



## **EQUITY AND EXCELLENCE: LIBERATING THE NHS**

### **A NATIONAL VOICES RESPONSE TO THE COALITION GOVERNMENT'S CONSULTATIONS**

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## SUMMARY

National Voices welcomes the opportunity to respond to the consultation papers associated with the White Paper on behalf of its 200 member organizations and its network of patients and service users. Despite significant improvements over the last decade years, more needs to be done to achieve consistently good care meeting people's needs. The Government's proposed reforms offer an opportunity to rethink the way health and social care are delivered in England for everyone's benefit. Our key observations are as follows:

- We welcome the vision of an NHS built around the principles of shared decision making, with greater choice and control for individuals and a greater focus on outcomes. We welcome the commitment to the founding principles of the NHS. We support the greater integration of social care, healthcare and public health.
- We support the focus on openness and transparency. All bodies commissioning and providing services for the NHS need to be transparent about their decisions and hold their meetings in public.
- Risks to health and well-being attend the implementation of these reforms, because of the pace and scale of the reorganizations already underway, alongside a major NHS efficiency drive and reductions in funding for benefits, local authorities and the voluntary sector. These risks need to be mitigated by the proactive use of patient feedback and the involvement of patient, service user and voluntary organizations in the transition to the new arrangements.
- Delivering a more affordable and higher quality NHS will require more investment in good care closer to home, integration of health and social care, a greater focus on prevention, and some disinvestment in the acute sector. It is essential that there is a common health and wellbeing outcomes framework to help drive integration and ensure that public health is not marginalized.
- There is a need to re-energise the forces of professional pride and clinical leadership among health professionals.
- Involving people to a greater extent in decisions about their health will improve care and reduce wasteful spending, for example on unnecessary hospital admissions. National Voices and its members are well placed to work with NHS professionals and regulators to help embed practical approaches to shared decision making, for example through the systematic spread of participative care planning and support for self management for those with long term conditions.
- We propose ways of strengthening the outcomes framework outlined in the Government's consultation to give greater weight to managing long term conditions, measuring people's experience, narrowing health inequalities and protecting vulnerable groups.

- A more concerted effort is needed to combat discrimination and prejudice against minority groups in health and social care.
- Patients and communities must be actively involved in commissioning at all levels. The governing bodies of general practice consortia need to be co- led by clinicians and lay people. National Voices and its members are well placed to support the development of commissioning at national and local level.
- Explicit arrangements are needed in the new commissioning procedures for people with rare, neglected and orphaned conditions.
- We support the creation of HealthWatch as a powerful agent for co-design of services and a voice for patients and communities. The impact of local HealthWatches will depend on the strength of their connections with local communities and their ability to work in partnership. They must be independent and properly funded.
- The credibility and impact of HealthWatch England will depend on the quality of its connections with local HealthWatches, and with patients, carers and voluntary organizations.
- We support the “any willing provider” model which is likely to spur innovation in care, and draw more productively on the expertise, energy and passion of voluntary sector providers, and promote new forms of social enterprise. This needs intelligent regulation. There is a large risk of market domination by entrenched foundation trusts which could stifle innovation and impede a transfer of resources into primary and community services.
- Lifting the cap on private income for foundation trusts would create a significant risk of detriment to NHS patients. There would need to be transparency about provider income and regulators would need to be alive to the risks and prepared to intervene in the interests of NHS patients.

National Voices

October 2010

## **SECTION 1: OVERVIEW**

### **Introduction**

National Voices welcomes the opportunity to respond on behalf of its members to the consultations associated with the White Paper “Equity and Excellence: Liberating the NHS”. We are a coalition of some 200 national voluntary organizations in health and social care, including a network of patients and service users, and we offer a definitive point of access to patient and service-user voices. Our mission is to strengthen the voice and power of citizens at all levels in health and social care, in England.

This response distils the views of our members, gathered in various ways, including the deliberations of our expert advisory group and key messages from our member conference on 16 September 2010 which was attended by Minister of State Paul Burstow MP and senior figures from the health professions, regulators, and Department of Health.

This overview section makes some general observations and highlights themes of particular concern to National Voices members. Section 2 provides responses to the separate consultation papers on outcomes, commissioning, local democratic legitimacy – including HealthWatch – and regulation. Annex A contains recommendations on shared decision making and Annex B provides a note on patient experience outcome indicators.

### **Good quality, person-centred care: where are we at?**

There has been considerable progress in the last decade in improving health and care in England. Key measures of public health such as deaths from cancer and cardiovascular disease, life expectancy, infant mortality, and smoking rates have improved. There have been notable improvements in hospital waiting times, access to primary care, and the control of hospital acquired infections. There has been increased focus on involving patients and communities in decisions about their care, and levels of public satisfaction with the NHS have increased. These changes are testament to considerable investment, reform, and the commitment and professionalism of care and managerial staff at all levels.

It is well recognized that further improvement is needed to equip services to cope with growing demand, to ensure greater consistency of quality and to make care more tailored to the diverse needs of individuals and communities. We know that there are large variations in quality, that death rates for several cancers lag those in other advanced countries, and that health inequalities have remained wide and in some cases – for example the life expectancy gap between rich and poor - have widened.

There also remains a large gap between the rhetoric and reality of person-centred care. The care of people with long term conditions – to which the majority of NHS resources are devoted - does not systematically follow good practice. More needs to be done to take unnecessary activity out of hospital settings and to provide people with the support and information they need

to be in control of their health and their conditions and be fully involved in decisions about their care.

More needs to be done to ensure that patient and citizen voices become powerful drivers of change in the NHS. A culture of positively inviting feedback and responding quickly has yet to take root. The measurement of patient experience and of patient reported outcomes are important developments but still in their infancy. Formal mechanisms of local public involvement have been subject to too much reorganization and have had variable impact.

The provision of adult social care is patchy and inequitable. The health and social care systems are often difficult and confusing to navigate. There is frequently poor coordination across the boundaries between NHS and local authority services and between primary, community and secondary care.

We know from our members that care systems struggle to respond effectively to the needs of particular people and groups, for example: frail elderly people; people with mental health conditions, learning disabilities and physical disabilities; some minority groups; chronically excluded groups, such as homeless people, sex workers, and asylum seekers; and people with rare conditions or with those which the NHS does not generally prioritise, such as musculo-skeletal conditions. Even for the most articulate and health-literate, the experience of care can sometimes be disempowering, frightening and lacking in respect and compassion.

### **Equity and Excellence: an overview response to the Government's consultations**

National Voices members are therefore not complacent about the status quo and are clear that reform is necessary if health and social care are to improve in quality while coping with increasing demand in a time of austerity. We believe that the Government's proposed reforms offer an opportunity to rethink the way health and social care are delivered in England and to make significant improvements.

We welcome the Government's commitment to uphold the NHS as a comprehensive service, free at the point of use and based on need not the ability to pay.

We strongly support the emphasis on quality and outcomes, and on empowering patients and citizens. We welcome the commitment to build on the work of Lord Ara Darzi on quality and to maintain the NHS Constitution. We applaud the vision of an NHS built around the principles of shared decision making, including better information and choice, and of "no decision about me without me".

We believe that general practice commissioning, if carefully introduced and supported, has the potential to make the design of local services more responsive to need. We believe that the principle of "any willing provider" – with appropriate safeguards and intelligent regulation – offers the potential to promote innovation and good practice, and to better marshal the expertise and initiative of the voluntary sector. We think that HealthWatch has the potential to be a powerful agent for the co-design of services, for local accountability and for supporting people. We welcome a strengthened role for local authorities in coordinating care.

We believe that health professionals need help and support to become empowered. Financial and accountability mechanisms, managerial cultures and other factors have contributed to dulling the forces of professional pride and ethos, and clinical leadership, among the medical and nursing professions as well as staff in non-clinical managerial positions. We think professionalism needs to be reinvigorated. National Voices and its members are well placed to work with the professions to articulate and embed a clear vision of clinical practice fit for the 21<sup>st</sup> century.

Our members have also highlighted risks associated with implementing the Government's reforms. A number of major changes are happening in parallel:

- an NHS change programme of unprecedented scale and pace, which is already underway
- an efficiency programme designed to release up to £20 billion of savings for reinvestment within the NHS
- the drive to achieve significant savings in the NHS management overhead
- cuts to benefits, local authority services and support to the voluntary sectors which are already in train, with further significant cuts expected as part of the comprehensive spending review.

In combination these factors risk undermining the intent of the NHS White Paper through:

- professionals losing focus on safety, clinical effectiveness and the experience for patients
- a loss of skills and expertise, especially in commissioning
- disruption of models of care that are working well
- short termist cuts in service provision with long lasting consequences
- a widening of health inequalities and harm to the health and wellbeing of poor and marginalized communities

As mitigation of these risks we believe it is essential that:

- NHS bodies step up their efforts in proactively seeking and swiftly responding to feedback;
- there is close monitoring of key indicators of clinical quality, safety and the experience of patients, service-users and carers;
- organizations representing patients, service-users and carers are closely involved in decisions at local and national level.

## KEY THEMES FOR NATIONAL VOICES MEMBERS

**Good care closer to home** There is growing evidence that a more economically sustainable health service, better geared to the health and social needs of the growing population with long term conditions, needs to invest in primary and community services, better integrate NHS and local authority services, and disinvest in some acute services. This also aligns with people's preferences: people want to live as normal a life as possible, to be supported to manage their health conditions with minimal intervention, and to receive care and treatment in primary care settings. The consistent call from across our membership is "good care closer to home".

The Government proposes a number of mechanisms that will facilitate these changes and which we support: they include personal budgets, a stronger role for clinicians in commissioning, greater choice of care and a statutory role for local authorities in promoting coordinated commissioning. There is a risk that these mechanisms will not be strong enough systematically to drive integration and the transfer of resources into primary and community services (which will include sometimes tough decisions about the reconfiguration or closure of hospitals services). We therefore recommend that commissioning is driven by a common health and well being outcomes framework (rather than a more narrowly conceived NHS outcomes framework).

**Shared decision making** We applaud the commitment to shared decision making, and ideas for embedding it are contained at **Annex B**. Progress requires a combination of factors including effective leadership, practical support, and patient and public pressure. The systematic adoption of participative care planning for people with long term conditions, of decisions aids, and of a different style of conversation between patients and clinicians, will make a big difference. In particular it requires a fresh outlook from health professionals and a new way of articulating good clinical practice. National Voices and its members are well placed to work alongside the health professions to make a reality of shared decision making.

**Information** Good information is vital to support patient choice, control and confidence, and we fully support the Government's vision of an "information revolution". We favour maximum transparency about performance, in particular to drive improvements in professional behaviour through benchmarking and peer to peer challenge. We believe that people should own their personal health records. Information is not just data – it is about good communication and people becoming activated. A key challenge will be to ensure that people – particularly the most vulnerable and least health literate – have access to the interpretation, navigation and support they need to make sense of information and gain the motivation to act on it. We look forward to working with the Department of Health on its forthcoming consultations relating to information and choice.

**Patient and public involvement** We support the proposal of strong, visible, independent, properly funded HealthWatches. We believe they have the potential to become influential community leaders and partners of local commissioners and providers, helping to co-design services, and to contribute to community development and public health. That will require them to be well linked into their local communities. We elaborate our thinking in Section 2.

**Commissioning** The new commissioning arrangements need to respond effectively to diverse needs at local, regional and national level. General practice consortia will need skills and infrastructure to support their work and the leadership role of the NHS Commissioning Board will be of vital importance.

GPs are well placed to understand the needs of their patients, but also need to understand the diverse needs of their populations, not all of which are manifest in the consulting room. GPs' interests are not identical to those of patients and communities and GPs are not proxies for patients. General practice commissioning will need to draw on the expertise provided by a range of health and social care professionals and on the expertise about particular conditions that lies with patient organizations and with patients themselves.

General practice consortia will be publicly funded and accountable bodies. They need to feel very firmly accountable to local communities. Consistent with the Government's commitment to shared decision making and meaningful public involvement, we consider it vital that there is equal lay participation in the governance of the consortia, and that their meetings are held in public. They need to involve local communities in their work. A significant lay involvement is also needed in the governance of the NHS Commissioning Board.

**Safety** A culture of candour is vital at a time of change and financial retrenchment. We strongly support the Government's commitment to require openness with patients when things go wrong, through early legislation to establish a duty of candour. This is a necessary but not sufficient condition for better safety, since new legal duties can also reinforce a culture of fear and defensive, tick-box compliance in NHS bodies. Positive culture change is needed to create the climate in which early feedback from staff, patients and families is encouraged, supported and heeded. This can include empowering patients to ask questions about safety (eg handwashing) and to correct mistakes in their health records.

**Health inequalities** Health inequalities have remained stubbornly wide for many groups in relation to health, healthcare outcomes and experience of services. Poverty, race, ethnicity, sexuality and other factors are associated with health inequality, as are a number of conditions and disabilities. As the Marmot review and other studies have made clear, not all the solutions are in the hands of the NHS and social care services, but many are.

There is a strong framework of law and policy to protect the rights of minorities, but there has been insufficient appetite to apply these with vigour. We therefore need strong leadership and constancy of purpose on equalities, on the application of equalities legislation, and a continual challenging of discrimination and stereotyping.

We also recommend that narrowing inequalities in health outcomes should be an explicit improvement area within the new outcomes framework. Health professionals need to see their contribution to public health and to narrowing inequalities as a key part of their professional ethos.

## SECTION 2: RESPONSES TO CONSULTATION DOCUMENTS

### 1. TRANSPARENCY IN OUTCOMES – A FRAMEWORK FOR THE NHS

#### General observations

We support the focus on outcomes. Healthcare, public health and social care outcomes strongly interconnect and a coherent health and well being outcomes framework – rather than a narrower NHS framework – would more strongly support joined up commissioning. National Voices members see the following outcomes in particular as key tests of the success of the planned reforms:

- Mortality on a par with the best results internationally
- A reduction in premature deaths among the very poorest
- Avoidable deaths and harm decline as a result of improved patient safety
- A better experience among vulnerable older people in care homes, on wards and in receipt of domiciliary care
- Fewer emergency admissions to hospital and shorter lengths of stay as a result of better management of long term conditions and better integration of primary, secondary and social care. In a phrase: “more good care closer to home”
- Patients becoming more activated (using the patient activation measure)
- People as involved in decisions about their care and treatment as they wish to be
- More people with long term conditions and disabilities, or recovering from serious illness, in employment
- A better experience among BME communities and chronically excluded groups
- A better experience for carers
- We build on the successes of recent years in improving access and reducing waiting times

We support the broad structure of the outcomes framework set out in this consultation paper, and we set out below how we think it should be strengthened in relation to management of long term conditions, measurement of patient experience, narrowing health inequalities and protecting vulnerable groups.

## Responses to consultation questions

### Principles

1. Do you agree with the key principles which will underpin the development of the NHS Outcomes Framework ?

*Generally, yes, but it needs to be framed more broadly as a health and well being outcomes framework.*

*The principle “focused on what matters to patients and healthcare professionals” needs to be broad enough to encompass the views and experiences of carers, service-users, including disabled people, and family members, and to apply also to social care professionals. “What matters to healthcare professionals” must not be allowed to downplay the needs of people whose needs are not sufficiently recognized or addressed by care professionals.*

3. How can we ensure that the NHS Outcomes Framework will deliver more equitable outcomes and contribute to a reduction in health inequalities?

*Reducing health inequalities should be an improvement area within each of the five proposed domains. Otherwise the proposed structure will have insufficient grip on inequalities.*

4. How can we ensure that where outcomes require integrated care across the NHS, public health and/or social care services, this happens?

*By having a common outcomes framework for healthcare, social care and public health. Also by ensuring that patient and carer experience of care coordination is a key measurable.*

5. Do you agree with the five domains that are proposed as making up the NHS Outcomes Framework?

*Yes, although we would widen the scope of domain two to include people with disabilities.*

6. Do they appropriately cover the range of healthcare outcomes that the NHS is responsible for delivering to patients?

*Yes, if suitably constructed*

7. Does the proposed structure of the NHS Outcomes Framework under each domain seem sensible?

Yes

### Domain 1 - Preventing people from dying prematurely

8. Is ‘mortality amenable to healthcare’ an appropriate overarching outcome indicator to use for this domain? Are there any others that should be considered?

*We would prefer mortality amenable to public service intervention.*

9. Do you think the method proposed at paras 3.7-3.9 (page 20) is an appropriate way to select improvement areas in this domain?

*We agree that priority should be given to improvements where England falls behind other countries. We propose that an additional criterion should be mortality where inequality gradients are especially sharp within England.*

10. Does the NHS Outcomes Framework take sufficient account of avoidable mortality in older people as proposed in para 3.11 (page 21)?

11. If not, what would be a suitable outcome indicator to address this issue?

*Reference is made to avoidable deaths in hospital, but it would be better to widen the locational scope, since avoidable deaths occur in all settings, including people's own homes and care homes.*

#### Domain 2 - Enhancing the quality of life for people with long-term conditions

13. Are either of the suggestions at para 3.19 (page 24) appropriate overarching outcome indicators for this domain? Are there any other outcome indicators that should be considered?

14. Would indicators such as those suggested at para 3.20 (page 24) be good measures of NHS progress in this domain? Is it feasible to develop and implement them? Are there any other indicators that should be considered for the future?

*All four overarching indicators suggested are pertinent. But specific measures are needed to support the overarching indicators relating to people feeling supported and confident to manage their condition. These are missing from the set on page 53.*

*It is important that there are indicators that patients are a) supported to manage their condition, b) involved in care planning, c) offered or in receipt of self-management education (preferably condition-specific), d) given full information about their condition and about relevant local services, e) know who their key contact is if anything goes wrong, f) can access support by telephone or electronic means (ie not just by presenting at a clinic/GP practice). People with long term conditions often report confidence in their ability to manage their condition but lower confidence in their ability to do so in the light of changes to their condition. Both measures are important. We advocate the use of the Patient Activation Measure which is a validated outcome measure of confidence and competence for patients to manage their conditions.*

#### Domain 4 - Ensuring people have a positive experience of care

20. Do you agree with the proposed interim option for an overarching outcome indicator set out at para 3.43 (page 32)?

21. Do you agree with the proposed long term approach for the development of an overarching outcome indicator set out at para 3.44 (page 32-33)?

22. Do you agree with the proposed improvement areas and the reasons for choosing those areas set out at para 3.45 (pages 33-34)?

23. Would there be benefit in developing dedicated patient experience Quality Standards for certain services or client groups? If yes, which areas should be considered?

24. Do you agree with the proposed future approach for this domain, set out at paras 3.52-3.54 (pages 36-37)?

*We think that the approach set out for this domain underplays the progress that has already been made in developing meaningful and statistically robust measures of experience – for example by the National Quality Board. We see no need for a two stage process, which is likely to mean that patient experience measurement falls behind measurement in the other domains of quality. We would advocate expediting a set of indicators relating to key aspects of experience. National Voices is well placed to support the Department here. A starting point would be the domains of experience set out in Annex B, which draws on evidence from the Picker Institute.*

*Indicators that relate strongly to the rights in the NHS Constitution include ‘patients given enough information, in a way they can understand, about their condition’; ‘patients given enough information about treatment options, including risks’; and ‘patients as involved in decisions about their care and treatment as they want to be’. As above, we recommend the use of the Patient Activation Measure.*

*We support the deployment of indicators for the improvement areas suggested, noting that a number of suitable indicators already exist. We would urge the development of an indicator of the experience of coordination of care across institutional boundaries and offer to bring the expertise of our members to bear on this.*

#### Domain 5 - Treating and caring for people in a safe environment and protecting them from avoidable harm

25. Do you agree with the proposed overarching outcome indicator set out at para 3.58 (page 38)?

Yes

26. Do you agree with the proposed improvement areas proposed at para 3.63 (page 39-40) and the reasons for choosing those areas?

*Yes. The specific indicators lack any relevant indicators of patient and carer experience. We see merit in developing indicators of people’s experience relating to raising concerns and their satisfaction with the way they resolved.*

#### General Consultation Questions

27. What action needs to be taken to ensure that no-one is disadvantaged by the proposals, and how do you think they can promote equality of opportunity and outcomes for all patients and, where appropriate, NHS staff?

*As stated above, we recommend that reducing health inequalities should be an improvement area within each of the five proposed domains. An additional step would be to extend the focus on vulnerable groups suggested for domain 5 to all five domains.*

30. How can the NHS Outcomes Framework best support the NHS to deliver best value for money?

*By supporting integrated commissioning and a transfer of resources from acute to primary and community sectors. We think this would work better if the outcomes framework spanned NHS, public health and social care.*

#### Potential indicators

32. What are the strengths and weaknesses of any of the potential outcome indicators listed in Annex A with which you are familiar?

33. Are other practical and valid outcome indicators available which would better support the five domains?

*Various suggestions have been made above*

34. How might we estimate and attribute the relative contributions of the NHS, Public Health and Social Care to these potential outcome indicators?

*From the point of view of patients, service-users and families it is not clear that this is a meaningful question. We need a framework that incentivizes shared responsibility, and collaborative working.*

#### Principles for selecting indicators

35. Are the principles set out on pages 48 and 49 on which to select outcome indicators appropriate? Should any other principles be considered?

*Broadly, yes, though we again question the focus on separating out the contribution of the NHS from that of social care and public health.*

## 2. COMMISSIONING FOR PATIENTS

### General observations

In the transition to the new commissioning arrangements it will be vital to guard against the risk of fragmentation and growing inequity as between consortia areas, and the unwitting loss of services and good practice. The leadership role of the NHS Commissioning Board will be of vital importance, in particular to guide the development of services at geographical levels beyond that of individual consortia. Patient, service-user, carer and community organizations need to be closely involved in supporting the transitional arrangements. GP consortia will need skills and infrastructure to support their work.

GPs are well placed to understand the needs of their patients, but also need to understand the diverse needs of their populations, not all of which are manifest in the consulting room. GPs' interests are not identical to those of patients and communities and GPs are not proxies for patients. General practice commissioning will need to draw on the expertise provided by a range of health and social care professionals and on the expertise about particular conditions that lies with patient organizations and with patients themselves.

GP consortia will be publicly funded and accountable bodies. They need to feel very firmly accountable to local communities. Consistent with the Government's commitment to shared decision making and meaningful public involvement, we consider it vital that there is equal lay participation in the governance of consortia, and that their meetings are held in public. They need to involve local communities in their work. A significant lay involvement is also needed in the governance of the NHS Commissioning Board.

- Where national approaches have worked well - eg the key elements of successful national strategies and service frameworks - we want to see them continued within the new framework, either at national level (eg in NICE quality standards and national commissioning guidelines) or at a suitably devolved level.
- National Voices and its members are well placed to work with the nascent Commissioning Board to support the development of commissioning guidelines, and to continue and to replicate some of the work that has previously been undertaken at national, regional and PCT level – eg on health inequalities
- National Voices and its members are also well placed to support the development of capacity in the general practice consortia to engage with local communities, building on existing knowledge and good practice models.
- We note the importance of clinical and professional networks – eg cancer networks – which need an equivalent in the new structures.
- There needs to be capacity and leadership to drive change at the right geographical scale - eg continuing London-wide service reconfigurations as exemplified by the work on acute stroke care.

- We support a continuing emphasis on research and innovation. This should include further research on “orphan” conditions (those lacking recognized cures, treatments and professional specialisms); further research to advance care and treatment approaches that deliver better outcomes, better experiences and better value for money; and continued effort to ensure that patients, service-users and carers are given every opportunity to be involved in - and help shape – the health research agenda. PCTs have been significant drivers of research and audit, and momentum needs to be maintained in the transition to new commissioning arrangements.

### **Responses to consultation questions**

1. In what practical ways can the NHS Commissioning Board most effectively engage GP consortia in influencing the commissioning of national and regional specialised services and the commissioning of maternity services?

*It is unlikely that the Board will establish an effective relationship with consortia purely by contractual means. The Board will need to develop a culture of open engagement and two way communication with consortia.*

2. How can the NHS Commissioning Board and GP consortia best work together to ensure effective commissioning of low volume services?

*The Board needs to set a clear framework for the commissioning of low volume services, based on clear needs assessment, in partnership with key patient organizations such as National Voices, Rare Disease UK and the Specialised Healthcare Alliance.*

4 How can other primary care contractors most effectively be involved in commissioning services to which they refer patients, e.g. the role of primary care dentists in commissioning hospital and specialist dental services and the role of primary ophthalmic providers in commissioning hospital eye services?

*We recommend a clear presumption that general practice consortia will involve a range of professionals in order to promote good care coordination. As well as GPs this would include other primary care professionals, and those from social care and from the acute sector.*

5. How can GP consortia most effectively take responsibility for improving the quality of the primary care provided by their constituent practices?

6. What arrangements will support the most effective relationship between the NHS Commissioning Board and GP consortia in relation to monitoring and managing primary care performance?

7. What safeguards are likely to be most effective in ensuring transparency and fairness in commissioning services from primary care and in promoting patient choice?

*The key drivers for improvement in primary care are likely to be incentives for peer review and challenge; the full availability of transparent data on comparative performance in primary care,*

*including measures of patient experience and patient reported outcomes; and the active involvement of HealthWatches. Consortia need to be clear about their accountability to the Board, but also to local communities. The Board needs to achieve the right balance of challenge, accountability and support in its relationship with consortia.*

*A focus on the link between general practice consortia and primary care would also be supported by ensuring equal lay participation in the leadership of general practice consortia.*

*There would be merit in consortia employing the equivalent role to that of PCT medical director to promote peer review and challenge.*

8. How can the NHS Commissioning Board develop effective relationships with GP consortia, so that the national framework of quality standards, model contracts, tariffs, and commissioning networks best supports local commissioning?

*By nurturing a culture of open engagement and two way communication with consortia.*

9. Are there other activities that could be undertaken by the NHS Commissioning Board to support efficient and effective local commissioning?

*Active engagement with national and local HealthWatch*

10. What features should be considered essential for the governance of GP consortia?

*We favour a model of co-leadership between clinicians and lay people, strongly linked in to existing channels of patient and lay engagement at local level.*

11. How far should GP consortia have flexibility to include some practices that are not part of a geographically discrete area?

12. Should there be a minimum and/or maximum population size for GP consortia?

*We understand the desire to avoid imposing a Whitehall blueprint. But we note that the larger the number of consortia and the less coterminous these are with local authority boundaries, the greater are the risks to financial control, fragmentation of services, and increases in transactional costs as a result of diseconomies of scale. There is the added risk of confusion in the local population as to how they engage with health and social care bodies. These considerations must inform the development of the new consortia.*

*We also note that a disaggregated commissioning landscape will, other things being equal, transfer more power to providers, increase the risk of provider capture, and make it harder for commissioners to challenge vested interests and established patterns of commissioning.*

13. How can GP consortia best be supported in developing their own capacity and capability in commissioning?

14. What support will GP consortia need to access and evaluate external providers of commissioning support?

*National leadership from the DH will be important in the early stages, particularly if capacity within the PCTs weakens in the next few months. There needs to be clarity about the skills, resources, processes and competencies required. We would regret the loss of commissioning expertise within the PCTs and would recommend a plan for the transfer of this expertise to the new consortia. At the same time, we recognize that commissioning within PCTs has been of variable quality. PCTs do not have a monopoly of wisdom in this area and we welcome the possibility of a competitive market emerging in which private and voluntary sector organizations have the opportunity to contribute their skills and expertise.*

*We enter two caveats, however. It is important in the interests of accountability that there is maximum transparency about the arrangements for supporting commissioning in each consortium area. We would not want to see this public interest trumped by the commercial confidentiality card.*

*We can envisage a situation in which support for commissioning becomes dominated by a small number of large organizations, in which case a level playing field for competition will not apply. We offer to work with the Government in exploring regulatory safeguards.*

17. What are the key elements that you would expect to see reflected in a commissioning outcomes framework?

*See our responses to the consultation on transparency in outcomes.*

*In particular we recommend that all commissioning guidelines emphasise the centrality of patient and public engagement in designing services/pathways, and that they focus on shared decision-making including use of patient decision aids at appropriate points in pathways. We recommend that all national commissioning guidelines for long term conditions emphasise commissioning integrated services, using participative care planning and supporting self care.*

19. What arrangements will best ensure that GP consortia operate in ways that are consistent with promoting equality and reducing avoidable inequalities in health?

*We support the proposal that consortia be bound by duties to promote equalities and to work in partnership with local authorities. As stated in our response to the consultation on outcomes, we recommend that reducing health inequalities should be an improvement area within each of the five proposed domains of the outcomes framework, and propose an explicit focus on vulnerable groups in each of the five domains.*

20. How can GP consortia and the NHS Commissioning Board best involve patients in making commissioning decisions that are built on patient insight?

21. How can GP consortia best work alongside community partners (including seldom heard groups) to ensure that commissioning decisions are equitable, and reflect public voice and local priorities?

22. How can we build on and strengthen existing systems of engagement such as Local HealthWatch and GP practices' Patient Participation Groups?

23. What action needs to be taken to ensure that no-one is disadvantaged by the proposals, and how do you think they can promote equality of opportunity and outcome for all patients and, where appropriate, staff?

*We support the intention that consortia will be bound by a duty of public and patient involvement. That is a necessary but not sufficient condition for meaningful involvement, since it can be implemented in an insincere “tick box” fashion. Culture and behaviour need to align with legal duties.*

*Lay governance of consortia is important. Consortia should seek both clinical and patient champions of stronger involvement and give them a key role in promoting involvement.*

*The development of a meaningful set of patient experience measures, and collection of data against these, is a priority.*

*Local authorities and HealthWatch should support general practice consortia in reaching out to the full range of community groups and voices in their areas.*

*HealthWatches need to be well connected with their communities.*

*Lessons can be learned from the most successful examples of patient and public involvement, drawing on the expertise of the National Association for Patient Participation, National Association of LINKs members, National Voices, NAVCA and other organizations. Dissemination of these lessons could form part of the emerging national HealthWatch functions. National Voices through its members and networks is well placed to support this work.*

*Patient and public participation should be a requirement in the design of new services and the reconfiguration of existing services*

24. How can GP practices begin to make stronger links with local authorities and identify how best to prepare to work together on the issues identified above?

*This process needs to get underway early.*

25. Where can we learn from current best practice in relation to joint working and partnership, for instance in relation to Care Trusts.

*We recommend drawing on the lessons from the analysis by the Audit Commission, Nuffield Trust, Integrated Care Network and Turning Point which shows that joint working is most effective when focused, not on the process of joining up (sharing management, pooling budgets, etc) but on the outcomes for patients and service users.*

26. How can multi-professional involvement in commissioning most effectively be promoted and sustained?

*Through a common health and well being outcomes framework.*

### **3. LOCAL DEMOCRATIC LEGITIMACY IN HEALTH, INCLUDING HEALTHWATCH**

#### **General observations**

We support the stronger role proposed for local authorities in promoting joined up commissioning and in public health.

We welcome the creation of HealthWatch and believe that it has considerable potential to promote active patient and community participation in the design of services; and to improve the help and support available at local level for individuals. Local HealthWatches also have the potential to contribute to community development, public health and active citizenship. In the meantime, contracts for LINKs services need to be renewed for the period between March 2011 and the planned advent of HealthWatch in April 2012.

HealthWatch should be a strong and visible brand. Local HealthWatches must be independent and seen to be so, with sufficient resources and skills. It must be clear to professionals, patients and the public that HealthWatch will cover social care as well as health, and have “Involve” alongside its “Watch” brief. “CareWatch” is worth considering as an alternative name.

We recommend that the focus in establishing local HealthWatch should be on getting the right services and outcomes for people, rather than on structures and organizations. For example, local HealthWatch services might be delivered under contract by networks of existing voluntary organizations, saving the infrastructure costs of establishing bespoke new bodies. We recommend that the best way of building on LINKs is to learn from the most successful LINKs and to mobilize the talents and energies of LINKs volunteers, at the same time as widening the pool of active participants. LINKs have worked best when they have worked in partnership with local agencies and had effective links with local communities and with voluntary and community organizations.

HealthWatch should support, not displace, local arrangements for involving patients and citizens that already work well – for example patient participation groups and user-led organizations.

The credibility and effectiveness of National HealthWatch will derive from its independence and its visible connectedness with the patients, carers and their organizations.

National Voices and its members and partners are well placed to support the development of a good practice model to inform the commissioning of HealthWatch and to support the transition from LINKs to HealthWatch. We offer to work with Government at national and local level to get this right.

The duty to consult, engage and involve is a potentially large cost-driver and there is some evidence that PCTs and other public bodies derived poor value for money from large scale consultation exercises in recent years. We think better value for money will be secured by establishing local HealthWatch as the key platform for engagement.

## Responses to consultation questions

### Strengthening public and patient involvement

1. Should local HealthWatch have a formal role in seeking patients' views on whether local providers and commissioners of NHS services are taking account of the NHS Constitution?

*As framed in the question, this sounds rather a bureaucratic exercise. We would favour a more general brief for HealthWatch to use the Constitution as a key tool for informing and empowering individuals and for holding services to account.*

2. Should local HealthWatch take on the wider role outlined in paragraph 17, with responsibility for complaints advocacy and supporting individuals to exercise choice and control?

*Yes. There needs to be an integrated service at local level that provides all the support and guidance that people are likely to need, including complaints advocacy and support to individuals on choice, under the banner of "HealthWatch". But it needs to be a local commissioning decision how this integrated service is best obtained – eg from one or more organizations.*

*Supporting individuals to exercise choice and control can be best done by supporting and coaching people to be able to have more productive interactions with their clinicians. There is a major opportunity to draw on the resources of volunteers and local community organizations.*

3. What needs to be done to enable local authorities to be the most effective commissioners of local HealthWatch?

*The following measures would help:*

*Local authorities need guidance to inform their commissioning decisions: National Voices would be keen to work alongside other expert organizations to help with this.*

*The proposal that local authorities hold HealthWatches to account for delivering services is in tension with the role of HealthWatch in holding local authorities to account for their provision of social care and other services. We see no perfect way of resolving this contradiction, but we think it would be an improvement if:*

- *funding is ring-fenced*
- *local HealthWatch services are commissioned from independent organizations within the voluntary sector, or from social enterprises and community interest companies*
- *HealthWatch England has a clear refereeing role in disputes between local HealthWatches and local authorities*
- *There are clear "Chinese Walls" between those parts of the local authority delivering social care services, and the department which commissions HealthWatch*

## Improving integrated working

4. What more, if anything, could and should the Department do to free up the use of flexibilities to support integrated working?

5. What further freedoms and flexibilities would support and incentivize integrated working?

*The evidence suggests that key success factors in promoting integrated working across health and social care are the quality of local leadership; good relationships between agencies based on trust; and a focus on people rather than structures. Key barriers to taking advantage of existing freedoms, eg to pool budgets, are the complexities of financial accountability and a reluctance by decision makers to cede control of their budgets. NHS reorganization and financial retrenchment are likely to disrupt some local relationships and intensify the reluctance to pool budgets.*

*We advocate a unified health and well being outcomes framework, as proposed above, as a powerful driver of integrated working.*

*National Voices would support a more active dissemination of good practice examples of partial or complete integration – including the present wave of integrated health and social care pilots - and would be keen to broker partnerships between health and social care professionals and voluntary organizations to agitate for their wider take-up.*

*We are excited by the potential of personal budgets for health and social care, including the potential for individuals to pool budgets and commission services jointly.*

6. Should the responsibility for local authorities to support joint working on health and wellbeing be underpinned by statutory powers?

*Yes, we see this as a necessary but not sufficient condition for better joint working.*

7. Do you agree with the proposal to create a statutory health and wellbeing board or should it be left to local authorities to decide how to take forward joint working arrangements?

*We think it should be a matter for local determination.*

8. Do you agree that the proposed health and wellbeing board should have the main functions described in paragraph 30?

*We think that the first three of these: joint strategic needs assessment; promotion of integration and supporting joint commissioning and pooled budget arrangements; should be functions deriving from the statutory responsibility to support joint working. We see merit in maintaining scrutiny as a distinct function of the overview and scrutiny committees.*

11. How should local health and wellbeing boards operate where there are arrangements in place to work across local authority areas, for example building on the work done in Greater Manchester or in London with the link to the Mayor?

*If it ain't broke, don't fix it.*

12. Do you agree with our proposals for membership requirements set out in paragraph 38 - 41?

*We agree that a mix of key players, as set out in the paper, and including patient champions and HealthWatch, should sit on the health and well being boards, or on the equivalent forums established at local level. The lay involvement must not be tokenistic. We would recommend that lay and user representatives account for 25 per cent of membership and receive suitable training and support.*

14. Do you agree that the scrutiny and referral function of the current health OSC should be subsumed within the health and wellbeing board (if boards are created)?

*No, because this would blur the important distinction between executive decision-making and the democratic scrutiny of that decision making.*

16. What arrangements should the local authority put in place to ensure that there is effective scrutiny of the health and wellbeing board's functions? To what extent should this be prescribed?

*We think this would be most readily achieved by allowing local authorities to maintain their overview and scrutiny committees.*

## **Responses to the questions in the separate document “Establishing HealthWatch”**

### Expanding the role of LINKs as HealthWatch

1. What needs to happen for local HealthWatch to fulfil its new functions around health complaints advocacy? In particular to support people who do not have the means or capacity to make choices about their care?

*This needs to be a local commissioning decision, taking account of the maturity and capacity of the LINK and the capacity and quality of other local providers. The emphasis should be on getting an integrated service, rather than on assuming that a single organization will provide all the services.*

2. What needs to happen for local HealthWatch to support people making choices, in particular to support people who do not have the means or capacity to make choices about their care?

*Supporting individuals to exercise choice and control can be best be done by supporting and coaching people, including carers, to be able to have more productive interactions with their clinicians. There is a major opportunity to draw on the resources of volunteers and local community organizations.*

### Embedding patient voice

3. What should be done to embed local HealthWatch as the local consumer voice, and HealthWatch England as the national voice for health and social care consumers?

*Local HealthWatches will be most strongly embedded if they are well publicised; engage widely with their communities; and develop non-confrontational, critical-friend relationships with local commissioners and providers. This will require resources and good training and support for participants.*

*HealthWatch England will gain credibility if it gives powerful voice to issues garnered from local intelligence and from the wider family of patient and voluntary organizations, if it is seen as strongly connected with the patient and voluntary sector world, and if its findings are seen to influence and inform the actions of the Care Quality Commission (CQC) and other agencies. National Voices' networks of voluntary sector organizations and service-users could bring strength and depth to supporting the developing HealthWatch model.*

4. How should HealthWatch England and local HealthWatch relate to and work with other patient and community groups and structures, and what principles should underpin this relationship?

*At local level, HealthWatch needs to act as broker and catalyst, helping to strengthen links between local patient and community organizations and between these organizations and local services. At national level, HealthWatch needs to retain active links with national voluntary organizations and their umbrellas. The key principle should be engagement.*

5. How should local HealthWatch work with the local authority and GP consortia to influence commissioning decisions?

*By fostering productive, critical-friend relationships with consortia and with local authorities. By providing a forum and platform for commissioners to engage and partner with local communities.*

6. What needs to happen for local HealthWatch to support the needs of vulnerable people – such older or very frail people? What needs to happen for HealthWatch to champion the rights of people who lack capacity to make decisions about their care?

*HealthWatches need strong links with local community organizations including those representing older and frail people and with carers.*

### Governance

7. What governance arrangements need to be put in place to ensure that accountabilities are clear for all parties?

*Local HealthWatches need to be sufficiently independent of local authorities, along the lines suggested above under responses to “local democratic legitimacy”. National HealthWatch needs to be visibly independent of the CQC.*

8. How should HealthWatch England be constituted within the CQC structure?

*HealthWatch England should have its own board with an expert lay leadership. Some of its suggested functions – for example support and advice to local HealthWatches; advice to the NHS Commissioning Board; the influence of national strategy and policy; will be more credibly undertaken in close partnership with national patient, carer and umbrella organizations.*

9. What role, if any, should HealthWatch England play in holding local authorities to account for how local HealthWatch is operated?

*None – this would confuse accountabilities. We prefer a model in which HealthWatch England plays referee where there are irreconcilable differences between local authorities and local HealthWatches.*

#### Independence and accountability

10. What needs to happen for local HealthWatch to be an independent consumer champion for health and social care?

*As per the answer to question 3 above. Local HealthWatches will also need support, advice and guidance on how to be effective. This is a function proposed for HealthWatch England in the White Paper, but not repeated in the consultations. We would support such a function, the lack of which has been a key weakness of the current LINks model. But local HealthWatches will need to feel a degree of buy-in to any such provider of support.*

11. What role should HealthWatch England and local authorities play in assessing the effectiveness of local HealthWatch?

*National Voices offers to work with the shadow HealthWatch England and other key stakeholders, eg NHS Alliance, to devise guidance setting out success criteria for local HealthWatch. This would include key metrics, including those relating to the quality of local relationships. The aim would be to provide a broad framework to inform commissioning and to monitor effectiveness. Performance against these metrics would be published annually.*

12. What needs to happen to ensure transparency over how HealthWatch funding is spent by local HealthWatch and by local authorities?

*We recommend that funding for local HealthWatch is ring-fenced.*

13. How will local HealthWatch cover both health and social care services?

*By retaining the current responsibilities of LINks to cover both.*

14. What role should local HealthWatch play in seeking patients' views on whether local providers and commissioners are taking account of the NHS Constitution?

*As framed in the question, this sounds rather a bureaucratic exercise. We would favour a more general brief for HealthWatch to use the Constitution as a key tool for informing and empowering individuals and for holding services to account.*

#### National/local balance

15. What needs to happen to ensure an effective balance is achieved between HealthWatch England and local HealthWatch?

16. What role should HealthWatch England play in achieving this balance?

*We conceive the bulk of HealthWatch activity being undertaken locally. We propose that National Voices works with the shadow HealthWatch England and other key stakeholders, eg NHS Alliance and the Local Government Group to devise guidance setting out success criteria for local HealthWatch. This would include key metrics, including those relating to the quality of local relationships. The aim would be to provide a broad framework to inform commissioning, leaving ample scope for local variation and adaptation.*

### Relationships

17. HealthWatch England will need to develop working arrangements with the NHS Commissioning Board, Monitor, Department of Health and CQC. What principles should underpin these relationships?

*Engagement, openness and parity of esteem.*

18. What needs to happen to build relationships between local HealthWatch and other local partners, such as local authorities or GP Commissioning Consortia?

*A broad national framework of principles and success criteria, as proposed in answer to Q16 above. At local level: engagement, openness and parity of esteem. A commitment on all sides to make it work. A commitment to acknowledge the deficiencies of the current arrangements and seek to overcome them in the new arrangements.*

### Transition

19. What do we need to take into account for the transition of LINKs into local HealthWatch?

*Resources, skills, modes of operation.*

20. What support will LINKs need during this period?

*A clear direction of travel and an opportunity to be involved in the decisions about their future.*

21. What additional skills will staff and volunteers require to deliver the expanded functions, and how can they be developed?

*An understanding of shared decision making and how to support and promote it. Community engagement skills; coaching skills; stakeholder engagement and negotiation skills.*

22. What are the organisational and resource implications of expanding LINKs' functions?

*They could be cost neutral or even provide a net saving if they resulted in less wasteful expenditure by NHS organizations on consultation exercises (better orchestrated by HealthWatches), and led to a reduction in complaints and litigation.*

#### 4. REGULATING HEALTHCARE PROVIDERS

1. Do you agree that the Government should remove the cap on private income of foundation trusts? If not, why; and on what practical basis would such control operate?

*We think that removing the cap creates a clear risk that foundation trusts will expand their private activities to the detriment of NHS patients. Should the Government pursue this option, we recommend that the levels of private activity, and key indicators of clinical effectiveness, safety and patient experience, including access and waiting times, are matters that Monitor and CQC keep under close review in their regulation of individual trusts, and that all relevant data are put in the public domain*

3. Do you agree that foundation trusts should be able to change their constitution without the consent of Monitor? And:

5. What if any changes should be made to the NHS Act 2006 in relation to foundation trust governance?

*Lay participation in governance is a key aspect of the current regime. We do not agree that foundation trusts should be able to reduce the degree of lay involvement in their governance without the consent of Monitor. It is essential that foundation trusts hold their meetings in public.*

4. What changes should be made to legislation to make it easier for foundation trusts to merge with or acquire another foundation trust or NHS trust? Should they also be able to de-merge?

*We are concerned at the potential for significant consolidation among foundation trusts to entrench the position of acute services and make it harder for to achieve a major transfer of resources into primary and community services. Reconfigurations of services that arise from mergers or demergers must be subject to meaningful local engagement, with patients, HealthWatch and local communities involved from the beginning.*

12. How should Monitor have regard to overall affordability constraints in regulating prices for NHS services?

13 Under what circumstances and on what grounds should the NHS Commissioning Board or providers be able to appeal regarding Monitor's pricing methodology?

14. How should Monitor and the Commissioning Board work together in developing the tariff? How can constructive behaviours be promoted?

*Monitor and the Commissioning Board need to give full account to the Government's intent to reward outcomes rather than activity. The current tariff system creates perverse incentives to undertake activity in acute trusts leading to inefficient resource allocation, the distortion of clinical priorities, and less than optimal experiences and outcomes for patients.*

15. Under what circumstances should Monitor be able to impose special license conditions on individual providers to protect choice and competition?

16. What more should be done to support a level playing field for providers?

17. How should we implement these proposals to prevent anti-competitive behaviour by commissioners? Do you agree that additional legislation is needed as a basis for addressing anticompetitive conduct by commissioners and what would such legislation need to cover? What problems could arise? What alternative solutions would you prefer and why?

*We see a risk that the market will be captured by large acute trusts which stifle innovation and resist the transfer of resources into primary and community services. We favour a regulatory regime which recognizes the power imbalance between entrenched foundation trusts and alternative providers of services in the private and voluntary sector; and which seeks to create favourable conditions for the growth of alternative providers, subject to quality and viability, in a variety of forms.*

*We need a pragmatic regulatory approach which does not deem effective integration of services along care pathways as anti competitive.*

## **ANNEX A: A NOTE ON SHARED DECISION MAKING**

**What is shared decision making?** Shared decision-making means involving patients as active partners with professionals in clarifying care options, discussing goals and priorities, and together planning and implementing a preferred course of action. It represents a shift in control to the patient and a move away from medical paternalism.

### **When is it appropriate?**

- When patients face treatment decisions with more than one feasible option (e.g. cancer, heart disease, osteoarthritis, mental health problems, menopausal problems, chronic pain, pregnancy and childbirth, diabetes, end of life care, conditions involving elective surgery etc.)
- For helping people with long-term conditions to plan their care, prioritise behaviour change strategies and enhance their ability to self-manage.

**What does it involve?** Effective shared decision making requires:

- access to balanced evidence-based information outlining treatment options, outcomes and uncertainties (patient decision aids)
- decision support counselling, usually a brief discussion with a clinician or health coach (in person or by phone), to clarify options and preferences
- a system for recording, communicating and implementing patients' preferences.

It does not have to be complicated and is in essence a shift in attitudes and behaviours, supported by straightforward tools.

**Do patients want it?** Evidence suggests that most do:

- almost everyone wants clinicians to listen, explain and answer their questions;
- most patients prefer a collaborative approach that takes account of their values and preferences; most want more health information than they're usually given, together with honest assessments of treatment benefits, risks and side-effects;
- most, but not all, want to be involved in treatment decisions;
- all those with long-term conditions have to self-manage and many would like more help with this.

**Do clinicians support the idea?** Many do, at least in theory if not in practice. The GMC's *Good Medical Practice* guidance for all doctors includes an expectation that shared decision making will be the norm for most medical decisions. Surveys reveal that doctors often think they are sharing decisions more than their patients do.

**Does it work?** Evaluations of patient decision aids and various other forms of self-management support show that they can lead to the following benefits:

- Improved knowledge and understanding (health literacy)
- More accurate risk perceptions

- Greater comfort with decisions
- More participation
- Fewer patients choosing major surgery
- Better treatment adherence
- Improved confidence and coping skills
- Improved health behaviours
- More appropriate service use, with cost neutral or cost-saving effects

In short shared decision making promotes better care and more rational resource allocation. Conversely a lack of sharing can lead to poor decisions and in extremes be unsafe, wasteful and unethical (such as unnecessary surgery). In times of rising demand, a greater focus on outcomes and scarce resources, shared decision making needs to be seen as an integral element of healthcare reform, not a discretionary add-on.

**Is it happening now?** Not nearly frequently enough: national NHS surveys show that at least half of those who experienced a hospital episode would have liked more involvement in decisions about their care and the trend shows no improvement over the last ten years or so.

International surveys by the Commonwealth Fund suggest that service delivery is more paternalistic in the UK than in other European and North American countries, with less involvement in decisions and less support for self-care and self-management.

Despite considerable rhetorical support for involving patients in their care, including a commitment in the NHS Constitution and some good initiatives (e.g. Diabetes Year of Care, Health Foundation and NHS Direct projects), as yet there have been few effective efforts to mainstream the concept.

**What could be done to embed it?** There is no single solution. It requires a combination of effective leadership, incentives, practical support, social marketing, accountability, education and training, and patient and public pressure.

- **Patient organisations** have a potentially powerful role in encouraging their members to expect to be informed and involved in their own care, to ask questions about treatment /management options and self-management, to be aware of their rights under the NHS Constitution, and to challenge clinicians if they feel decisions are being taken without their involvement.
- **The Royal Colleges** could ensure that trainees have relevant skills for shared decision making by including relevant assessments in membership exams and in their assessment of training sites and supervision arrangements. They could take a much stronger leadership role in promoting shared decision making as a key ingredient of good clinical practice.
- **Local commissioners** could ensure that all contracts with providers include a requirement to involve patients/service users in decisions and to demonstrate that this is done. They could also insist on communication skills training and shared decision making competencies being included in continuing professional development, and they

could require the provision of patient information and decision aids, health literacy support, health education, and patient-held records by all providers.

- **Providers (primary and secondary care)** could ensure that patients are given reliable information about treatment/management options and that all staff are trained to anticipate patients' information and support needs. They could also do a great deal more to ensure that collaborative care planning is the norm for all long-term conditions, supported by integrated care pathways and patient-held records. Many could get much better at regularly asking their patients very simple questions about their experience of care and how it could be improved.
- **Local health and well being boards, and local and national HealthWatch** could ensure that people's satisfaction with their involvement in decisions about their care (across health and social care, and including carers) is a key indicator to be monitored and used to hold local services to account.
- **The NHS Commissioning Board** could require evidence of shared decision making as part of holding commissioning consortia and primary care providers to account, using patient feedback surveys as a monitoring tool; they could publish commissioning guidelines drawing attention to key decision points for patients and showing how patients can be involved; they could incentivise improvements using CQUIN and other mechanisms.
- **The Department of Health** could clarify its expectations by, for example, including shared decision making in the Health Bill (mirroring the approach of the Obama administration); by including relevant indicators in the National Outcomes Framework; by re-energising the unfulfilled commitment to care planning for all those who want it; by including relevant questions in national patient experience surveys and by giving due emphasis to patient decision aids in the forthcoming information and choice consultations.
- **NICE** could ensure that its clinical guidelines identify decision points for patients and incorporate self-care strategies.
- **The Care Quality Commission** could continue to monitor patient involvement in national patient surveys, taking note of the lack of improvement to date, but could make greater efforts to hold providers to account for improving performance in this area.
- **The General Medical Council** could build on its stated commitment to shared decision making by ensuring that relevant skills and competencies are taught in undergraduate and postgraduate training; and by ensuring this topic is formally assessed at all levels of education and training, including revalidation.
- **Referral management centres** could incorporate shared decision making support into assessment and triage and/or Choose and Book systems, with access to web-based patient decision aids and decision support counselling (face-to-face, telephone or email).

## ANNEX B: A NOTE ON PATIENT EXPERIENCE OUTCOME INDICATORS

The following have been demonstrated to be statistically robust indicators closely correlated with patients' overall satisfaction:

Did the doctor<sup>1</sup> **listen carefully** to what you had to say?

Were you given **enough time** to discuss your health or medical problem with the doctor?

Were you **involved** as much as you wanted to be in decisions about your care and treatment?

If you had **questions** to ask the doctor, did you get answers that you could understand?

Did the doctor explain the reasons for any treatment or action in a way that you could understand?

Did you have **confidence and trust** in the doctor?

Overall, did you feel you were treated with respect and dignity (while you were in the GP surgery/hospital etc)?

### *New medicines<sup>2</sup>*

Were you involved as much as you wanted to be in decisions about the best medicine for you?

Were you given enough information about the **purpose** of the medicine?

Were you given enough information about any **side-effects** the medicine might have?

Were you given enough information about **how to use** the medicine?

### *Cleanliness*

In your opinion, how clean was the (hospital room or ward/outpatient clinic/GP surgery) that you were in?

How clean were the toilets and bathroom that you used while in (the hospital/GP surgery)?

Was the main reason you went to your GP practice/ health centre (or outpatient clinic) dealt with to your satisfaction?

### Or

Overall, how would you rate the care you received?

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<sup>1</sup> In any of the questions, the word 'doctor' can be replaced with 'nurse(s)' or 'other professional' as appropriate

<sup>2</sup> For the following questions, a 'filter' question is needed so that only those patients who were given a new medicine need to answer. In acute (hospital) surveys, these questions are usually asked with regard to medicines given to the patient to take home.

From statistical analysis of patient survey data: the ‘core’ domains of patient experience:

<b>Domains of hospital patients’ experience</b>	
<i>Inpatients</i>	<i>Outpatients</i>
Involvement in decisions	Dealing with the issue
Doctors	Doctors
Nurses	Other professionals
Cleanliness	Cleanliness
Pain control	Information about discharge
	Information about treatment
<i>Plus</i>	<i>Plus</i>
Consistency and coordination	Organisation
Respect and dignity	Respect and dignity

The two sets are clearly similar. This becomes even more apparent when it is noted that questions on:

- how much information the patient was given about their condition or treatment, and
- the extent to which they were involved in decisions,

appear in both the domains of ‘involvement in decisions’ (inpatients) and ‘dealing with the issue’ (outpatients).

To summarise, these analyses showed that, out of all the elements of care that had some importance to patients, the *most* important were:

- cleanliness
- communications with doctors, nurses and other professionals, and
- being involved in decisions about care and treatment.

These indicators are capable of adaptation to capture the experience of social care.