

Patient Involvement and Public Accountability

A report from the NHS Future Forum

Members

- **Geoff Alltimes – Chair, Patient Involvement and Public Accountability**
Chief Executive,
London Borough of Hammersmith and Fulham
- **Dr Charles Alessi**
Senior GP Partner, The Churchill Practice
- **Dr Frank Atherton**
President, Association of Directors of Public Health
- **Sally Brearley**
Patient representative
- **Ratna Dutt**
Chief Executive, Race Equality Foundation
- **Moira Gibb**
Chief Executive, London Borough of Camden
- **Mark Goldring**
Chief Executive, Mencap
- **Prof. David Kerr**
Professor of Cancer Medicine, Oxford University
- **Chris Long**
Chief Executive, Hull PCT
- **Tom Riordan**
Chief Executive, Leeds City Council
- **Cllr. David Rogers**
Chair, Local Government Association Community Health and Wellbeing Board
- **Jeremy Taylor**
Chief Executive, National Voices

Foreword



Throughout my career, I have listened to stories of people who have often not felt in control of their own care – who have felt powerless as decisions were taken with little regard to what they felt was right for them and left with little choice in plans that would impact upon the rest of their lives.

Slowly but surely with increased patient choice and personal budgets, we are seeing health services that are being shaped around the needs of people. I have seen first hand the difference that seamless services can make to people's mental and physical wellbeing. It can transform the experience for patients, carers and staff alike.

These experiences are what drove me to say yes to being part of the NHS Future Forum, and in particular to lead the group on Patient Involvement and Public Accountability. It has been a very rewarding eight weeks and I believe that the recommendations we have developed can make a significant contribution to the reforms needed in the NHS and social care.

Joint commissioning in Hammersmith & Fulham has shown me the potential I know exists elsewhere in the country to engage people and their carers more productively in their care planning and improve patients' experience. Breaking down the silos and barriers within different health services and between the NHS and social care makes for a better, more efficient, NHS. It removes duplication, cuts down assessment time and puts people at the heart of decision-making. This contributes significantly to improved quality and value for money.

General practices, like local councils, are rooted in their communities. They are the vital points of continuity in the care and support of people who make most use of the NHS and social care. I have been very encouraged to see many local GPs, community nurses and hospital clinicians, amongst others, express their desires to progress more integrated approaches. Many of the pathfinder consortia have made integration a priority for their future commissioning plans.

However, we have heard a real concern that these health reforms will unpick existing integration across health and with social care – that they would be a step backwards. That is why one of our key recommendations is that the Government makes the promotion of joint-commissioning and integrated services a central ambition of its modernisation plans.

In the NHS today, financial pressures are a significant challenge resulting not just from efficiency programmes. Whilst many people's experience of the NHS might be a

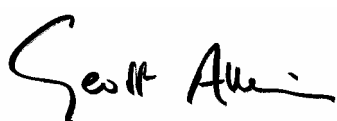
visit to their GP with a minor illness or to hospital for treatment for a minor accident or for planned routine surgery, this consumes less than a third of NHS resources. The recent advances in healthcare mean that many more people of all ages, and particularly older people, are now living longer managing long-term conditions. People requiring long-term care now consume over two thirds of NHS resources. In the shift from episodic illness to long-term conditions, and with the impact of increased costs of technology and treatments, the current configuration of health and care services is no longer fit to meet the demands of the population they serve. It is only through integrated approaches across care pathways, by delivering more care in people's homes and less in acute wards, that we will create a system that can survive and thrive in the face of such pressures.

We heard again and again the high value placed on the NHS and real concern for its future. This is not surprising, given how over a generation we have all benefited from the many gains in our health and wellbeing achieved through the creativity, skill and dedication of our health and social care professionals. However, this is not to be confused with an endorsement of the status quo. We have heard how many people (patients, public and professionals) want to see those very same qualities now shape and secure NHS and social care services so that they are fit for our current and future needs. This will involve all of us wrestling with and resolving some very challenging problems whether it be the future funding of adult social care that Andrew Dilnot will shortly report on or the rebalancing of local care services to achieve the best health outcomes. This will be difficult, at times controversial, but it would be a gross dereliction of our responsibilities to the most vulnerable in our communities and to the generations to come, if we fail now to forge a sustainable future for the NHS and social care.

I have heard from many who are passionate about improving our health and care system. There is a consensus that patients should be at the heart of decision-making and that we need strengthened local accountability and shared responsibility to develop and deliver improved services through health and wellbeing boards. Yet I have also heard that the case for the reforms and how they would be put in place has not been explained. The fear is that they are not adequate nor sustainable.

Our task has been to reflect on these concerns, and to come up with a set of recommendations that will get us back on track, so that we can move towards truly patient-centred care that is determined by the needs in our communities and delivered seamlessly.

The report reflects what we have heard and is the result of many hours of hard work from other Forum members. I hope this does their work justice and I thank them for their tireless efforts.



**Chair, Patient Involvement and Public Accountability
Chief Executive,
London Borough of Hammersmith and Fulham**

Summary of Recommendations

If the fundamental purpose of the Government's proposed changes to the NHS – putting the patient first – is to be made a reality, the system that emerges must be grounded in systematic patient involvement to the extent that shared decision-making is the norm. There must also be robust public accountability of the organisations responsible for commissioning and providing care.

There are three inter-connecting priorities that the Forum has identified in this theme of patient involvement and public accountability:

- Integrated care for patients and communities;
- the voice of patients and the public embedded in our health services, including the voices of children, vulnerable adults, carers and those who are often excluded; and
- effective systems of accountability and governance.

Our findings and recommendations look to ensure that these three priorities can become a reality by improving the modernisation plans.

Integrated care for patients and communities

1. *NHS commissioners and local authorities should be jointly responsible for improving outcomes where they depend on joint working:*
 - a. *Through the joint health and wellbeing strategy, health and wellbeing boards should set and monitor outcomes.*
 - b. *A proportion of the quality premium used to incentivise commissioning consortia should be dedicated to outcomes derived from the joint health and wellbeing strategy.*
2. *The authorisation process for commissioning consortia should consider how consortia boundaries will support joint working with local authorities. Although co-terminosity should not be an absolute requirement, the boundaries of commissioning consortia should not normally cross those of local authorities, and any departure should be clearly justified.*
3. *The Government should have a stated policy ambition that all local areas will undertake joint commissioning arrangements between the NHS and local authorities where appropriate. Acting on this, the Government and NHS Commissioning Board should actively enable a set of joint commissioning demonstration sites to evaluate the effectiveness and efficiency of joint commissioning, including joint budgets between health, social care and public health.*

The voice of patients and the public embedded in our health services

4. *The Government should include a stronger and clearer definition of patient and public involvement in the Bill:*
 - a. *There should be duties to involve patients and the public at all levels of the health and wellbeing system.*
 - b. *Involvement in respect of discharging the duties 'to involve' and 'to promote patient involvement' should mean embracing the principle of shared decision-making.*
5. *The Government should reaffirm and actively promote the NHS Constitution, emphasising its place as the cornerstone of the NHS now and in the future. The Bill should place a duty on NHS commissioners to actively promote the NHS Constitution.*
6. *Examination of consortia arrangements for shared decision-making in commissioning should be included in the authorisation process for commissioning consortia.*

7. *Health and wellbeing boards should be the place where local commissioners (NHS and local authority) explain and are challenged on how they are involving patients and the public in the design of care pathways and development of their commissioning plans.*
8. *There should be independent membership on commissioning consortia governance bodies, to provide independent challenge, including ensuring that consortia fulfil their duty for genuine patient and public involvement.*
9. *Appropriate training and support should be available for those organisations and individuals charged with engaging and representing patients and the public, and for patient representatives themselves, including NHS foundation trust governors.*
10. *Healthwatch locally should provide a patient advocate role, championing issues for patients, and a scrutiny and challenge function in relation to local commissioners and providers.*
11. *Local authorities should commission local Healthwatch. Health and wellbeing boards should be the place where local authorities explain and are challenged on how they are carrying out their responsibilities. Local Healthwatch should refer any disputes to Healthwatch England if resolution locally is not possible.*
12. *Commissioners and providers of services should be under a duty to have 'due regard' to local Healthwatch's findings.*

Effective systems of accountability and governance

13. *Nationally, the Secretary of State's responsibility for promoting a comprehensive health service should be made clearer to the public in order to allay any concerns and remove any confusion. As part of this responsibility, he/she should report to the nation annually.*
14. *Transparency and openness should run throughout the health and wellbeing system, particularly in relation to how public money is spent:*
 - a. *Commissioners of NHS services should have a governing body that holds meetings in public and publishes details of their contracts with providers. Members of the governing body should abide by the Nolan principles of conduct in public life.*
 - b. *Commissioners should be required to consult publicly under the statutory consultation rules on their commissioning plans.*
 - c. *All significant providers of NHS-funded services should be required, as an absolute minimum, to publish Board papers and minutes and hold their Board meetings in public.*
15. *Health and Wellbeing Boards must be the focal point for decision-making about health and wellbeing, bringing together NHS and local authority commissioners with patient representatives. The Bill needs to strengthen their role:*
 - a. *Health and wellbeing boards should agree commissioning consortia commissioning plans which should be developed in line with the joint health and wellbeing strategy.*
 - b. *If it is not possible to secure agreement locally on the plans, the health and wellbeing board should be able to refer their concerns to the NHS Commissioning Board.*
 - c. *The NHS Commissioning Board should take account of the views of health and wellbeing boards and the extent of joint working as part of their authorisation process and the ongoing assessment of commissioning consortia's performance.*
16. *Health and wellbeing boards should have a role in identifying any potential or actual conflicts of interest in respect of commissioning consortia decisions.*

Introduction

There was widespread support amongst those we heard from for many of the objectives behind the Government's modernisation plans, such as "no decision about me without me", and empowering communities through clinical and locally-responsive commissioning bodies. However, this support was tempered by concerns that without significant changes, the current proposals would fall far short of translating these objectives into reality.

We heard concerns that the proposed reforms would set the system back, and in some cases exacerbate existing gaps: in delivering seamless care for people; in reducing inequalities in involvement and outcomes for different groups; and in transparency and accountability to local communities. These challenges are made more pressing within the context of tighter finances across the board.

The NHS Future Forum members who have been focussing on Patient Involvement and Public Accountability have seen this NHS Listening Exercise as providing a useful opportunity to suggest improvements to the Government's NHS modernisation plans through the lens of ensuring that the NHS delivers patient-centred care that is defined, designed and accountable to people and their communities.

Throughout the many events and listening opportunities we have attended and the thousands of people we have met, three major, inter-connecting priorities in relation to patient involvement and public accountability have emerged:

- Integrated care for patients and communities
- The voice of patients and the public embedded in our health services, including children, vulnerable adults, carers and those who are often excluded
- Effective systems of accountability and governance

Our findings and recommendations seek to deliver these priorities by suggesting improvements to the modernisation plans for the NHS, and are summarised in the following chapters.

Throughout this report we have referred to the health and wellbeing system to describe all bodies at a local and national level involved in commissioning, regulating and providing care, including the NHS, local authorities and public health.

We have heard various different terms used to refer to those who need to be involved in decisions in the NHS, alongside healthcare professionals and managers: lay representatives, citizens, people, service users, customers, carers and patients. Throughout this report, we refer to 'patients' and 'patient representatives' by which we mean all of the above.

1. Integrated care for patients and populations

Across the NHS Future Forum's workstreams, the central importance for patients, carers and the public of providing care that is more integrated has been emphasised. This challenge is equally about commissioning care jointly across NHS and local authority boundaries and providing care along integrated pathways which span primary, secondary and tertiary health services.

There is a long history of joint working between local health services and local authorities, in particular with local authorities' social care and wider community services. Evidence suggests that a more integrated health system offers the best prospects for improving patient care and meeting the health challenges of the future by improving the co-ordination of services, reducing hospital admissions and providing care closer to people's homes:

- evidence suggests that integrated systems deliver high quality care, better patient experiences and more personalised services;
- by breaking down boundaries between professionals, integrated systems are better able to co-ordinate services, especially for people with long term conditions; and
- evidence shows that integrated care has been successful in reducing hospital admissions and providing care closer to people's homes.¹

There needs, however, to be a transformation in the scale and intensity of this collaboration and resulting integration.

Seamless, more efficient care for individuals and communities

We heard from patients, carers and the public about their demand for more seamless, joined up pathways of care that reflect their particular circumstances rather than the way services happen to be organised. Too often people find themselves having to adapt to the specifications of the services caring for them, rather than the services being centred around their needs. We heard about how failures to integrate the commissioning and delivery of these services leads to a lack of person centred care, lack of control for patients and users about how their care is delivered in the context of their lives, as well as poorer quality services and outcomes for those patients and users.

We heard from both the health service and local government about the vital need to manage the resource pressures that health, social care and public services will inexorably face as we go forward. There is an urgent need to join up the commissioning and delivery of services in a way that promotes health and wellbeing

¹ *Where next for the NHS reforms? The case for integrated care.* The Kings Fund. 23 May 2011

in local communities, reduces the prevalence of acute conditions and reduces the demand for avoidable, expensive hospital and social care. A significant theme from the NHS Listening Exercise has been concern that the Government's current proposals will not give sufficient impetus to integrated care.

Integrated care within the context of population health

The modernisation plans, including the proposed Health and Social Care Bill, stress the health of the population – they envisage a system within which services are delivered and prioritised in the context of the entire local population. Concern has been expressed that this emphasis should not be lost in the implementation of the Government's plans.

Population Health

'Population Health' can be described as a system within which services are delivered and prioritised in the context of a whole population, with the objective of health improvement, not just provision of health care.²

Population Health makes the commissioning process real, providing the link between the different levels of commissioning (individual, locality, strategic). It also connects commissioning to outcomes as clinicians and professionals become the key link between the patient, providers, the outcomes they achieve and functions they discharge as commissioners.

A focus on Population Health outcomes achieves improvements in the health of a population by developing a common understanding of the issues it faces. Agreeing priorities and prioritising investment as a result of that understanding will improve health and reduce inequalities on a population basis as well as on an individual basis.

Fiscal responsibilities and resource allocation are an integral part of this process as commissioners will need to work together to prioritise services within the global resources allocated.

Population Health gives coherence to the proposed changes in a variety of ways:

- delivery of better Population Health outcomes needs to be understood at level and consortia levels;
- anyone who acts in a decision-making capacity within commissioning consortia should follow the principles of Population Health commissioning to ensure their responsibilities to the population are discharged, rather than just focussing on clinical commissioning where there is a responsibility to individual patients with a particular condition;

² *What is population health?* Kindig & Stoddart. Am J Public Health. 2003 March; 93(3): 380–383

- consortia will need to consider all aspects of care (including prevention, detection, diagnosis, treatment and ongoing care) when they are designing a pathway of care to ensure they also discharge their Population Health responsibilities; and
- integrated care needs to be framed within Population Health. Integrated health and social care delivery systems and integrated care between primary and secondary healthcare therefore become means to achieving Population Health rather than ends in themselves.

The principle that decision-makers should be responsible for the health of populations is asserted throughout the NHS Future Forum's reports, and has been taken as the starting point for recommendations in this report regarding the need to integrate care and to ensure that there is sufficient accountability.

Aligning outcomes and performance

We heard from many who were trying to work together across health and care that the lack of joined-up performance and outcome measurement was a barrier to integrated care. This is not a new issue, and what we heard has cemented our belief that alongside the alignment of accountability between local commissioning organisations, accountability for improving outcomes must also be aligned.

We recommend that:

[1] NHS commissioners and local authorities should be jointly responsible for improving outcomes where they depend on joint working:

- a. Through the joint health and wellbeing strategy, health and wellbeing boards should set and monitor outcome goals.*

This would mean looking at the various outcomes frameworks and including those outcomes in joint health and wellbeing strategies that require joint-working to deliver. The local system would then be held jointly accountable for delivering the outcomes. National bodies such as the NHS Commissioning Board and the National Institute for Health and Clinical Excellence would need to include these outcomes in their performance reviews and quality standards.

There should be incentives in the system to encourage local commissioners to jointly commission for improved outcomes. In respect of commissioning consortia, we recommend that:

- b. A proportion of the quality premium used to incentivise commissioning consortia should be dedicated to outcomes derived from the joint health and wellbeing strategy.*

Joining Up in Leeds – A healthy city partnership

Leeds is a large metropolitan area of over 700,000 people - the third biggest city in the UK - with a history of joint working between health and care. This approach has continued with the formation of new commissioning consortia who are already working together with Leeds City Council, local NHS providers, the foundation trust, community services and the third sector to join up commissioning and planning of healthcare for the city.

Leeds provided a cross-sector view to the Forum, advocating the need under the new proposals to adopt single commissioning approaches to streamline the patient pathway and join up services to provide better outcomes for people. They support the idea of a strong health and wellbeing board, which would bring together local decision-making and hold the ring on local accountability. The partnership in Leeds has in place:

- a shared local authority and NHS perspective on implementation with a focus on outcomes;
- strong commissioners working closely with established and emergent commissioning consortia in a pathfinder programme;
- good practice engagement and clinical leadership in the system;
- a well established NHS foundation trust; and an acute trust and community trust that will be authorised by 2013;
- partnerships with the independent and third sectors; and
- an emerging shared understanding and commitment about how to manage £200m of efficiency savings that are needed in the NHS and £140m reductions in local authority budgets.

Leeds aspires to be a leading example of how to work together to seek solutions that help manage risk, lessen bureaucracy, integrate services, drive effective relationships and create healthy organisations for an even healthier city.

The boundaries of responsibility

We heard many views about the importance of co-terminosity of commissioning consortia with the boundaries of local authorities and health and wellbeing boards. The responsibility for commissioning services for a defined geography and population is, we believe, particularly important to ensure that people are covered by health and other local services in an integrated way, and for a Population Health perspective to be effective.

Geography needs to be more clearly addressed in the new system, and there should be explicit recognition of the benefit of alignment of commissioning authorities' boundaries.

We recommend that:

[2] The authorisation process for commissioning consortia should consider how consortia boundaries will support joint working with local authorities. Although co-terminosity should not be an absolute requirement, the boundaries of commissioning consortia should not normally cross those of local authorities, and any departure should be clearly justified.

Supporting and promoting integration

We heard various examples of where successful joint commissioning arrangements had been hampered, or needed to be put on hold as a result of the transfer of responsibility for commissioning NHS services to new structures. This goes against the objective of facilitating and encouraging integration of services. We urge the Government to preserve and encourage local areas that have already achieved successful integration of care or commissioning arrangements in their areas.

Health and social care – Total joint-commissioning demonstration sites

There are already many examples of where services are completely jointly-commissioned across the country. For example, in North East Lincolnshire, the local authority and NHS commissioners (currently the Primary Care Trust) jointly commission all health and social care services³. In Herefordshire, the local authority and the NHS commissioner (Herefordshire PCT) jointly commission health and social care services through integrated structures. Herefordshire has also integrated health and social care provision where appropriate, most notably through an integrated care organisation⁴ which brings together acute and community health and adult social care services in a single provider organisation.

It is examples like these, where joint-commissioning goes over and above one or two services, which should be supported as demonstration sites for other communities. They demonstrate a focus on the individual patient and commitment to working together to design, fund and deliver care for populations.

The Government and the NHS Commissioning Board should support areas which have already made significant progress in joining up across health and social care, and actively encourage others to look towards them as exemplars. Evaluation of these demonstration sites should be undertaken so that the benefits and learning can be captured and shared. And at a very minimum, the Government must ensure that the changes do not create additional barriers.

³ North East Lincolnshire Care Trust Plus has been responsible for health and adult social care services in North East Lincolnshire since September 2007

⁴ The integrated care organization in Herefordshire is called Wye Valley NHS Trust

We recommend that:

[3] The Government should have a stated policy ambition that all local areas will undertake joint-commissioning arrangements between the NHS and local authorities where appropriate. Acting on this, the Government and NHS Commissioning Board should enable a set of joint commissioning demonstration sites to support and evaluate the effectiveness and efficiency of joint commissioning, including joint budgets between health, social care and public health.

This support should be based on the model used for the pathfinder consortia and early implementer health and welling board programmes.

2. The voice of patients and the public in our health services

Many of our discussions centred upon the critical role that patients and the public need to be able to play in delivering health and care services. We heard from those representing patients with particular conditions about the importance of people making informed decisions about and being supported to manage their own care. We also spoke to those representing communities of interest – be that by type of condition, age, ethnic group, locality or the users of specific health services.

This chapter explores what ‘patient involvement’ should mean, and how it should permeate the health and wellbeing system at all levels. It also looks at the role and function of Healthwatch locally and nationally, and makes recommendations as to how these bodies might have the most impact in championing the patients’ interests.

Real patient involvement means shared decision-making

We have heard from a large number of patients, carers, parents and members of the public about how they want to be involved in their health and their community’s health, and what involvement means to them. We believe that both the language and practice of ‘involvement’ or ‘engagement’ commonly used in the NHS embody a lingering paternalism. We are unanimous in our belief that ‘shared decision-making’ must be the focus when we talk about ‘patient involvement’. Shared decision-making means joint ownership of decisions between patients and professionals.

In short: it is right in principle to share decisions with us as citizens and taxpayers, since they are our services; and it is right in practice, since the evidence is that shared decision-making at both individual and collective levels leads to better decisions.

We were also struck by the arguments that shared decision-making is a fundamental aspect of quality. Early evidence shows promising benefits of shared decision-making at the individual level, on patient participation and communication and health outcomes, particularly in relation to the care of people with long term conditions.^{5 6} Many of the tools of shared decision-making, such as active care planning, support for self management, and the use of decision aids are being adopted in the UK and internationally.

Two duties already exist in the Bill regarding patient involvement:

⁵ *Shared Decision-Making in Medicine*. Loh et al. *Dtsch Arztebl*; 104(21): A1483–8. 2007

⁶ *Interventions to improve the management of diabetes mellitus in primary care, outpatient and community settings*. Renders et al. Cochrane Review. In *Cochrane Library Issue 3*, 2001.

- a duty on commissioners ‘to promote patient involvement’ in decisions about their care, referring to shared decision-making at the individual patient level; and
- a ‘duty to involve’ on the national and local commissioning authorities: the NHS Commissioning Board and commissioning consortia.

Whilst these duties are welcomed, what we have heard emphasises the lack of clarity on what constitutes involvement. The Bill language of ‘informing and consulting’ is too weak. We favour a model that affirms the value of collective shared decision-making as a continuous process of dialogue at every level of the system, rather than occasional episodes of consultation. We recommend that:

[4] The Government should include a stronger and clearer definition of patient and public involvement in the Bill:

- a. There should be duties to involve patients and the public at all levels of the health and wellbeing system.*
- b. involvement in respect of discharging the duties ‘to involve’ and ‘to promote patient involvement’ should mean embracing the principle of shared decision-making.*

Rights, equalities and the NHS Constitution

Individuals being involved and owning decisions about their own care goes to the heart of the concept of choice and personalisation. The Government promotes its changes as seeking to embed patient involvement in decisions about their care at the heart of the NHS, with the mantra ‘no decision about me without me’. Following the variety of discussions and representations we have received, we believe that for this to be a reality, clinicians and healthcare professions will need to acknowledge the inevitable cultural change required, and to accept shared decision-making as part of how the NHS operates.

Making this culture a reality is the responsibility of leaders throughout the system – from the General Medical Council, Nursing and Midwifery Council and other professional regulators in regulating professionals; to the Royal Colleges and professional organisations in educating professionals; to commissioning authorities in contracting with providers and involving people in the commissioning process; to leaders of clinical teams and provider organisations in setting their expectations amongst employees.

The other side of the equation is individuals wanting and being able to be involved in the decisions about their care. We believe that people need to be aware of the rights that they have in relation to the NHS, if they are genuinely to be involved in decisions about their care.

We heard many voices expressing concern about the inequality they saw in the current system and concerns that inequalities in access and outcomes could be exacerbated. Too often people are excluded from accessing high quality care, for

example, the homeless without an address for appointments to be sent to; the mentally ill or people with learning disabilities who find it difficult to communicate their needs and preferences; or older people who are not included in decisions about their care, simply because of their age. In the case of black and minority ethnic communities, we heard that there is uneven quality of healthcare combined with difficulties in accessing services.

We heard particular anxiety about involvement of children by the NHS or rather its absence, which respondents thought contributed to poorer outcomes for children (in some childhood cancers for example) than in other comparable countries and the high rates of inappropriate admissions to hospital. For example, 75 per cent of children's asthma admissions could have been prevented with better primary care⁷.

The NHS Constitution is a landmark statement of rights and responsibilities for patients and staff, and is especially important as a protection of the rights of the most vulnerable and marginalized individuals and groups in society. The NHS Constitution is an incredibly powerful document and we recommend that:

[5] The Government should reaffirm and actively promote the NHS Constitution, emphasising its place as the cornerstone of the NHS now and in the future. The Bill should place a duty on NHS commissioners to actively promote the NHS Constitution.

All public authorities are of course subject to the equality duty⁸, requiring them to have due regard to eliminating harassment, advancing equality of opportunity across the protected characteristics⁹. The Equality Delivery System¹⁰ will provide a template for organisations to use to embed equalities into all aspects of service provision.

Another tool in increasing shared decision-making will be giving people more control over their care. Personal budgets are a key tool, especially for people with long term conditions, giving independence and real choice to people about what they need and how they want to be cared for.

The NHS Future Forum's report on Choice and Competition includes an ambition that within five years, everyone who is eligible for personal budgets should be offered one. We strongly support this recommendation.

That report also describes how the modernisation plans should look to promote and increase choice for people. The proposals focus on clarifying the choice offer for

⁷ *The asthma divide: inequalities in emergency care for people with asthma in England.* Asthma UK, 2007

⁸ Public sector equality duty, section 149, Equality Act 2010

⁹ Protected characteristics are: age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex, and sexual orientation

¹⁰ The Equality Delivery System is currently being developed by the NHS Equality and Diversity Council. It will link into the NHS Outcomes Framework and NHS Constitution.

people, extending the definition of what choice means and then ensuring robust accountability for making choice a reality for people. These recommendations will support and incentivise the behaviour of shared decision-making called for in this report.

Shared decision-making for communities

Involvement must extend beyond the decisions about an individual's care, and apply to decisions that affect the design and provision of care for communities:

- as part of designing services for a particular group or condition;
- in strategic decisions about commissioning of services at the local level; and
- at a national level, in decisions about commissioning and the operation of the health and wellbeing system.

Shared decision-making in the design of pathways

Similarly, commissioners cannot expect to design integrated, efficient pathways to deliver high quality care if they do not involve the people who will be using the services in their design, as well as patient representatives and patient organisations.

Transforming Diabetes care: Co-creating Health at the Whittington

Whittington Health in north London serves a diverse, relatively deprived population where diabetes outcomes were poor. The clinical teams from the hospital, community and local primary care wanted to bring about a fundamental change in local diabetes care and successfully applied to participate in the Health Foundation's *Co-creating Health Programme*.

Co-creating Health improves outcomes by training both patients and clinicians in self-management support. Patients work in a group setting which is facilitated by a trained lay tutor (expert patient) who has diabetes, together with a clinician tutor. To date 260 patients have gone through the course at the Whittington. There have been clinical improvements in both glycaemic control and cholesterol. People's quality of life and experience have been improved as well. In the words of one 'graduate':

“On a personal level – this course gave me the tools to seek help and advice from my health carers and to find the solutions to the various problems. I now have improved health, taking less medication and feeling a lot better. The feeling that I was alone and did not have anyone who cared or listened to me has gone. I feel in control of my own health. I know who to talk to.”

It should be the responsibility of commissioners to secure the right people's involvement when redesigning how care is delivered, not only because it is the right

thing to do, but also because evidence suggests that patient involvement can lead to design of better care pathways.^{11 12}

In the interests of balancing the need to retain flexibility for commissioning consortia in how they operate, with the need to provide assurance that they are involving the people they serve, we recommend that:

[6] Examination of consortia arrangements for shared decision making in commissioning should be included in the authorisation process for commissioning consortia.

[7] Health and wellbeing boards should be the place where local commissioners (NHS and local authority) explain and are challenged on how they are involving patients in the design of care pathways and development of their commissioning plans.

Local shared strategic decision-making

Strategic decisions by commissioning consortia as to how care is designed and delivered will impact on the care and lives of those in the communities they serve. It is only right therefore that communities are involved in the decision-making process.

Whilst we are reluctant to prescribe governance models for the new local commissioning authorities, we believe that the commissioning consortia that deliver the best health outcomes, will as a matter of course include patient representation on their governing bodies, not because they have to but because it is only through shared decision making that they can arrive at the right decisions for their community. We recommend that:

[8] There should be independent membership on commissioning consortia governance bodies, to provide independent challenge, including ensuring that consortia fulfil their duty for genuine patient and public involvement.

Support for patient representatives

The involvement we envisage will require informed patient representatives, with the skills and capabilities to understand the decisions they are being involved in and the wider constraints and complications within which the decisions must be made. We cannot just assume that those being asked to be involved in decisions will have these skills and such understanding.

NHS foundation trust governors are an example of people being asked to represent their local communities and patients of that trust, and to scrutinise the organisation on their behalf. This is a critical role and has not been given sufficient recognition, nor adequate support.

¹¹ *Bringing User Experience to Healthcare Improvement*. Bate and Robert. Radcliffe Oxford. 2007

¹² *Co-production: an emerging evidence base for adult social care transformation*. Needham, C. SCIE Research briefing 31. 2007.

We recommend that:

[9] Appropriate training and support should be available for those organisations and individuals charged with engaging patients and the public, and for patient representatives themselves, including NHS foundation trust governors.

Healthwatch

The Forum heard support from many about the concept of Healthwatch as the new powerful consumer advocate at local and national level. However, there were also many who questioned whether the expectations were too great as to what Healthwatch could achieve, given what are likely to be limited resources and an uncertain history of patient involvement initiatives over the last ten years.

Local Healthwatch

We have heard many differing views about the role of Healthwatch locally, and a resounding message that there is a lack of clarity in the current proposals as to what its role is or should be. There are questions regarding:

- their hosting arrangements: current proposals suggest they are hosted by the local authority;
- how they will be funded: there is debate as to whether their funding should be ring fenced in local authority budgets; and
- the extent of their role: whether local Healthwatch should be purely patient advocates as part of a wider patient involvement system or culture or whether it should itself constitute the network for patient involvement.

Our view is that real shared decision-making will only come about if there is a network or involvement at a local level and throughout the system – and that this creates a culture of routine and genuine patient involvement across health and care.

We agree that expectations as to what local Healthwatch will be responsible for are too great, particularly given that their funding is likely to be limited. The Government's ambition that local Healthwatch will be a powerful consumer champion and that they will be built on existing Local Involvement Networks (LINKs) has created tensions, given the varying degree of effectiveness of existing LINKs.

It is essential that the new local Healthwatch structures are effective, and so their role needs to be clear. We believe that local Healthwatch should have a dual role of patient advocacy – the powerful consumer champion in the system – and scrutiny and challenge – of organisations in the health and wellbeing system. Healthwatch will be particularly well placed to provide this challenge given their role on health and wellbeing boards.

We do not agree that budgets for local Healthwatch should be ring fenced. Local authorities will be held to account for funding Healthwatch through both the health and wellbeing board and the authority's overview and scrutiny functions. If there

are issues or conflicts which cannot be resolved locally, Healthwatch England will have a role as an independent arbiter. The onus should be on local Healthwatch to be transparent and clear in their areas of focus, as the most likely route to providing value for money and secure funding. We recommend that:

[10] Healthwatch locally should provide a patient advocate role, championing issues for patients, and a scrutiny and challenge function in relation to local health and wellbeing commissioners and providers.

[11] Local authorities should commission local Healthwatch. Health and wellbeing boards should be the place where local authorities explain and are challenged on how they are carrying out their responsibilities. Local Healthwatch should refer any disputes to Healthwatch England, if resolution locally is not possible.

It cannot be assumed that just because local Healthwatch exists in its role as a consumer champion and to provide scrutiny and challenge, that commissioners and providers will be receptive to it looking into areas of concern and take notice of any findings. We endorse the Bill's intention to transfer the existing duty on providers to allow LINKs to 'enter and view' their operations, to local Healthwatch. This does not address the issue of whether local Healthwatch is listened to. In addition, we recommend that:

[12] Commissioners and providers of services should be under a duty to have 'due regard' to local Healthwatch findings.

Healthwatch England

Healthwatch England will have a key role as the key leadership body for local Healthwatch, setting clear standards of excellence for the local bodies to follow. It will also act as an arbiter where there are conflicts or disputes between the local Healthwatch and the local authority. As one of the key national players in the new system, the Government should look to establish it as soon as possible, with sufficient funding. Although it is to be technically part of CQC, it needs to be allowed the independence to discharge its functions freely. To ensure that links with its local counterparts, local Healthwatch should be represented on the governance committee alongside independent members.

The NHS Future Forum's report on Choice and Competition recommends a Citizens Panel as part of Healthwatch England, with the role of reporting on how effectively the choice mandate is being delivered by the health and wellbeing system. We endorse this recommendation as offering patients a further voice at a national level, and a useful accountability mechanism.

Once again, our proposals in this area are dependent upon accountability and governance systems that champion the model of involvement and support we envisage. The following chapter sets out what we heard regarding public accountability and our recommendations for strengthening the emerging model.

3. Effective systems of accountability and governance

In a democratic country, with taxpayer funded public services, public accountability is vital to secure quality, integrity, value for money and public confidence. There has to be good governance at every level of the system, in every organisation dealing with taxpayers' money, and amongst those individuals accountable within those organisations.

We heard various concerns about the mechanisms or perceived lack thereof for public accountability in the Government's proposals, particularly that they were too weak, unclear, did not protect against conflicts of interest or cherry-picking of 'simple' cases and that they could lead to a reduction in local democracy.

It is clear that the aspirations that we have heard from so many – about integration and effective shared decision-making – cannot be secured without the right systems of accountability and governance. These systems need to be capable of incentivising behaviours that will help secure the objectives of more integrated and more responsive services.

There are three gaps in the current proposals regarding accountability, that we believe need to be addressed, and this chapter will take each in turn:

- reinforcing national accountability;
- transparency and openness throughout the system; and
- strengthening local accountability.

We recognise, however, that a robust system of accountability requires a regular assessment of risks, and must be continuously learning and improving. The Government will need to keep the system of public accountability under review, particularly considering any recommendations from the forthcoming Francis Inquiry.¹³

Reinforcing national accountability

We heard commentary on the likely balance of power and influence of the NHS Commissioning Board in the new system compared to that of local organisations, such as commissioning consortia, local service providers including local authorities, and health and wellbeing boards. We agree with the view that unless the power of health and wellbeing boards and the internal governance of commissioning consortia is strengthened, the reforms run the risk of reinforcing the dominance of national,

¹³ The Mid Staffordshire NHS Foundation Trust Public Inquiry – Chaired by Robert Francis QC

top-down performance management by the NHS Commissioning Board, rather than achieving the aim of a more liberated, devolved system.

We support the role of the NHS Commissioning Board as set out in the Bill to secure the delivery of the Secretary of State's national health outcomes, allocate and account for NHS resources, authorise the establishment of commissioning consortia and hold them to account for their commissioning of services within an overall financial envelope and defined standards of performance and quality. It is also right, in our view, that it has powers of direction over commissioning consortia in specified areas and circumstances – such as risk of failure – and that it should commission some services directly.

We have heard concern from various quarters that the Secretary of State for Health will no longer have a responsibility or duty in respect of promoting a comprehensive health care service, which could in some way lead to the erosion of the NHS. We understand that this is not in fact the case as far as the proposed Bill is concerned. However, we recommend that:

[13] the Secretary of State's responsibility for promoting a comprehensive health service should be made clearer to the public in order to allay any concerns and remove any confusion. As part of this responsibility, he/she should report to the nation annually.

The Secretary of State will remain ultimately responsible for improving the health of the nation, and the modernisation plans see her/him setting out the outcomes that the NHS must achieve¹⁴, and for which she/he will be held to account by Parliament. We endorse the intention that the Secretary of State should report to the nation annually as to the performance of the health service (including the NHS and Public Health England). We would urge the Government to use this opportunity to provide an overarching account of the state of the nation's health, and to ensure that it is accessible to the ordinary person.

Transparency and openness throughout the system

All public bodies are expected to be transparent in their activities, decisions and performance, and to account for how they are spending public money. This includes mechanisms such as publicly held board meetings, making information about contracts and the delivery of those contracts publicly available, and for providers, publishing accurate information about the quality of their services.

We have heard that there is a lack of clarity on whether these same transparency and openness requirements will apply to new commissioning consortia, as there is uncertainty about their governance arrangements.

There was support for the Government's current position of keeping governance requirements to a minimum so as to avoid stifling local flexibility and innovation.

¹⁴ Outcomes for the NHS are to be set out annually in the NHS Outcomes Framework

Conversely, there was a widespread and strongly held view that the absence of Bill provisions on the governance arrangements for commissioning consortia did not give sufficient assurance of public accountability, especially given that they would be statutory public bodies responsible for large amounts of public money.

The Forum believes there is a balance to be struck between the need for good governance and the need to avoid over prescription – a principle which is reflected in the NHS Future Forum’s report on clinical advice and leadership in respect of the constitution of commissioning consortia boards. With this balance in mind, we recommend that:

[14] Transparency and openness should run throughout the health and wellbeing system, particularly in relation to how public money is spent:

- a. Commissioners of NHS services should have a governing body that holds meetings in public and publishes details of their contracts with providers. Members of the governing body should abide by the Nolan principles of conduct in public life.*
- b. Commissioners should be required to consult publicly under the statutory consultation rules on their commissioning plans.*

During the course of our discussions we have heard many concerns involving the openness of NHS provider organisations, especially NHS foundation trusts. Similar concerns have arisen about the involvement of the third and independent sectors, and the extent to which they could be held to account for their performance in the NHS. We believe in the principle that any and all organisations operating as part of the NHS should be held to account for their decisions. We recommend that:

- c. All significant providers of NHS-funded services should be required, as an absolute minimum, to publish Board papers and minutes and hold their Board meetings in public.*

We have already stated that NHS foundation trust governors have a key role in scrutinising trusts on behalf of their patients and communities, and recommended that they need to have appropriate training and support to be effective.

In addition, we would see the health and wellbeing board (and Healthwatch as part of their scrutiny and challenge role) as being tasked with assuring adequate transparency of all its local commissioners, including identifying actual or potential conflicts of interest of commissioners, which is discussed later in this chapter.

Strengthening local accountability

The Forum heard widespread optimism and support for the creation of health and wellbeing boards as the vehicle to enable local integrated strategic planning, joint decision-making and collective management of population health, as well as a mutual accountability mechanism between the local commissioners and communities they serve.

However, there was also widespread scepticism that the current reform proposals would be able to provide the right incentives to create this mutual accountability and make joint-working a reality. Many were worried that the current changes would not go far enough, but would mean a retreat for many localities where hard-won progress had already been made.

There was also a degree of uncertainty as to what role health and wellbeing boards would have in the new system. Having reflected on what we have heard, we believe that health and wellbeing boards must be the focal point for decision-making about health and wellbeing, bringing together NHS and local authority commissioners with patient representatives. They must be tasked with agreeing the priorities for health and care for that community and each party must account to the Board for their obligations to deliver those priorities.

The right incentives need to be in place to encourage commissioning consortia and local authority commissioners to work collaboratively and cooperatively. The environment should encourage and reward joint-working in:

- defining local needs through the joint strategic needs assessment (JSNA);
- deciding on local priorities through the joint health and wellbeing strategy and considering where joint-commissioning of services or solutions may provide more effective or efficient outcomes for communities;
- monitoring the performance of commissioners (NHS Commissioning Board, commissioning consortia and local authority) in delivering their obligations in the joint health and wellbeing strategy; and
- ensuring that there is a network of patient and public involvement in their local health and wellbeing system.

There is significant scope within this environment to explore the development of joint-commissioning support functions between NHS and local authority commissioners. This would help ensure that resources are used in a coherent way and incentivise integrated delivery in areas including community care, learning disability, mental health and other adult care services. There may be some need to look at the flows of funding to respective commissioners in order to reinforce this.

Strengthening duties to health and well being boards

We have concluded that local health and wellbeing boards are a vital part of the system that needs to be put in place. We heard different views on the issue of accountability to health and wellbeing boards: on the one hand many people have called for them to have sign-off powers over the annual commissioning plans which will be developed by commissioning consortia; others reason that this model of dual accountability will be confusing and unworkable.

We heard concerns that the Bill does not provide strong enough incentives for commissioning consortia to work together in cooperation with health and wellbeing boards and local authority commissioners in their planning and commissioning of

health services. The requirement on commissioning consortia simply to ‘have regard to’ the health and wellbeing board was felt not to be strong enough to prevent consortia from commissioning services that do not adequately take into account the joint health and well being strategy.

We recommend that:

[15] Health and wellbeing boards must be the focal point for decision-making about health and wellbeing, bringing together NHS and local authority commissioners with patient representatives. The Bill needs to strengthen their role:

- a. Health and wellbeing boards should agree commissioning consortia commissioning plans which should be developed in line with the joint health and wellbeing strategy.*
- b. If it is not possible to secure agreement locally on the plans, the health and wellbeing board should be able to refer their concerns to the NHS Commissioning Board.*
- c. The NHS Commissioning Board should take account of the views of health and wellbeing boards and the extent of joint working as part of their authorisation process and the ongoing assessment of commissioning consortia’s performance.*

Membership of health and wellbeing boards

We discussed with a number of people how, beyond the issues of powers and accountability, to help local boards be effective. The issue of membership was one raised a number of times.

We believe that these boards need to have a lean membership built around those with ultimate responsibility for leadership in the local health and well-being system. The constitution of boards will depend on local circumstances, and should not be overly prescribed. Local areas should be able to determine how their boards will operate and take decisions, for example, who should have voting rights.

We have developed a suggested format which we believe will support local joint working and strong accountability:

- there should be a relatively small and equal number of local authority and commissioning consortia representatives which make up the majority of the board;
- local authority representatives would be drawn from the elected members of the Cabinet in the authority;
- given the NHS Commissioning Board’s role in commissioning primary care and specialised services, their local representative should be a member of the board;

- there should be patient representation (for example, including Healthwatch) in the membership of the board; and
- a representative from the local clinical senate to provide wider clinical input (the concept is discussed in detail in the NHS Future Forum's report on Clinical Advice and Leadership) should be the final full member.

The board would clearly need to be supported by professional advice from officers from both the local authority and the relevant commissioning consortia. This would include Directors of Adult Care Services and Children Services, as well as the Director of Public Health.

Managing perceived conflicts of interest

We heard concerns about potential conflicts of interest amongst the clinicians who will be involved in taking commissioning decisions. These fell under two broad headings:

- GPs within commissioning consortia could potentially benefit from commissioning decisions, if they also act as providers for a pathway of care; and
- secondary care clinicians could be conflicted if they are involved in the redesign of a pathway of care that will adversely affect activity within their employer organisation.

It needs to be emphasised that in the vast majority of cases, health services being commissioned by GPs with advice from secondary care clinicians benefits both the patient and the community. Concerns we heard were more about the theoretical risk of developing pathways that did not benefit populations.

Throughout our report, we have made several recommendations that will act as safeguards against conflicts of interest, including requiring commissioning consortia to have governance bodies with independent membership, which meet in public; to consult publicly on their commissioning plans; and to publish details of their contracts. In addition to these safeguards, we recommend that:

[16] Health and wellbeing boards should have a role in identifying any potential or actual conflicts of interest in respect of commissioning consortia decisions.

The NHS Commissioning Board should regularly review the safeguards against actual and potential conflicts of interest within the health and wellbeing system, to ensure that it is robust and fit for purpose.

Local overview and scrutiny arrangements

There was widespread support for strengthening democratic accountability across health and social care by extending health scrutiny powers to cover all commissioners and providers. The mandate for councillors to use health scrutiny powers to bring professionals, patients and communities together to tackle

inequalities and improve services was recognised as valuable, especially in light of current challenges. However, there were concerns about whether the proposals to allow councils to change the way health scrutiny operates would risk a loss of independence for overview and scrutiny.

We believe that the function of local overview and scrutiny, led by elected representatives is essential as a mechanism of public accountability. The additional flexibility being introduced offers an opportunity for local areas to develop their scrutiny functions to best meet their particular circumstances and constitutions.

Local authorities must seize this opportunity and there is no doubt that local Healthwatch will be particularly interested in ensuring that this parallel scrutiny function operates effectively. Likewise, part of the scrutiny function will include whether local authorities are appropriately commissioning local Healthwatch.

Conclusion

During this listening process we have been struck by the passion and enthusiasm that we have heard for a health and wellbeing system that puts patients at its heart, that is collaboratively designed and locally accountable. We heard that people want to build on the progress that has already been made, and to push ahead towards a system that is fit for the difficult challenges that we will face over the next decades.

We also reflected upon the genuine concerns from patients, carers and their representatives, third sector organisations, professionals, clinicians and other local and national stakeholders that the reforms as they stood do not go far enough to make that vision a reality. There was support for the vision of “no decision about me” but this did not translate into truly hard-wiring shared decision-making into every part of the health system. Many welcomed the idea of local determination but felt that the current proposals for health and wellbeing boards did not go far enough. And while people championed the concept of better accountability and governance, the reforms suggested did not make clear who was accountable for what, and to whom.

Many were also afraid of losing momentum and progress in places such as Leeds, which are already working towards single-commissioning across health and care. For projects such as personal budgets and diabetes self-management at the Whittington, which are putting people back in control of their health and lives through shared decision-making; and in the many other cases we heard about where people are working together in innovative ways to make their local communities healthier.

The recommendations we have made to the Government’s proposals strive to create a system that:

- delivers integrated care for patients and their communities – through the removal of barriers and strengthened incentives for all local commissioners to work together;
- embeds the voice of patients and the public in decision-making – through shared decision-making at all levels; and
- has effective mechanisms for accountability and governance – through transparent and open governance arrangements for local and national organisations.

The recommendations outlined in this report are this group’s proposals to improve the Health and Social Care Bill and accompanying policies in a way that builds on the progress already made and that we believe will help to make the vision behind the rhetoric a reality.