of excellence for rare conditions) and local commissioners, in order to challenge existing patterns of provision

<p>Big Shout 7</p> <p>Proper governance and transparency</p>	<p>Solutions</p>
<p>Our NHS should be properly run in our interests, and according to strategies and plans on which we have had a say</p>	<ul style="list-style-type: none"> • The NHS Commissioning Board will have sources of advice from relevant patients and service users; and from people with expertise in involving patients and the public • The NHS Commissioning Board will include lay representation at various levels • Require commissioning consortia to have clear governance arrangements • Require consortia governance to include significant lay representation drawn from their practice populations • Lay representatives on consortia, like lay school governors, to be charged with safeguarding the public interest in the use of public resources, including by stopping conflicts of interest, and by ensuring all commissioning decisions have been informed by patient and public involvement • Make statutory provision for the boards of all NHS bodies (including FTs and commissioning consortia) to meet in public, make papers available in advance, and publicise decisions taken • On information governance, clarify and guarantee that only aggregated, anonymised patient data will be provided to commissioners, regulators, research bodies and other organisations

<p>Big Shout 8</p> <p>Real involvement, genuine influence</p>	<p>Solutions</p>
<p>Patient and public involvement mechanisms need to be protected from disruption due to cuts and reforms, and vastly improved.</p> <p>The whole NHS system must be crystal clear on what kind of involvement to create, and must be in no doubt that it is a 'must do'.</p>	<ul style="list-style-type: none"> • The Bill's duties to involve the public should be fully defined so that everyone knows what they mean • Commissioning bodies should be under performance management pressure to fulfil and report on these duties • Patients, service users, and their organisations to be given strong influence through advising commissioners on service design • Lay people must be represented where commissioning decisions are made (at the NHS-CB and on the boards of consortia) – not just 'consulted' beforehand, or 'informed' afterwards • Local HealthWatch to be genuinely independent of both NHS and local authority interference • Protect local HealthWatch funding – currently being cut due to the pressures on local authorities. Ring fencing is the best route to enable an effective local consumer champion • Require local HealthWatch to be inclusive – reaching out to all sections of the population and to people who need specific help to be heard • Local HealthWatch to be able to elect or otherwise appoint part of the HealthWatch England committee • Make the HealthWatch England committee independent of its host, the Care Quality

	<p>Commission, and give it resources to carry out its own research and outreach</p> <ul style="list-style-type: none"> • The government will commission, or ensure that others commission, from independent sources, high quality, comprehensive training programme or programmes for lay people who are involved either in co-producing public services or in holding them to account • The complaints system will be fundamentally reviewed to make sure our complaints have an impact on standards and redress is swift.
<p>Big Shout 9</p> <p>Tell us when things go wrong</p>	<p>Solutions</p>
<p>Do not hide or cover up service mistakes</p> <p>Honest disclosure – and support to put things right</p> <p>Use the lessons from Mid Staffordshire</p>	<ul style="list-style-type: none"> • The government to institute a statutory ‘duty of candour’ for serious failings in health and social care, supported by remediation under the oversight of the Care Quality Commission • The government and CQC to start a dialogue with the professions, NHS organisations and patient organisations about widening the list of ‘never events’ to include those breaches of basic care, respect and dignity that should be reported on a mandated basis and driven out of the system • Government should publish a plan for the transition of patient safety issues from the abolition of the National Patient Safety Agency to the assumption of some of its responsibilities by the NHS-CB – including details of the resources available • Government should clarify how the lessons from the public inquiry into Mid Staffordshire can be incorporated into its reforms, including the Bill (which on current plans will make its parliamentary progress before the Inquiry report is published)