

Liberating the NHS:

No decision about me, without me

Government response

DH INFORMATION READER BOX

Policy	Clinical	Estates
HR / Workforce	Commissioner Development	IM & T
Management	Provider Development	Finance
Planning / Performance	Improvement and Efficiency	Social Care / Partnership Working

Document Purpose	Policy
Gateway Reference	18444
Title	Liberating the NHS: No decision about me, without me - Government response to the consultation
Author	Department of Health
Publication Date	13 December 2012
Target Audience	PCT Cluster CEs, NHS Trust CEs, SHA Cluster CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Cluster Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads, Directors of Children's SSs
Circulation List	Voluntary Organisations/NDPBs
Description	This document provides the Government response to the consultation - Liberating the NHS: No decision about me, without me. Further consultation on proposals to secure shared decision-making
Cross Ref	Liberating the NHS: Greater choice and control - A summary of response
Superseded Docs	N/A
Action Required	N/A
Timing	N/A
Contact Details	NHS Commissioning Policy & Sponsorship Department of Health Richmond House 79 Whitehall London SW1A 2NS
For Recipient's Use	

Contents

Executive Summary	1
1. Introduction	3
2. What we heard: key themes	7
3. Greater patient involvement	15
4. Greater patient choice: all along the patient pathway	19
5. Conclusion: making it happen	24
Annex A: Organisations that responded	33
Annex B: Consultation questions	36
Annex C: Summary of issues	37

Executive summary

1. The White Paper, *Equity and Excellence: Liberating the NHS*¹ set out the Government's vision of an NHS that puts patients and the public first, where "no decision about me, without me" is the norm. It included proposals to give everyone more say over their care and treatment with more opportunity to make informed choices, as a means of securing better care and better outcomes.
2. We have consulted widely on how to make this vision a reality. The first consultation document *Liberating the NHS: Greater choice and control*² sought views on the choices that people wanted to make, when they wanted to make them and the support people needed to be able to have more say in decisions about their care. Drawing on these responses, we began last year to introduce choice of provider in community services through the Any Qualified Provider policy and to extend choice to named consultant-led team in secondary care, where clinically appropriate.
3. In May this year, we published a further consultation, *Liberating the NHS: No decision about me, without me*, which set out proposals for making "no decision about me, without me" a reality, all along the patient pathway: in primary care, before a diagnosis, at referral and after a diagnosis. The consultation asked for views as to whether these proposals met this objective, whether they were realistic and achievable and whether there were any areas we had not recognised sufficiently.
4. The responses received were broadly supportive of the proposals set out in the consultation document as a means for patients to become more involved in their care, in partnership with professionals.
5. Some respondents expressed the view that providing greater patient choice, be it over clinical team, setting, location or provider, did not equate to the widespread adoption of shared decision-making. We agree. We consider that greater patient involvement and greater patient choice are all part of the same goal: to ensure that "no decision about me, without me" becomes the norm.

1

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_17353

² http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_119651

6. Other themes raised regarding the practical implementation of the proposals relating both to patient involvement and patient choice were:
 - i. The importance of providing accurate and accessible information in order for people to make informed decisions about their care.
 - ii. The need for a culture change to enable patient involvement to become routine in the NHS.
 - iii. The importance of making “no decision about me, without me” a reality for everyone, and the concern that, without proper implementation, the proposals might exacerbate health inequalities.

We outline below how we are responding to comments made by respondents and how we are implementing proposals on patient involvement and choice.

7. The legal framework for this debate has changed. The Health and Social Care Act 2012 makes clear the duties on the NHS Commissioning Board and the clinical commissioning groups to promote the involvement of patients and carers in decisions about their care and treatment, and to enable patient choice. The Care and Support Bill, expected to be introduced to Parliament next year, focuses on the personalisation of care, with people, not institutions, in control. The draft Bill also creates a right to a care and support plan, which should be prepared in consultation with the person and carer.
8. We heard clearly that a key element of patients being truly involved in decisions about their care and treatment is the ability of a patient to have a care plan. A written record of the care-planning discussion between a patient and clinician is a vital part of empowering patients to manage their condition. This is why we are introducing a pledge into the NHS Constitution to involve patients in care planning discussions and to offer them a written record of what is agreed, if they want one. The Government’s mandate will hold the NHS Commissioning Board to account for delivering this.
9. The Department of Health’s Choice Framework for NHS funded care and treatment in England will set out, for the first time, the choices that people can expect to be offered. This will raise awareness of these choices, including where people have legal rights to make choices, as well as setting out where they can find information to support these choices and what they can do if they aren’t given the choices they are entitled to.
10. These measures should all add up to a greater understanding of the rights of patients to be involved in their care and treatment, and the choices that they have available to them. This will all help to make “no decision about me, without me” a reality in the NHS.

1. Introduction

- 1.1 This document sets out the Government's response to the consultation exercise "*Liberating the NHS: No decision about me, without me*"³.

Greater Choice and Control

- 1.2 The White Paper, *Equity and excellence: Liberating the NHS*, set out the Government's vision of patients and the public being at the heart of the NHS. Central to delivering this vision is ensuring that all patients are fully involved in decisions about their own care and treatment so that the principle of shared decision-making - "no decision about me, without me"- becomes the norm across the NHS.
- 1.3 The Department of Health committed to consult widely on the best ways to implement the White Paper commitments to give patients greater choice and control over their care and treatment. Our consultation document, *Liberating the NHS: Greater choice and control*⁴, published in October 2010, set out some preliminary proposals to implement the White Paper commitments and asked a wide range of questions about how best to achieve these aims. Over 600 unique responses were received to this initial consultation.
- 1.4 Guidance was published in 2011 to support implementation of the proposals to give patients greater choice of any qualified provider in community services and to give patients an opportunity to choose a named consultant-led team, where clinically appropriate.⁵ In both these areas, the response was brought forward because of the need to make rapid progress against the timetable set out in the White Paper and to ensure momentum was sustained. We published a summary of the responses received⁶ to the first consultation, alongside a subsequent consultation document, *No decision about me, without me*, in May this year.

³ http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_134221

⁴ http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_119651

⁵ <http://healthandcare.dh.gov.uk/any-qualified-provider-2/>

<http://www.dh.gov.uk/health/2011/10/named-consultant/>

⁶ http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_134188

No decision about me, without me

- 1.5 In *Liberating the NHS: No decision about me, without me*, we outlined more detailed proposals to increase opportunities for patients and their representatives to have more involvement in decisions about their care all along the patient pathway. We asked whether these proposals met this objective, whether they were realistic and achievable and whether there were any areas we had not recognised sufficiently. The consultation questions are set out in Annex B.
- 1.6 Our detailed proposals were shaped by broad engagement undertaken by the Department of Health and others. In 2011 the Future Forum were asked to make recommendations on promoting choice and managing competition. We took account of their recommendations as well as responses to the consultation in developing the proposals.
- 1.7 These proposals also support the delivery of the Government's Open Public Services agenda, which was set out in the 2011 Open Public Services White Paper⁷. This agenda aims to ensure that everyone has access to the best possible public services, and that the best become better still. This will be achieved by improvements driven by decentralising power to ensure that public service providers are accountable to the people that use them.

Consultation responses

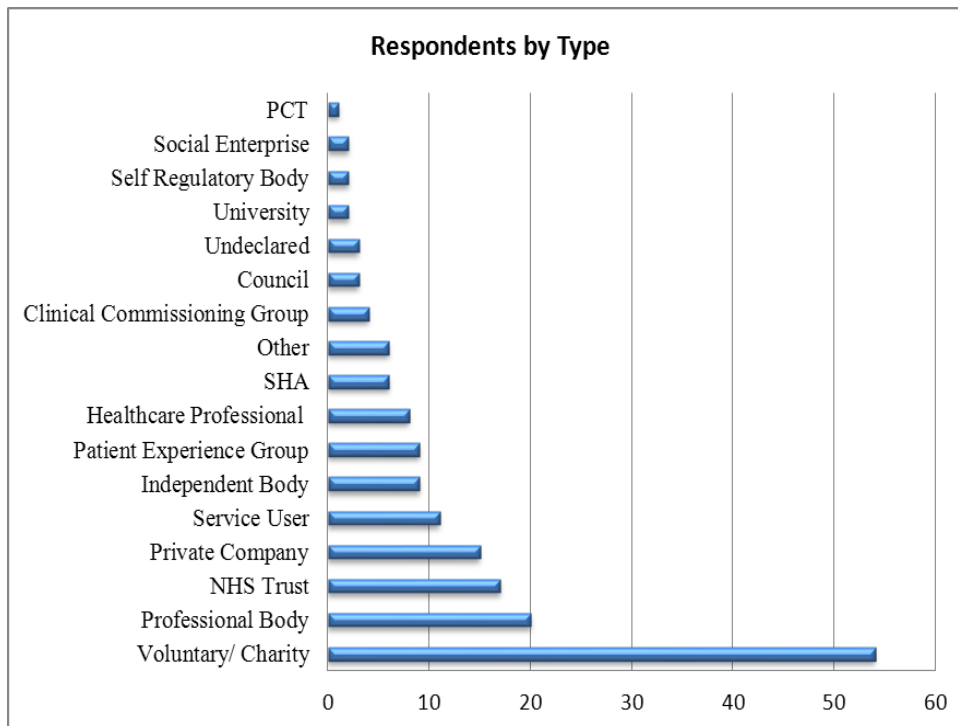
- 1.8 This second round of consultation was originally expected to run for a period of 8 weeks as it was clearly linked to the earlier consultation. The consultation period was extended to fourteen weeks after a number of organisations requested additional time to undertake discussion meetings with their members before submitting formal responses. The published consultation documents, including accompanying Impact Assessment and Equality documents, were made available via the Department of Health website from 23rd May 2012 until 31st August 2012⁸. Respondents were able to submit their replies online, by email or by post.
- 1.9 The consultation document was intended to be accessible to all. It was also published as an Easy Read document and in audio CD format to encourage responses from the largest possible audience. A set of information slides were made available to assist organisations when undertaking engagement with their members or as part of discussion forums.

⁷ <http://files.openpublicservices.cabinetoffice.gov.uk/OpenPublicServices-WhitePaper.pdf>

⁸ http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_134221

1.10 In total, 172 valid⁹ responses were received to the consultation. Of these, 47 were from individuals with the remaining 125 from a range of organisations including voluntary organisations, local authorities, NHS organisations, Royal Colleges and patient representative groups. Some respondents chose not to respond directly to the questions posed, preferring instead to submit overarching comments on the proposals or general aims of the White Paper commitments.

1.11 The chart below provides a breakdown of the respondents.



Our response

1.12 In subsequent chapters of this document we provide a summary of the responses that we received to this consultation exercise and describe our final proposals informed by what we've heard.

1.13 It is not possible to provide detail of all of the responses. Annex C sets out tables summarising the key issues raised by respondents as well as providing an indication of the relative importance of the issues based on the frequency with which they were raised.

1.14 In this document, whenever we refer to involving patients in decisions and giving them more choice, it applies equally to adults and children who are patients, service users and carers, their families and others who represent and support them, unless otherwise stated.

⁹ Two further responses could not be linked to the consultation questions and so were discounted.

- 1.15 Chapter 3 sets out the key cross-cutting themes that have emerged, outlines the issues raised and our response.
- 1.16 In chapters 4 and 5, we discuss responses concerning specific proposals on increasing patient involvement and patient choice in turn. We set out issues that have been raised regarding our proposals in these areas and we describe how we have addressed these points.
- 1.17 Chapter 6 concludes this document setting out the next steps we will be taking to make “no decision about me, without me” a reality in the NHS.
- 1.18 The Health and Social Care Act (2012)¹⁰ establishes new organisations, which will have a key role in implementing the proposals to give patients more say and greater involvement in care and treatment decisions in the new healthcare system. These will include, but are not limited to, the NHS Commissioning Board, Monitor, clinical commissioning groups and providers as well as the Department of Health. The proposals set out in this document are the proposals of the Department of Health. New organisations will consider these proposals and the response to this further consultation as they take on their functions.

¹⁰ <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

2. What we heard: key themes

- 2.1 Respondents were broadly supportive of the proposals set out to increase patient involvement and patient choice and the benefits that the proposals will bring.

“Proposals to empower patients to make shared decisions at all stages of care and treatment is acknowledged by the County Council as a step in the right direction in providing patients with greater choice and flexibility in how and when they receive their treatment.” [Staffordshire County Council]

“Bupa supports the Government’s ambition to involve patients fully in their own care by giving them a choice over their care and treatment.” [Bupa]

“The potential benefits of SDM [shared decision-making] include better consultations, clearer risk communication, improved health literacy, more appropriate decisions, fewer unwanted treatments, healthier lifestyles, improved confidence and self-efficacy, safer care, greater compliance with ethical standards, reduced costs and better health outcomes.” [Royal College of General Practitioners]

- 2.2 Respondents identified a range of issues relating to how the proposals are implemented, which we have considered and taken into account. In this chapter we summarise the key themes that emerged from the consultation responses and how we have addressed these points, or taken them into account in our proposals. There are themes that apply equally to proposals to involve patients more and to give them more choice. We consider issues specific to greater patient involvement or patient choice respectively in subsequent chapters.

Patient involvement and patient choice

- 2.3 In response to the consultation document, some respondents clearly expressed the view that providing greater patient choice, be it over clinical team, setting, location or provider, did not equate to the widespread adoption of shared decision-making. We agree.
- 2.4 We consider that greater patient involvement and greater patient choice are all part of the same goal: to ensure that “no decision about me, without me” becomes the norm. This would be achieved through greater patient involvement in decisions about their care where patient involvement may mean better shared decision making, better care planning, or more support for self-care. This would

also be achieved through greater patient choice. We believe everyone should have choice as a patient; choice of who provides care, of when and where care is provided, and a choice of clinical team.

- 2.5 We recognise that shared decision-making is not a new concept. It has been the subject of much academic research and has a specific meaning:

“Shared decision making is a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient’s informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients’ informed preferences.”¹¹

- 2.6 We acknowledge this definition of shared decision-making and that this is but one element of patient involvement and one means of securing “no decision about me, without me”. Greater involvement of patients in decisions about their care and treatment should encompass all instances where patients make decisions about any aspect of their care and treatment. This could be achieved through better personal care planning, self-management, as well as through shared decision-making as defined above.
- 2.7 “No decision about me, without me” will also be achieved by giving patients more choices about where they might be treated and by whom. By having more say in who provides their treatment, where and when that treatment takes place, as well as what treatment to have, people will be able to become far more active participants in decisions about their health and healthcare.
- 2.8 Bringing this about will require a change in the relationship between patients and clinicians, to recognise that both are experts. Clinicians provide clinical expertise and knowledge about diagnosis and treatment, while patients are the experts in their condition and have knowledge of their personal preferences. By sharing their knowledge, the patient and clinician can work together and choose the best next step in the patient’s care and treatment.
- 2.9 We have fully considered these points in developing our approach. The following chapters address patient involvement and patient choice in turn, where we describe the key points raised in responses to the consultation under these headings and outline our final proposals in light of what we heard during the consultation.

¹¹ Coulter A. and Collins A. Making shared decision-making a reality: No decision about me, without me. The Kings Fund 2011.

Culture change

- 2.10 A recurring theme throughout the consultation responses was the need for a culture shift in the NHS for “no decision about me, without me” to become the norm:

“We would support any steps towards changing the culture among health professionals, so that patient involvement is the natural expectation.” [Sign Health]

- 2.11 We agree that there is a significant challenge in changing the culture of both health professionals, and of patients, so that both expect there to be greater patient involvement in decisions. Some respondents suggested the use of specific training and education programmes, particularly for primary care professionals, to equip clinicians with the skills necessary to help patients and the public understand their options to be involved in decisions about their care. Many clinicians already view patient involvement as a key part of any consultation but we want to make sure that best practice becomes common practice.

“If SDM is to become part of the NHS culture, it starts with the culture change in the NHS which requires education and support for NHS clinicians.” [North West London Hospitals Trust]

- 2.12 This is why the Right Care Shared Decision Making Programme¹² is developing training and education resources to embed the principles of shared decision-making into the curricula for a wide range of healthcare staff, including nurses, GPs, consultants and NHS managers, as well as for commissioners. In addition, the programme aims to raise awareness of shared decision-making amongst patients, their family and carers and the wider public, by working with advocates within the voluntary sector.

- 2.13 We were pleased that the Royal College of General Practitioners are “glad to support” our proposal to work with the Royal Colleges and other organisations to explore the potential and opportunities to ensure education reinforces shared decision-making as the norm. We look forward to working with the RCGP and their colleagues to make progress in this area.

- 2.14 Some respondents raised concerns that the time currently allotted to consultations was insufficient to involve patients fully in discussions and decisions about their care. There is no evidence to suggest this is the case. The

¹² The Right Care Shared Decision Making Programme is run as part of the QIPP programme, hosted by the East of England SHA. <http://www.rightcare.nhs.uk/shareddecisions/>

accompanying Impact Assessment assesses in full the expected impacts, costs and benefits of these proposals, including the impact on consultation times.

Ensuring everyone benefits from “No decision about me, without me”

- 2.15 There was strong support for the proposal that every patient should be as actively involved in making decisions about their health and healthcare as they wish to be:

“Carers UK shares the Government’s aim of increasing patients’ involvement in decisions about their care and welcomes the publication of this further consultation giving greater detail on where patients can expect to share decision making.” [Carers UK]

- 2.16 However, some respondents were concerned that the proposals would not be accessible to everyone, if those who required specialist or extra support to make decisions about their care, did not receive the support they needed:

“There is a risk that shared decision-making will have a distorting effect on consultation time spent with patients – put simply, the more articulate, better educated and more assertive patients may be encouraged to demand more time with their GP to discuss options – whilst those who are less literate but who have greater needs may lose out.” [Royal College of General Practitioners]

- 2.17 We fully acknowledge these concerns. One of the main purposes of giving patients more say in decisions about their care and treatment is to deliver greater equity within the NHS. A report by the King’s Fund¹³ found that more affluent people have historically been better at navigating their way around the NHS or have the choice of opting out of the NHS altogether. Making “no decision about me, without me” accessible to everyone means inequalities can be reduced by providing a choice for those who previously had no choice but to stay with their local services or providers. We fully consider the impacts of our policies in the Impact Assessment and Equality Analysis published alongside this document.

- 2.18 We have been clear in the Government's information strategy for health and care in England¹⁴ that information must be provided in a way that is appropriate to the individual, and that people, carers and their representatives should be fully supported in accessing and using that information to make an informed

¹³ Dixon, R. Robertson, J. Appleby, P. Burge, N. Devlin, H. Magee (2010). *Patient choice: How patients choose and how providers respond*. The King’s Fund, 2010.

¹⁴*The power of information: Putting all of us in control of the health and care information we need*, 21 May 2012 - <http://www.dh.gov.uk/health/2012/05/information-strategy/>

decision. This is backed up by the right in the Constitution to “be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this”¹⁵.

- 2.19 We are also clear that commissioners of health and care services should recognise the benefits of ensuring appropriate information and communication support being made available for those who need it. This may include the use of a translator service for those where English is not their first language, or considering alternative forms of information.
- 2.20 We recognise that each patient will have specific needs in terms of information and support. While we cannot account for every circumstance, we strongly encourage commissioners to consider individual needs, in line with the relevant duties in the Health and Social Care Act 2012 Act¹⁶ to reduce inequalities between patients with respect to the accessibility of health services, and the outcomes achieved by the provision of those services.
- 2.21 We also acknowledge the importance of ensuring that no one should be disadvantaged as a result of the chosen means of providing information. For example, some rural communities may lack access to the internet, and in some cases may lack the skills to go online. Action is being taken by, the Government and a range of partners to address these issues, but we also recognise that alternative means of communication and information provision may also need to be considered in certain circumstances
- 2.22 Many community organisations exist to meet the needs of people who are vulnerable or disadvantaged or, because of cultural issues, face barriers when accessing state or publicly run services and do not receive the support they need. We encourage GPs and clinical commissioning groups to consider the role of the voluntary sector, especially when they are in a position to offer better-targeted information.
- “A focus on education and new forms of information and information channels will be required as people could not make informed decisions if they do not have the right information.” [SHA Long Term Conditions Leads]*
- 2.23 Further, local Healthwatch will have an important role in providing, or signposting, people and carers to information about local health and care services and how best to access these services. It will have a seat on the new health and wellbeing boards, ensuring that the views and experiences of

¹⁵

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132961

¹⁶ http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga_20120007_en.pdf; 14T

patients, carers and other service users are taken into account when local needs assessments and strategies are prepared. Local Healthwatch will also be able to help and support clinical commissioning groups to make sure that services really are designed to meet citizens' needs.

- 2.24 Many respondents specifically welcomed the steps proposed in the consultation to achieve equal opportunities for choice for users of mental health services, wherever possible.

“The focus on mental health in the consultation is welcome. As the document itself recognises, this is an area of health care where progress on real patient choice has often fallen behind” [Independent Mental Health Services Alliance]

“We agree that it is important that where possible the choices available to patients using secondary care are also available to patients who undergoing treatment for mental health issues.” [The Patients Association]

- 2.25 The Health and Social Care Act 2012 made it clear that a comprehensive health service must address both the physical and mental health needs of patients in England. Section 1 of the NHS Act 2006 now states that the National Health Service should improve both the physical and mental health of the population and that it should give equal priority to the prevention, diagnosis and treatment of both physical and mental illness.

Information

- 2.26 Many responses to the consultation highlighted the importance of providing information for people to be able to make informed decisions.

“The consultation document rightly notes the importance of good quality information to enable patients to become actively involved in decisions about their care.” [Specialised Healthcare Alliance]

- 2.27 We agree that central to the vision of patient-centred care, is the principle of providing a wide range of appropriate, accessible and timely information enabling people to make informed decisions. From April 2011, providers have been required to publish information about their services so that people can use this to make informed choices about their healthcare¹⁷. As we explain above, the NHS Constitution¹⁸ sets out the right for people to make choices about their NHS care and to information to support these choices.

¹⁷ The Operating Framework for the NHS in England, Department of Health, December 2010

¹⁸ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_132958.pdf

- 2.28 Where possible, information should be available in a variety of formats so that all groups can access it, including those with learning disabilities, those with hearing or sight impairments and non-English speaking people. This may include the provision of interpreters so that patients with specific language or communication difficulties can communicate freely with healthcare professionals.
- 2.29 Part of the Right Care Shared Decision Making programme has focused on delivering 36 patient decision aids in a variety of formats, to help patients understand and consider the pros and cons of possible treatment options. The decision aids are a valuable tool in providing information in a format that helps patients to make an informed decision and encourages communication between patients and healthcare professionals.
- 2.30 Some respondents raised concerns about the capacity and compatibility of the IT systems to be able to support the proposals. Having chosen a hospital, and perhaps a named consultant-led team, a patient would expect that team to have received their health and care record and any test results, to best inform their clinical advice.

“The proposals are challenging and caution must be taken to ensure uncoordinated care pathways are not inadvertently introduced: IT systems and interrelationships with different providers must be strong and resilient for these proposals to be successful.” [The Royal College of Physicians of Edinburgh]

- 2.31 We recognise that the systems currently in place are not always as joined-up as they need to be, and a key ambition of the Information Strategy is: *“Information recorded once, at first contact, and shared securely between those providing our care – supported by consistent use of information standards that enable data to flow whilst keeping our confidential information safe and secure.”*¹⁹
- 2.32 The strategy proposes an approach, based on nationally set information standards, which will enable information to be captured once and shared right across the health and care system. It will be for the Department of Health and the NHS Commissioning Board to agree, by April 2013, how to take this forward.
- 2.33 The strategy also sets out the steps to enable electronic access to people’s own GP records. This will support individuals to take more control of their own health and care and to work with professionals to ensure that there really is “no decision about me without me”.

¹⁹ <http://www.dh.gov.uk/health/2012/05/information-strategy/>; Chapter 3

Quality and continuity of care

- 2.34 Some respondents were concerned about the risk of fragmentation of care as a result of providing a choice of provider, and the risk of a variation in the quality of care if it was provided by non-NHS service providers:

“The consultation document does not make clear how governance will work across the full patient pathway. With fragmentation of care amongst providers there are dangers that no one organisation will have responsibility for ensuring that the quality of care meets required standards.” [North East Yorkshire and Humber Clinical Alliance]

- 2.35 It is precisely by giving people more choice over their care that the Government aims to enable all patients to access the highest quality providers of healthcare services. Encouraging people to ‘vote with their feet’ by making choices about their care will strengthen the incentives of the NHS to meet patient requirements and improve the quality of services.
- 2.36 We are not advocating a ‘one size fits all’ approach to patient choice: it is for commissioners to decide how best to commission services. Where integration is particularly important, commissioners might decide that one provider is responsible for care planning and delivery, whilst still offering choice of treatment, setting and lead clinician.
- 2.37 Where patients are offered choice of provider, the providers will be contractually obliged to co-operate so that patient care is safe, transfers are co-ordinated properly, and patient experience is good. As is the case now, GPs will be there to help patients navigate the system, advising patients to make sure they have continuity. If continuity of care or integration issues arise, clinical commissioning groups will be able to address these with providers directly.
- 2.38 The Health and Social Care Act 2012 places a clear duty on both the NHS Commissioning Board, and the clinical commissioning groups²⁰, to ensure health services are provided in an integrated way so as to improve the quality of those services (including the outcomes that are achieved from their provision), and to reduce inequalities.

²⁰ http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga_20120007_en.pdf; 13N and 14Z1

3. Greater patient involvement

- 3.1 This chapter outlines the specific issues we heard regarding proposals on increasing patient involvement, and our response.
- 3.2 The NHS Act 2006 places a clear duty on the NHS Commissioning Board, and the clinical commissioning groups to:

“...promote the involvement of patients, and their carers and representatives (if any), in decisions which relate to—

- (a) the prevention or diagnosis of illness in the patients, or*
- (b) their care or treatment.”*²¹

- 3.3 The consultation proposed a number of ways to help support this duty including proposals to formalise an offer of personalised care planning, the further roll out of personal health budgets (subject to evaluation), and a greater focus on those with long-term conditions. Respondents raised a number of specific issues relating to these points.

Ensuring everyone is involved in decisions about their care

- 3.4 We clearly heard the importance of care planning in ensuring people are as involved as they wish to be in deciding which care and support services to use:

“National Voices is heartened to see that the important role of personalised care planning is acknowledged in the consultation document. However, we are concerned that the Department of Health’s statistics overestimate the extent to which care plans are already in use.” [National Voices]

“The RCN is supportive of the wider provision and use of personalised care planning, both within healthcare, and across healthcare and social care.” [Royal College of Nurses]

- 3.5 We know from survey evidence²² that most people with long-term conditions will have a discussion with their health professional about how to manage their

²¹ <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted> 13H

²² The GP Patient Survey showed that 83% of people with a long-term condition had had a discussion about their condition(s). Many also reported that they were given information about their condition(s) and felt the doctor or nurse took notice of their views.

condition. This is a good start but we want to go further. Wherever possible we want this discussion to lead to a formal personalised care plan, developed jointly and agreed between the professional and the patient, to facilitate greater patient involvement in decisions about their care, treatment and support.

- 3.6 We have been actively looking at ways to strengthen the role of personalised care planning. We set out further details in Chapter 6.
- 3.7 We have been clear about the role of telehealth and telecare technology²³ in supporting more involvement in care decisions. We have developed the 3 million lives²⁴ initiative, which aims to improve the lives of 3 million people with long-term conditions over the next 5 years using telehealth and telecare technologies. The programme will also help to educate healthcare providers and patients on how this technology can best be used in health and care services.

Mental health

- 3.8 We also heard the importance of involving all patients and service users, including those using mental health services, in decisions about their care and treatment:

“People with mental health problems are often experts in their own symptoms and support needs, meaning shared decision-making can lead to more effective treatment and improved patient outcomes, while involvement in making decisions can be an important part of the recovery process in itself.” [Mind]

- 3.9 As we set out earlier, the Government for the first time has made clear the equal status of mental and physical health in law, through the passing of the Health and Social Care Act 2012. The Secretary of State’s mandate specifically tasks the NHS Commissioning Board to put mental health on a par with physical health, and close the health gap between people with mental health problems and the population as a whole. The Board will be held to account to deliver on the mandate.
- 3.10 In other areas, we heard from several groups that there was the risk that those who required tailored information and support may be left behind by these proposals, unless they were properly implemented.

Mental capacity

²³ <http://www.nhs.uk/Planners/Yourhealth/Pages/Telecare.aspx>

²⁴ <http://www.3millionlives.co.uk>

- 3.11 Concerns were raised about the ability of some GPs and other clinical staff to adequately manage the needs of patients with conditions that affect their mental capacity, such as dementia or learning disabilities.

“For patients who lack capacity, the views of carers and other interested parties must be collated in order to make a best-interests shared decision. All principles in relation to Mental Capacity Act legislation should be adhered to in the process.” [The Royal College of Psychiatrists]

- 3.12 The Mental Capacity Act 2005 is a vital piece of legislation underpinning the NHS that requires all health professionals to take 'all practicable steps' to help people make their own decisions, even where they have a mental impairment. Just because a patient has a mental impairment does not mean that those patients and their carers should not be involved in decisions about their care. Options may need to be communicated in different, or more appropriate ways and patients need to be supported in understanding the options and their implications, as well as being assisted in making and communicating their choices. The principles of the Mental Capacity Act must be adhered to in any decision making where a patient lacks capacity or their capacity is predicted to deteriorate over time.

- 3.13 In cases where people's capacity is predicted to deteriorate over time, for example if they are diagnosed with early stage dementia, personalised care plans would be a useful way to enable them to plan how they would like their health needs met when they lose capacity. They will also be an important tool to help those who have fluctuating capacity retain more control when they become unwell. When planning care with people who lack mental capacity, it is important that the person be supported to have the fullest input possible into decisions affecting them. Their family, carers and representatives should also be fully involved in developing the plans for the future.

Children and young people

- 3.14 Other people responded specifically to highlight that involvement of children and young people in decisions about their care and treatment was not appropriately recognised in the consultation document:

“Children and young people want to engage in shared decision making and government should consider the barriers they experience to achieving this, alongside good practice, and children and young people's own suggestions for improvements.” [National Children's Bureau and the Council for Disabled Children]

- 3.15 We agree that the principles of patient involvement apply equally to all people, regardless of age, and acknowledge that children and young people may require additional support to be fully involved in decisions about their care.
- 3.16 In January 2012, the Secretary of State for Health established a Forum to help develop a new strategy for improving care for children and young people. The Forum published its report²⁵ in July 2012 setting out recommendations on how the health and care system can help deliver the necessary improvements to improve care for children and young people. The Department is now using the Forum Report as a basis for finalising the composition of the Children and Young People's Health Outcomes Strategy, which is due to be published shortly.
- 3.17 The Department of Health has also published quality criteria for young people friendly health services – *You're Welcome*²⁶. The criteria set out principles to help commissioners and service providers to improve the suitability of NHS and public health services for young people, based on the evidence of what works in the health service, and in response to what young people tell us about the importance of services designed around their needs.

Personal Health Budgets

- 3.18 Respondents also gave their clear support to the proposals regarding the availability of personal health budgets.

“Personal Health Budgets, where they have been used to date, have been seen to improve patient experience and outcomes.” [African Health Policy Network]

- 3.19 Personal health budgets are currently being piloted, with an evaluation of the pilot due later this autumn. Subject to the evaluation, all people (including children) receiving NHS Continuing Healthcare will have the right to ask for a personal health budget by April 2014. Clinical commissioning groups will also be able to offer them more widely on a voluntary basis.

²⁵ <http://www.dh.gov.uk/health/2012/07/cyp-report/>

²⁶

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073586

4. Greater patient choice: all along the pathway

- 4.1 We heard that while increasing patient choice of provider alone will not make a reality of patient-centred care, it plays a vital role alongside the policies on patient involvement.

“Giving patients a greater say in their care and giving them more opportunities to choose for themselves what they want is certainly commendable and to be welcomed.” [The Patients Association]

- 4.2 The NHS Act 2006²⁷ makes this point clearly with a duty for the Board and clinical commissioning groups to promote both patient involvement and patient choice. The Act requires the Board and clinical commissioning groups to:

“act with a view to enabling patients to make choices with respect to aspects of health services provided to them.”

- 4.3 In April 2011 the NHS Future Forum was asked to report on the role of choice and competition in improving quality in the NHS. A recommendation of the Forum was for the Secretary of State’s mandate to the NHS Commissioning Board to set clear expectations for the Board regarding choice.
- 4.4 In response to this recommendation the Department of Health is publishing a Choice Framework for NHS funded care and treatment in England that sets out, for the first time, the choices available to patients all along the care pathway and across services. The NHS Choice Framework supports the delivery of the Government’s Open Public Services agenda. This agenda aims to ensure that everyone has access to the best possible public services, and that the best become better still. By making clear the choices that the public have over their healthcare, more people will be encouraged to make choices that best meet their needs and preferences. This will drive improvements in the services provided, as they will be more directly accountable to their patients. We say more about the NHS Choice Framework in the next chapter.

Choice of GP

- 4.5 Many responses welcomed proposals to enable people to register with the GP practice that best suits their needs.

²⁷ As inserted by the Health and Social Care Act 2012

“Looking ahead, we are particularly supportive of greater choice in primary care - giving patients the choice of GP practice rather than just of GP. This proposal will enable patients to choose GPs who offer the best, most responsive services, and which suit the needs of different communities and reflect changing lifestyles.” [The NHS Partners Network]

- 4.6 Choice of GP practice is currently being piloted in three areas in England. This pilot scheme is subject to a full independent evaluation and due to report in the summer of 2013. The results of the evaluation will inform future arrangements.

Mental health services

- 4.7 People also welcomed the proposal to provide a right for mental health service users to choose any team led by a clinically appropriate professional²⁸.

“In relation to mental health services, it should also be noted that as many mental health teams do not operate along a consultant led model, there is a danger that the public will perceive this as a deficit, given the current focus on consultant led services...Extending this approach to choice of team led by a clinically appropriate professional would help in this respect, but this distinction will need to be communicated effectively to patients.” [The Foundation Trust Network]

- 4.8 The Handbook to the NHS Constitution currently sets out patients’ legal rights to choose.²⁹ The scope of this legal right is currently limited to choice of provider when referred to most elective services. Having received positive responses to our proposals in the consultation, the scope of this right will be extended to include the named consultant-led team you see when referred to secondary care and, for the first time, a right to choose the named professionally led team that you see for secondary care mental health services for your first outpatient appointment. The legal basis for these rights will be the Standing Rules regulations and we intend to update the Handbook to the NHS Constitution to reflect the extended scope.

²⁸ Schedule 1 of the Mental Health Act 1983 Approved Clinician (General) directions 2008 defines clinically appropriate professionals as: a chartered psychologist who is listed in the British psychological Society's Register of Chartered Psychologists and who holds a relevant practising certificate issued by that Society; a first level nurse, registered in Sub-Part 1 of the Nurses and Part of the Register maintained under article 5 of the Nursing and Midwifery Order 2001 with the inclusion of an entry indicating their field of practice in mental health or learning disabilities nursing; an occupational therapist registered in Part 6 of the Register maintained under article 5 of the Health Professions Order 2001.

²⁹ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_132959.pdf

- 4.9 Some respondents were concerned that the payment systems for mental health services were not sufficiently developed to enable choice to be put on a par with most acute elective health services.

*“In mental health, more work is also needed on standard specifications and national tariffs before choice between organisations can be developed further.”
[Tees, Esk and Wear Valleys]*

- 4.10 For too long people who are referred to mental health services have not been given the same choices as those referred to other elective services. Currently, mental health services are an exception to the 'free choice' offer that states that a patient has the right to choose any provider in England for a first outpatient appointment with a consultant or a member of the consultant's team for most elective care. This must change. As we set out earlier, the Government is committed to ensuring mental health has equal priority with physical health, and the Health and Social Care Act 2012 is clear that equal priority must be given to the prevention, diagnosis and treatment of both physical and mental illness.
- 4.11 Having heard clear messages of the importance of ensuring equal priority of mental and physical health services, we intend to remove this exception to free choice in due course. This will give us time to bring about the changes that are necessary for removing the exemption, including in relation to payment systems and integration between mental health, social care and other services.
- 4.12 Some respondents also questioned the availability of real choice, due to limited capacity of some services.

“There is currently insufficient supply of high quality mental health services to meet demand. This means that far from being offered choice of service, patients are more likely to face long waiting times to receive mental health interventions.” [Mind]

- 4.13 To increase capacity of mental health services, the Government is investing over £400 million to increase access to NICE Approved Psychological Therapies. We are continuing to increase the choice of therapy options in the Improving Access to Psychological Therapies programme and we are extending the scope of the programme to include children and young people, people with a long-term condition, severe mental illness or personality disorder.
- 4.14 Patients will have an increased choice of provider in the community through the Any Qualified Provider programme and we are developing a robust payment system to incentivise routine patient choice of therapy. Personal health budgets are also being piloted for people with mental health needs as a way of giving people more choice and control and could be rolled out in due course, subject to evaluation.

Maternity

- 4.15 We heard clear support for our proposals on maternity: women, together with their midwife or clinician, should be able to plan their care throughout the maternity pathway.

“We welcome the maternity-specific initiatives mentioned in the document, and are confident that they will help to empower women to make decisions about their care. However, we do not believe that these initiatives alone will be sufficient to enable truly shared-decision making” [Royal College of Midwives]

- 4.16 We agree that we should do more to promote the choices available to women on the maternity pathway. This is why we have set out clearly the choices available to women in the Choice Framework. The Framework explains the choices women have over who provides their care, where to give birth and how to receive care after the birth.

Diagnostic testing

- 4.17 A concern we heard about the proposals to increase choice in diagnostic testing was that there were limitations due to the lack of interoperability of some systems including clinical access to comprehensive diagnostic test data and reports. One issue raised was the interaction of the Radiology Information Systems and Choose and Book.

“We note the existing concern relating to incompatibility of Radiology Information Systems (RIS) and Choose & Book “. [British Medical Association]

- 4.18 We fully recognise the point and this has been identified as an area for further work both in the ‘*No decision about me, without me*’ consultation, and in the Information Strategy. We are currently looking at how best to improve the compatibility of these systems.
- 4.19 We want patients to have a choice of diagnostic test provider, whether tests take place in community care settings (through any qualified provider), or in secondary care. As well as being able to choose any provider in England when referred to a consultant-led first outpatient appointment for diagnostic tests, patients can expect to have choices over their diagnostic care provider where the test does not take place as part of a first consultant-led outpatient appointment. We set out in May that the National Clinical Directors would confirm the priority areas where this offer should apply.
- 4.20 We can now confirm that the categories of diagnostic test that are priority areas are:

- Endoscopy (gastroscopy, colonoscopy, cystoscopy, flexible sigmoidoscopy)
- Imaging (e.g. non-obstetric ultrasound, CT, MRI, DEXA, plain film scans)
- Physiology (e.g. audiology assessments, electrocardiogram, echocardiogram)
- Other diagnostic tests (e.g. genetics and pathology) are priority areas, but a decision on which tests to include has not yet been made.

4.21 The Department of Health is currently considering different tariff options for diagnostic testing, which could further support patient choice.

5. Conclusion: making it happen

- 5.1 We have reported and discussed the issues that were raised during the consultation: both positive messages about the benefits of our proposals and also clear messages about the importance of implementing the proposals correctly. This chapter sets out the steps we are taking to make the vision of a patient-centred NHS a reality.

The legal framework

- 5.2 We acknowledge the message that patient involvement and patient choice are distinct, yet complementary, parts of “no decision about me, without me”. The NHS Act 2006 (as inserted by the Health and Social Care Act 2012) places clear duties on the NHS Commissioning Board and the clinical commissioning groups to:

“...promote the involvement of patients, and their carers and representatives (if any), in decisions which relate to—

- (a) the prevention or diagnosis of illness in the patients, or*
- (b) their care or treatment.”*

And to:

“act with a view to enabling patients to make choices with respect to aspects of health services provided to them.”

The Mandate

- 5.3 On 13 November, the Secretary of State published a Mandate³⁰ to the NHS Commissioning Board. This document sets out the objectives the Board should seek to meet and those where the Secretary of State will hold the NHS Commissioning Board to account. The Board will be required to publish a business plan at the start of each year setting out how it will achieve its objectives.

³⁰ <http://mandate.dh.gov.uk/>

- 5.4 The mandate sets out a clear ambition that the NHS should become dramatically better at involving patients and their carers, and empower them to manage and make decisions about their own care and treatment. The mandate also expects that by 2015, the Commissioning Board will have fully embedded all patients' legal rights to make choices about their care, and extended choice in areas where no legal right yet exists.

The NHS Constitution

- 5.5 Patients are currently entitled to make choices and be involved in decisions about their health and care, as set out in the NHS Constitution:

“You have the right to make choices about your NHS care and to information to support these choices.”

And

“You have the right to be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this.”

- 5.6 The consultation on the Constitution has been launched³¹ seeking views on proposals for strengthening the content in the NHS Constitution. The consultation seeks views on the proposals to strengthen the Constitution with an amended principle that the NHS aspires to put patients at the heart of everything it does. The consultation also proposes amending several rights and pledges to reflect more clearly that the NHS supports individuals to manage their own health and involves them, their families and carers in decisions that affect them. In support of views about the importance of care planning, it also proposes creating a new pledge to involve patients in discussions about planning their care and to offer them a written record of what is agreed. The consultation is open to responses until Monday 28 January.

Providing information to support decisions

- 5.7 The provision of information is a key part of the vision of “no decision about me, without me” becoming the norm. We set out in the Information Strategy³² the vision of people being able to access and share their own health and care records, to help people take part in decisions about their own care in a genuine

³¹ <http://www.dh.gov.uk/health/2012/11/constitution-consultation/>

³² The power of information: Putting all of us in control of the health and care information we need, 21 May 2012 - <http://informationstrategy.dh.gov.uk>

partnership with professionals. The strategy emphasises the importance of providing support to those who need it in interpreting and using the information available, to ensure that everyone has the opportunity to participate in decisions about their own care and treatment. It also sets out an approach, based on nationally set information standards, to achieve fully joined-up systems to enable information to be captured once and shared right across the health and care system

- 5.8 Since 2007 NHS Choices³³ has been the online “front door” to the NHS. It is the country's biggest health website and provides the information a patient needs to make choices about their health. This includes information on choosing between treatment options and choosing healthcare providers.
- 5.9 We also provide Choose and Book; an electronic referral and booking system that allows patients to see the appointments available to them at different providers, and then to book an appointment either with the GP who refers them, or via the internet or telephone. The system is a key means in ensuring that patients and their referrers have the opportunity to choose clinically appropriate providers and appointments that suit them, both in terms of where the appointment takes place, and when it takes place.

Promoting patient involvement

- 5.10 The responses to the consultation clearly expressed the importance of policies on patient involvement in ensuring “no decision about me, without me” becomes a reality. These policies will include work on embedding care planning, shared decision-making and providing information and support necessary to enable people to manage their own condition, where they wish to do so.

Helping those with Long-Term Conditions

- 5.11 Having heard the vital role of personalised care planning, we are consulting on introducing a pledge on care planning into the NHS Constitution: "to involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one (pledge)".

“We further welcome the use of personalised care plans being incorporated into QIPP. We hope that this will see much more widespread use of personalised

³³ www.nhs.uk

care plans, and as such see many more patients fully involved in decisions about their care.” [The Patients Association]

- 5.12 This commitment is echoed in the Mandate to the NHS Commissioning Board, which the Board will be held to account for delivering. The Mandate states: *“everyone with long-term conditions, including people with mental health problems, will be offered a personalised care plan that reflects their preferences.”*
- 5.13 We continue to support the use of telehealth and telecare to support those with long-term conditions. This underpins delivery of our 3millionlives initiative. We have also delivered on our commitment to publish an updated Long-Term Conditions Compendium of Information. It brings together the information and evidence to reinforce to health and social care professionals, as well as commissioners, why a focus on long-term conditions should continue to be a priority.
- 5.14 There is also the Government commitment to roll out personal health budgets more widely, subject to the results of the evaluation that is due this autumn. Subject to the evaluation, all people (including children) receiving NHS Continuing Healthcare will have the right to ask for a personal health budget by April 2014. Clinical commissioning groups will also be able to offer them more widely on a voluntary basis.

Healthwatch

- 5.15 Healthwatch England started on 1st October 2012 and local Healthwatch will start on 1st April 2013.
- 5.16 Healthwatch England is a national body that enables the views of the people who use (or may use) NHS and social care services to influence national policy, advice and guidance. The views of the public, patients and service users will, through Healthwatch, form part of the advice to the Secretary of State, the NHS Commissioning Board, Monitor and the English local authorities, all of whom must have regard to that advice.
- 5.17 In addition, local Healthwatch will give citizens and communities a stronger voice to influence and challenge how health and social care services are commissioned and provided in their local area. As well as championing patients’ and users’ views and experiences, local Healthwatch will signpost people to information to help them make choices and ensure people know where to go for help, advice and, if necessary, expert support when things go wrong.

Shared Decision-Making programme

- 5.18 The Right Care Shared Decision Making Programme³⁴ is run as part of the QIPP programme, hosted by the East of England SHA. The programme works to embed the practice of shared decision making among patients and the wider public and among health professionals and their educators.
- 5.19 The programme is working to establish shared decision-making as a part of education and training resources for healthcare staff and commissioners. It is also providing training and other resources for advocates within the voluntary sector to raise awareness amongst and promote demand from patients, their family and carers. Another workstream includes developing 36 patient decision aids to help patients understand and consider the pros and cons of possible treatment options. These will also encourage communication between patients and their healthcare professionals.

Care and support

- 5.20 Caring for our future, the Government's White Paper for care and support, set out the ambition to reform adult social care and transform people's experience of care and support. Central to this vision is the need to put people in control of their own care, including the public money available to them and provide them with the ability to choose how their needs should be met. The White Paper focuses on personalising care and support so that it is built around the needs, goals and outcomes of people, not around institutions.
- 5.21 The draft Care and Support Bill continues this focus to embed personalisation in legislation. The draft Bill enshrines new legal principles to promote the person's well-being, including the control they have over their day-to-day life and the care and support they receive. It also creates a new entitlement to a care and support plan (or a support plan, in the case of a carer), and places clear duties on local authorities to help the adult decide how they want their needs to be met, so that they are at the heart of the planning process.
- 5.22 The care and support plan will also include, as a standard element, the adult's personal budget, which is created in law for the first time. This new entitlement to a personal budget will be a key factor in empowering people to take more control over how their care and support is provided, by giving them knowledge of the money available to meet their needs. The personal budget will be linked to existing rights to take a direct payment from the local authority to access that money, where the person chooses.

³⁴ <http://www.rightcare.nhs.uk/shareddecisions/>

Delivering patient choice

- 5.23 We are committed to expanding the offer of patient choice as part of making “no decision about me, without me” the norm in the NHS.

The NHS Constitution

- 5.24 Patients are currently entitled to choice and information to support their choices as set out in the NHS Constitution. As we outlined earlier, we will be extending the scope of this offer to include, for the first time, the right to choose the named consultant-led team that you see and the professionally led team that you see for secondary care mental health services for your first outpatient appointment. We intend to update the Handbook to the NHS Constitution to reflect these additional rights to choice.

Monitor and section 75 regulations

- 5.25 All patients must be able to exercise their rights to make choices in primary and elective care, as set out in the NHS Constitution. These are national rights and patients should be able exercise them wherever they live in England.
- 5.26 The Department of Health is currently consulting on proposals to establish regulations that would include requirements to safeguard patients’ rights to exercise choice. The regulations would prohibit commissioners from reaching agreements or taking any other actions that would be inconsistent with a patient’s right to exercise choice as set out in the NHS Constitution.
- 5.27 Monitor, the sector regulator with a main duty to protect and promote the interests of patients, would oversee the regulations. This means that, in future, Monitor would be able to consider complaints that a commissioner has taken action that is inconsistent with a patient’s right to choose. Monitor will have powers to investigate and powers to direct commissioners to change their approach if they have breached the regulations.

NHS Standard Contract

- 5.28 Placing requirements on providers would be a key mechanism in embedding choice in the NHS. Requirements could include instruction to:

- i. list all services eligible for patient choice on the Choose and Book system;
- ii. list services against a lead healthcare professional (e.g. consultant) as and where appropriate, including on Choose and Book;
- iii. accept all clinically appropriate referrals made through Choose and Book;
- iv. publish the information needed to support these choices; and
- v. work together with commissioners to ensure that service users are not delayed or inconvenienced by insufficient appointment slots being made available to Choose and Book.

5.29 It will be for the NHS Commissioning Board to consider how these factors might be reflected in its planning guidance, including any impact on the standard contract, both of which will be published following its receipt of the Government's mandate.

The Choice Framework

5.30 The Department of Health's Choice Framework for NHS funded care and treatment in England published alongside this consultation response, brings together, for the first time, the choices available to patients all along the care pathway. This supports the Government's Open Public Services agenda, which aims to ensure that everyone has access to the best possible public services.

5.31 The NHS Choice Framework sets out clear expectations for the NHS Commissioning Board and commissioners about the choices patients ought to be able to make, and ensures that patients have clarity over what choices they can reasonably expect to have about where they go and who they see for treatment.

5.32 The Framework summarises the outcome of the consultation process on the proposals to make "no decision about me, without me" through increasing patient choice. It sets out what choices people can expect to have in the following areas:

- Choosing your GP practice
- Choosing where to go for your first appointment as an outpatient
- Choosing which consultant will be in charge of your treatment

- Choosing asking to change hospital if you have to wait longer than the maximum waiting times (18 weeks and two weeks to see a specialist for cancer)
- Choosing who carries out a specialist test if you need one
- Choosing maternity services
- Choosing services provided in the community
- Choosing to take part in health research

5.33 The Choice Framework outlines the choices you can expect to have in the areas listed above, who to contact about that choice and how to complain if you don't think the choice has been offered. The Choice Framework can be found on the Department of Health's website and on gov.uk.

5.34 In addition to the choices set out in the Framework, the consultation also set out our expectation that self-referral will be available where there are benefits to patients of having it. It is for local commissioning organisations to make their own decisions about this route of access where it is clinically appropriate and of value to the healthcare system and local community.

5.35 Many respondents were also positive that choice of treatment was a key part of making shared decision-making a reality in the NHS. All patients who wish to be involved in decisions and choices about their treatment and management of their condition should receive the relevant information and professional support to do so.

5.36 We also remain committed to establishing a national choice offer for people and their families to be able to choose to die at home, including care homes. For this to be a realistic offer, we need to be confident that the right services are in place to provide the support that they may need. Implementation of the End of Life Care Strategy³⁵ will be reviewed in 2013 to assess the feasibility and timescale for introducing this right.

No decision about me, without me

5.37 The role of the NHS Commissioning Board is key in delivering the vision of “no decision about me, without me”. To make this a reality in the NHS, we expect that the following become routine:

³⁵<http://www.dh.gov.uk/health/category/policy-areas/social-care/end-of-life/>

I. Patient involvement:

- Shared decision-making: involving the patient and their carers in decisions about their care and treatment.
- Self-care: the patient being supported in taking more responsibility for the things that they can do to maintain and improve their health.
- Care planning: the patient jointly agreeing with the clinician a plan for their care, including as appropriate advanced planning for terminal care.

II. Patient Choice: the ability for patients to choose the provider of their care, when and where it takes place, and who provides it.

5.38 Together the set of policies being put forward add up to significantly more control for patients, putting them first and making real the idea of “no decision about me, without me”.

Annex A: Organisations that responded

Advancing Quality Alliance (AQuA)
Afasic
African Health Policy Network
Age UK
Alliance Boots
Alzheimer's Society.
Arthritis Research UK
Association of the British Pharmaceutical Industry
Astellas Pharma Ltd.
Barnet and Chase Farm Hospitals NHS Trust
Birmingham Community Healthcare NHS Trust
Bliss
Boehringer-Ingelheim
British Acupuncture Council
British Association for Counselling and Psychotherapy (BACP)
British Dyslexia Association
British Geriatrics Society
British HIV Association
British In Vitro Diagnostics Association (BIVDA)
British Lung Foundation
British Medical Association
British Society of Hearing Aid Audiologists
British Psychological Society (The)
Bupa
Cancer52
Cancer Partnership Group Mid-Yorks Trust
Cancer Research UK
Carers UK
Cerner Corporation
Changemakers
Changing Faces
Chartered Society of Physiotherapy (The)
Children's Heart Federation (The)
Chronic Pain Policy Coalition
Coloplast
College of Optometrists (The) / Optical Confederation
Community Health & Learning Foundation
Contact a Family

Coventry LINK.
Darlington Borough Councils', Health and Partnership Scrutiny Committee
Deafness Support Network
Diabetes UK
Dorset Cancer Network Patient Partnership Panel
East Riding of Yorkshire CCG
Foundation Trust Governors' Association
Foundation Trust Network
Gender Identity Research and Education Society (GIRES)
Homeless Link
Human Givens Institute
Improving Access to Psychological Therapies (IAPT)
Independent Healthcare Advisory Services
Independent Mental Health Services Alliance (IMHSA)
Informed Medical Decisions Foundation
Institute of Biomedical Science
King's Fund (The)
Lesbian and Gay Foundation/ National LGBT Partnership
Local Authority
Manchester Local Medical Committee
Marie Curie Cancer Care
Mental Health Foundation
Milton Keynes Wheelchair Users Group
Mind
Motor Neurone Disease Association (MNDA)
Medical Protection Society
Multiple Sclerosis Society
Multiple Sclerosis Trust
Myeloma UK
Nacro
National Aids Trusts (NAT)
National Clinical Homecare Association
National Council for Palliative Care
National Council of Women of Great Britain.
National Voices
NCB and Council for Disabled Children
NHS Confed BME Leadership Forum
NHS Midlands and East
NHS Partners Network
NICE
Norfolk LINK
North East regional registrars in public health group

North East Yorkshire and Humber Clinical Alliance
Outcomes Research Group, St. George's, University of London
Patients Association (The)
Parkinson's UK
Parliamentary and Health Service Ombudsman
Participation Works Partnership
Pfizer Ltd
Plymouth LINK
Positively UK
PPS Interim Support Ltd
Priory Group
Prostate Cancer UK
Pharmacy Voice
Rethink Mental Illness
Royal College of General Practitioners
Royal College of Midwives (RCM)
Royal College of Nursing
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Physicians
Royal College of Physicians of Edinburgh
Royal College of Psychiatrists
Royal College of Radiologists
Royal National Institute of Blind People (RNIB)
Roche Products Ltd
Runnymede Health and Social Care Task Group
SECTCo
SHA Long Term Conditions Leads
Shared Decision Making in Child and Adolescent Mental Health project team
SignHealth
Southern Health NHS Foundation Trust
Speaking Up Southwark
Specialised Healthcare Alliance
St. Oswald's Hospice
Tees, Esk and Wear Valleys NHS FT
Trans Yorkshire
Tunstall Healthcare Ltd
Turning Point
Urology Trade Association (The)
Urology User Group Coalition (The)
Vanguard Healthcare
Wish

Annex B: Consultation questions

Q1. Will the proposals provide patients with more opportunities to make shared decisions about their care and treatment in the following areas?

- a) in primary care?
- b) before a diagnosis?
- c) at referral?
- d) after a diagnosis?

Q2. Are the proposals set out in this document realistic and achievable?

Q3. Looking at the proposals collectively, are there any specific areas that we have not recognised appropriately in the consultation document?

Q4. Have we identified the right means of making sure that patients will have an opportunity to make shared decisions, to be more involved in decisions about their care across the majority of NHS funded services?

Q5. Do you feel that these proposals go far enough and fast enough in extending choice and making “no decision about me, without me” a reality?

Annex C: Summary of issues

Issue	No. Mentions
Information required by patients and healthcare professionals to deliver choice	77
Training required for healthcare professionals to deliver choice	56
Other – any concern mentioned only twice or less	53
Health Inequalities brought about by the offer of choice	46
The proposals refer to provider choice not the recognised definition of Shared Decision Making	39
Staff resource required to implement the proposals	34
Competence of healthcare professionals to deliver choice	32
The culture change required for the proposals to succeed	22
Concerns around implementation of the proposals in Mental Health	21
Any Qualified Provider	21
How choice will be commissioned	16
Incompatibility and unpopularity of the Choose and Book system	14
Regulation required to ensure that choice is offered to patients	14
The proposals will result in the fragmentation of care	13
Concerned about the quality of data that will be provided to patients	12
Access to Information Technology (IT)	12
The success of the proposals will be dependent upon staff buy in	12
Mental Capacity	10
IT systems are incapable	9
Carers have not been recognised enough	8
Area Not Addressed	7
The proposals will lead to the duplication of work and tests	7
Funding required to implement the proposals	6
Choice of treatment not mentioned enough	6
Pace of the proposed changes is too fast	5
Self referral	5
Children and young people's involvement in choices is not mentioned	5
Pathology/diagnostics	4
Healthwatch	4
Patients do not want choice just good local services	3
Care plans	3

Specific responses in support of the proposals³⁶	
Choice of GP practice	18
The extension of choice into the mental health sector	14
Choice of diagnostic testing provider	9
Personal care plans	8
Personal Health Budgets	8
Named Consultant Lead Team	8
The extension of choice into maternity services	6
The inclusion of choice in the standard contract	4
The option to self refer	3
Information strategy	2
The proposal to extend choice in mental health to any Clinically Appropriate Professional	2

³⁶ Many responses were supportive of the proposals in general but did not specifically refer to particular elements. These are not captured here.

Government response to the consultation
‘Liberating the NHS: No decision about me, without me’
Department of Health
© Crown Copyright
December 2012