

Liberating the NHS:

# No decision about me, without me

Further consultation on proposals to secure  
shared decision-making

**DH INFORMATION READER BOX**

<b>Policy</b>	Estates
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<b>Circulation List</b>	
<b>Description</b>	This further consultation document sets out our final policy proposals which aim to give patients greater choice and control. A number of focussed consultation questions seek views on whether we have identified the right areas as well as the right levers for making sure the NHS empowers patients and service users and delivers real choice across the majority of NHS services.
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<b>For Recipient's Use</b>	

## Foreword

Patients should be at the heart of everything we do. In *Liberating the NHS* we set out the Government's ambition to achieve healthcare outcomes that are among the best in the world by involving patients fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone: "no decision about me, without me".

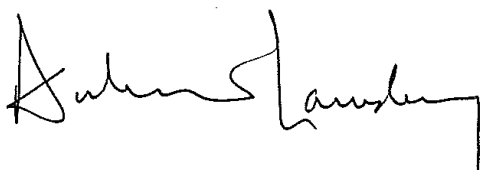
Genuinely shared decision-making is about giving everyone more say in decisions about their own care. It's about being sensitive to people's preferences and aspirations for their care and treatment and it's about having the right information to make informed decisions, supported by professionals.

We've been looking at how we can achieve this and at those areas where we can give patients and service users, their carers and families more say. Giving people more choice over their care and treatment all along their pathway is an important part of this. They should be able to share in decisions about their care in clinical areas other than elective care, such as mental health services, maternity care, long-term conditions and community services.

It means giving patients and service users the opportunity to share in decisions about their care all along their pathway: more say in primary care, before a diagnosis, when referred to secondary care and after a diagnosis has been made.

It means building on the work already underway to give patients more say over who provides their community and mental health services and to give patients more say over which team provides their hospital care.

Our proposals don't change the principles upon which the NHS was founded: healthcare free at the point of use and available to everyone based on need, not ability to pay. These proposals will put patients first so that services fit around them and not the other way around. This will mean more flexible services, greater convenience and crucially better outcomes for all: equity and excellence.



**Secretary of State for Health**

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## Executive summary

1. The White Paper, *Equity and Excellence: Liberating the NHS*<sup>1</sup> set out the Government's vision of an NHS that puts patients and the public first, where shared decision-making: "no decision about me without me" is the norm. It includes proposals to give everyone more say over their care and treatment with more opportunity to make choices, with information and support as a means of securing better care and better outcomes.
2. The Government published detailed proposals in the consultation document *Liberating the NHS: Greater choice and control*<sup>2</sup> seeking the views of patients, the public, healthcare professionals and the NHS on the choices that people want to make, when they want to make them and what information and support they need to be able to have more say and to share in decisions about their care. We published the *Liberating the NHS: An Information Revolution consultation*<sup>3</sup> alongside the choice consultation document, recognising the importance of appropriate, timely and accessible information to enable people to make informed decisions about their care.
3. The NHS Future Forum undertook a listening exercise from April to June 2011 and set out a number of recommendations in its report "Choice and Competition *Delivering Real Choice*"<sup>4</sup> about how the Government could ensure that patient choice and competition is taken forward in patients' and the public's interests. The report has informed our proposals.
4. Our proposals support the delivery of the Government's Open Public Services agenda as set out in the 2011 document, *Open Public Services White Paper*<sup>5</sup>. The Open Public Services 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 treating all patients and the public as grown-ups - by giving them more opportunities to be involved in decisions about their care and to exercise choices.
5. In the first chapter, we set out our approach to this consultation document. We provide details of the consultation process overall and set out the process and timetable for responding to it. The associated document, *Liberating the NHS: Greater choice and control, A summary of responses* published separately, sets

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<sup>1</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_117353](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353)

<sup>2</sup> [http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH\\_119651](http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_119651)

<sup>3</sup> [http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH\\_120080](http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_120080)

<sup>4</sup> [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_127541.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_127541.pdf)

<sup>5</sup> <http://files.openpublicservices.cabinetoffice.gov.uk/OpenPublicServices-WhitePaper.pdf>

out a summary of the responses received and how we have taken account of these in developing our proposals.

6. We have heard that patients want greater clarity over when and how they can share in decisions about their care, about the choices they have and when they apply. In chapter two, we propose a model of shared decision-making all along the patient pathway, which should be relevant irrespective of patients' conditions, their clinical pathway or progress along it. The model indicates where patients would be expected to have more say in decisions about their care in primary care; before a diagnosis; at referral to secondary care; and after a diagnosis had been made.
7. We also underline the importance of making sure that patients are empowered to make informed decisions about their care and treatment. Not least by being able to access high quality information and being supported by professionals to be confident in having their say in all decisions about their care. We recognise that empowered patients will be clear about what shared decision-making means and where it is and is not available, for example, where some choices would be clinically inappropriate or unsafe. Our Information Strategy, *The power of information - Putting all of us in control of the health and care information we need*, published 21<sup>st</sup> May 2012, sets out our approach to providing patients with information to help them have more say and take part in shared decision making. <http://informationstrategy.dh.gov.uk>
8. In chapter three, we set out how people will be able to share in decisions about their care in primary care. Primary care is where most people have their initial contact with health services and where patients with long-term conditions are often treated and managed. Not only do we want to make sure that people can choose to register with the GP practice that best suits their needs, we also want to ensure that whichever GP practice people are registered with, personalised care planning is offered consistently to those with long-term conditions who engage with professionals in primary care. We reiterate our commitment, set out in response to the Future Forum report, to phase in the introduction of any qualified provider with a focus on the services where patients say they want more choice, for example starting with selected community services.
9. In chapter four, we identify how people will have more say over who provides the tests they need before they receive a diagnosis. We propose that patients who need the most common diagnostic tests will be able to choose for them to be carried out by any qualified provider of those tests as well as having a say over where and when the test is carried out, unless there are compelling clinical reasons not to.

10. In chapter five, we set out how, this year, people will not only be able to make decisions about where they are treated but also over who provides their secondary care services. Patients who are referred for a first outpatient consultant-led appointment are already able to choose from any clinically appropriate provider in England and we have extended this by giving people a say about which named consultant-led team they see, where appropriate. In addition, we propose giving people more say in decisions about who they are referred to in specific areas such as maternity services and mental health care.
11. Chapter six outlines proposals for giving everyone more say in decisions about their care after they have been given a diagnosis. Patients should be able to choose their treatment wherever this is clinically appropriate, safe and affordable.
12. In chapter seven, we set out proposals to enable patients and their carers to take part in shared decisions in all aspects of their care. The Health and Social Care Act (2012) places certain duties on the NHS Commissioning Board and clinical commissioning groups, which support our proposals by requiring them to promote the involvement of patients and carers in decisions about their care and treatment and to enable patients to make choices. This complements the right already set out in the NHS Constitution for patients to make choices about their NHS care and to have access to information to support those choices. As recommended by the NHS Future Forum, we will set out clear expectations for the NHS Commissioning Board and commissioners on the choices patients ought to be able to make, as part of ensuring that patients have clarity over what choices they can reasonably expect to have.
13. Chapter seven also discusses how we will make sure that patients have the means of recourse if they are not given an opportunity to share in decisions about their care or to have a say. We consider how systems and processes will be developed to make “no decision about me, without me” the norm and the role that other organisations such as HealthWatch and Monitor will play in supporting that objective.

## 1. Introduction

- 1.1 The White Paper, *Equity and Excellence: Liberating the NHS* 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 includes proposals to give everyone more say in decisions about their care and treatment, more opportunity to make choices with information and support as a means of securing better care and better outcomes.
- 1.2 Giving patients and the public more opportunities to share in decisions that affect them is consistent with the aims and objectives of the Government’s Open Public Services agenda. The Open Public Services White Paper<sup>6</sup> outlined the Government’s desire to ensure that everyone has access to the best possible public services, and that the best become better still. This will be achieved by treating all patients and the public as grown-ups – by giving them more opportunities to be involved in decisions about their care and treatment and more choice and control over their healthcare.
- 1.3 The White Paper set out the principle that everyone should have an opportunity to share in decisions about their care and treatment. The consultation document *Liberating the NHS: Greater choice and control* set out some preliminary proposals to achieve this and asked a number of open questions about how the commitments to give patients more say as set out in the White Paper could be implemented.
- 1.4 The document, *Liberating the NHS: Greater choice and control, A summary of responses*, published alongside this document, includes detailed feedback from a range of patients, the wider public, third sector and other organisations, healthcare professionals and the NHS on our initial proposals and what we should do to make “no decision about me, without me” a reality for all. This feedback has informed the proposals set out here and our response to the specific points raised is set out at the end of each section of that document.
- 1.5 Over the last year, we have developed further our policy proposals to implement the White Paper choice commitments in light of the responses to the consultation and our face-to-face engagement with a wide range of individuals and organisations. In developing these proposals, we have taken account of the recommendations from the 2011 NHS Future Forum-led NHS

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<sup>6</sup> <http://files.openpublicservices.cabinetoffice.gov.uk/OpenPublicServices-WhitePaper.pdf>



Listening Exercise, specifically taking steps to ensure that choice is promoted where it is in patients' interests.

- 1.6 When responding to the NHS Future Forum's recommendations in June 2011<sup>7</sup>, the Government set out some important principles on choice and competition. It committed to ensuring that the NHS Commissioning Board and clinical commissioning groups would take active steps to promote the NHS Constitution, including its principles and values. It acknowledged that whilst choice of provider could bring benefits to patients, what really mattered was the quality of care provided. The Government also committed to giving Monitor a role in protecting and promoting the interests of patients and put duties on commissioners to promote integrated care to address the needs of patients and for Monitor to support this.
- 1.7 We have already published our response to the consultation for our proposals to give patients more say by extending choice of provider through the any qualified provider policy and by extending choice to named consultant-led team, where clinically appropriate. In both these areas, our response was brought forward because of the need to make rapid progress against the timetable set out in the White Paper and to ensure that momentum was sustained. Our any qualified provider response<sup>8</sup> and policy guidance was published in July 2011 and was followed by our response and contract guidance for choice of named consultant-led team in October 2011.<sup>9</sup>
- 1.8 In this further consultation document, we set out policy proposals aimed at giving patients more say through an opportunity to make shared decisions. We ask a small number of focussed consultation questions to seek views on:
  - whether we have identified the right areas as well as the right levers for making sure our proposals will give patients more opportunities to make shared decisions about their care and treatment, all along the pathway,
  - whether our proposals are realistic and achievable,
  - whether we have missed any key issues,
  - whether we have identified the right means of delivering our proposals.
- 1.9 Our proposals are consistent with the principles the Government committed to, following the NHS Listening Exercise. The responses to these proposals will

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<sup>7</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_127444](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127444)

<sup>8</sup> [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_128539.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128539.pdf)

<sup>9</sup> [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_130448.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_130448.pdf)

inform our final response which we expect to publish later this year. Alongside this document, we have published the associated consultation Impact Assessment and Equality Analysis documents.

- 1.10 The Health and Social Care Act (2012)<sup>10</sup> establishes new organisations, which will have a key role in implementing the proposals to give patients more say and opportunities to make shared decisions in the new healthcare system. These would 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.
- 1.11 In 2010 we published the *Liberating the NHS: An Information Revolution* consultation at the same time as the *Liberating the NHS: Greater Choice and Control* consultation document. We recognise that it is important for people to be fully involved in decisions about their own care and to have the information they need to make those decisions. The Information Strategy, *The power of information - Putting all of us in control of the health and care information we need*, published 21<sup>st</sup> May 2012, builds upon the *Information Revolution* consultation and sets out our approach to providing patients with information to help them make informed choices. <http://informationstrategy.dh.gov.uk>

## Responding to this consultation

- 1.12 This consultation will run for eight weeks from 23 May 2012 until 20 July 2012 and builds upon our initial 13 week consultation on *Liberating the NHS: Greater choice and control*.<sup>11</sup> You can respond online at <http://consultations.dh.gov.uk/choice/choice-future-proposals>, by email to [choice@dh.gsi.gov.uk](mailto:choice@dh.gsi.gov.uk) or by post to the Choice Team, Department of Health, Room 4N11, Quarry House, Leeds, LS2 7UE. We welcome views from patients, carers and users, the wider public, organisations, health professionals and the NHS. We also intend to undertake a series of events and activities to engage with and involve individuals and organisations to raise awareness of the consultation and to encourage them to share their views on our proposals. All responses will help inform the final policy guidance and exact details of how these proposals will be implemented in the new system.
- 1.13 In responding to this consultation, we would also like you to think about the associated costs, benefits and risks when providing patients with more

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<sup>10</sup> <http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/HealthandSocialCareBill2011/index.htm>

<sup>11</sup> [http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH\\_134188](http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_134188)

opportunities to share in decisions about their care as outlined in the accompanying Impact Assessment document.

- 1.14 We are committed to ensuring that our proposals are fully consistent with the requirements of the Equality Act 2010, public sector equality duty and other relevant equality legislation. We have published alongside this document an accompanying Equality Analysis and we would welcome feedback on this.
- 1.15 We ask a small number of questions at Annex A about whether we have identified the right options for giving people more say all along the care pathway and if they are realistic and achievable.

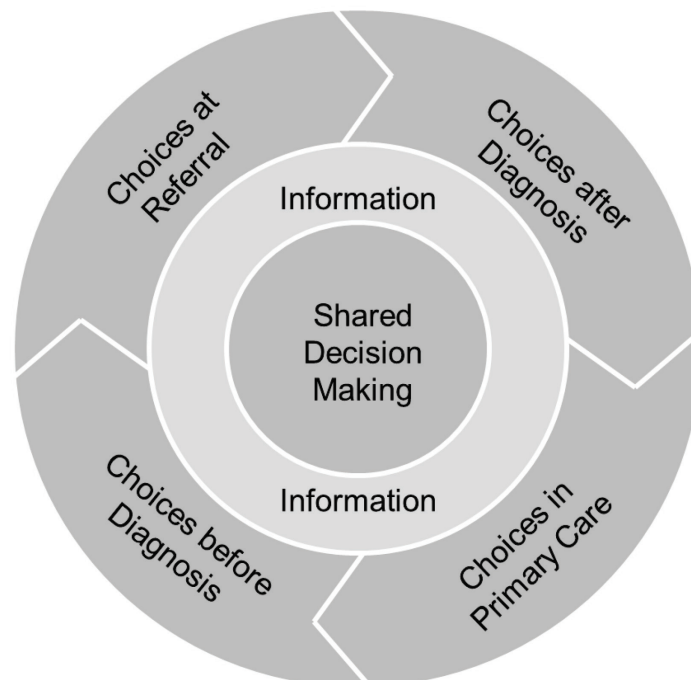
## 2. A model of shared decision-making

- 2.1 We clearly heard during our first round of consultation that patients, service users and the general public wanted greater clarity over where, when and how they could share in decisions about their care and treatment; over what choices they were entitled to make, and the mechanisms and support available to allow them to make informed decisions.
- 2.2 In this document, we propose a model of shared decision-making all along the patient pathway giving patients greater involvement in their own care and more say. We have developed the model to demonstrate and to confirm to patients, their families and carers, the choices that should be available to them all along the pathway.
- 2.3 Patients and service users should have more say in decisions about their care in primary care, before diagnosis, when referred to secondary care and after a diagnosis is made. The model indicates where patients would be expected to have opportunities to make shared decisions in line with the White Paper commitments. We want this to be achieved through more choices being available at all these stages of care and treatment, irrespective of a patient's clinical pathway and their progress along it.
- 2.4 At the heart of our model is the principle of shared decision-making, which underpins our proposals: "no decision about me, without me". Shared decision-making involves a patient and their clinician(s) working together to clarify options and goals for their care, treatment and self-management, sharing information about those options and aiming to reach agreement on the best course of action. Shared decision-making is fundamental throughout the entire healthcare pathway irrespective of setting.
- 2.5 The structure of this document mirrors the model, which is presented as a diagram, below. Our model of shared decision-making envisages information and more choice all along the pathway as the foundations for giving patients more say. Without the meaningful engagement and support of healthcare professionals we cannot ensure that everyone will have an equal opportunity to have a say and to make decisions about their care. We also view information as essential to provide a firm underpinning of informed patient choices. The Department of Health's Information Strategy , *The power of information - Putting all of us in control of the health and care information we*

need, sets out a vision for how we can help people to access the information they need to support them to make choices.

- 2.6 Our proposals build upon the responses received to the *Liberating the NHS: Greater choice and control* consultation, although it should be noted that a range of different responses were received and it would not be possible to reflect all of these. We have been clear about where we don't propose to give patients more choice because it is not considered to be safe, sustainable or affordable.

**Figure 1: Our model of shared decision making all along the pathway**



### **Making “no decision about me, without me” a reality for all**

- 2.7 Our summary consultation response, *Liberating the NHS: Greater choice and control, A summary of responses*, published alongside this document provides detailed information and analysis of the views and concerns surrounding shared decision-making. In brief, the responses indicated clear support for the aim of making shared decision-making between patients and healthcare professionals the norm and for patients to take greater responsibility for becoming involved when making decisions about their care and treatment. However, respondents were clear that for patients to become empowered to make shared decisions, the opportunities to do so cannot be constrained to a

particular stage of healthcare provision. Many people believe that a cultural change across all areas of healthcare is needed, with healthcare professionals taking the lead by routinely including patients, carers and their families as equal partners in decisions about their care and treatment.

- 2.8 The information strategy for health and social care in England; *The power of information - Putting all of us in control of the health and care information we need*, sets out a clear vision and next steps to enable people to access and share their own records. It also aims to promote better use of technology which, in turn, will help people take part in decisions about their own care in a genuine partnership with professionals. Linking with this Government's broader Open Public Services agenda<sup>12</sup> and Transparency agenda, the strategy also sets out how transparency and open data will also support the public, patients and carers, service providers and commissioners to make better, more evidence based decisions.
- 2.9 We also recognise that sometimes people may not value sharing in decisions and making choices and our proposals take account of this. For the avoidance of doubt, patients will continue to be entitled to delegate decisions to their healthcare professional. We are also clear that greater shared decision-making has to be seen in the context of what is clinically appropriate. Our proposals do not mean that patients will be able to make choices where they contradict professional views on clinical appropriateness, nor do we expect all treatments or options to always be available. We are proposing that the NHS will be transparent about the options that *are* available and involve people in deciding which option is best for them.

## **Information to support shared decision-making**

- 2.10 We have heard from respondents about the importance of a wide range of appropriate, accessible, understandable and timely information to allow patients to make informed decisions. This could be information about the quality of care, clinical outcomes, waiting times, patient experiences, infection rates, location and facilities offered by different providers. That is why we have recognised the central role of information in the model as underpinning and supporting patients' decisions at all points along the patient pathway.
- 2.11 We recognise that informed decision-making relies in part on professionals providing and sharing information with patients. However, other information such as that provided by information intermediaries that is directly accessible to patients is crucial in supporting patients to make meaningful and truly

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<sup>12</sup> <http://www.openpublicservices.cabinetoffice.gov.uk/>

informed choices taking account of clinical and non-clinical issues. We published the *Liberating the NHS: Greater Choice and Control* consultation document alongside the consultation on the Department of Health's Information Strategy for this reason. We are continuing to look at ways of ensuring that the Information Strategy will support the implementation of the commitments to extend shared decision-making across the majority of NHS services.

## **Urgent care and the limits for shared decision-making**

- 2.12 We do not propose that our model of shared decision-making will necessarily encompass urgent or unplanned care. The consultation responses suggested that when healthcare is required in these circumstances, it is more important that people understand they have access to the correct health services quickly, rather than having opportunities to share in decisions. Healthcare professionals and the public also recognise that some choice is already available in some form for urgent and unplanned care, through access to Accident and Emergency (A&E) services, NHS Walk-in Centres and NHS Direct.
- 2.13 We continue to look for ways to personalise services and to extend the set of choices that patients have. Plans are in place to ensure that every area of England has a coherent 24/7 urgent care service in place by April 2013. This will be supported by the new NHS 111 telephone number, which will enable patients with urgent healthcare needs to be directed to their most appropriate local health services.

## 3. Decisions in primary care

### Choice of GP practice

- 3.1 The GP practice is the front door of the NHS. With the exceptions of urgent or unplanned care, the majority of people will access NHS services through their GP practice. Many patients with long-term conditions will have their condition(s) managed mostly or solely in primary care. Currently, most people have to choose a GP practice near their home and make sure they live within its catchment area.
- 3.2 For many, this makes sense and they are happy with the service they receive from their local GP practice, but we believe that people should have the choice to register with the GP practice that best suits their needs. Some people may prefer to register with a practice that is near to their place of work as it provides the flexibility of being able to access an appointment that fits in with their working day. Others may wish to choose a GP practice close to where they live, or may wish to remain registered with their current practice when they move house.
- 3.3 In the 2010 GP Choice consultation<sup>13</sup>, 77% of the public (1,840 respondents) who responded supported the principle that people should be able to register with any Primary Medical Services Contractors (“GP practices”) with an open list. Some clinicians raised concerns through the consultation about our proposals to give people this choice. We have listened to these concerns and are piloting models to secure greater choice of GP practice in areas of central London, Nottingham and Manchester/Salford. Patients, such as commuters, will be able to access a GP practice away from where they live. The intention is to enable, in pilot areas, patients to be either on a patient list, or to visit a practice for a consultation without being on the list of the GP practice. The piloting of GP choice in this way will inform and strengthen any future proposals before we consider wider implementation.
- 3.4 We also want to support those patients who move house just a few miles down the road to remain on the patient list with the practice where they have a well established relationship if they would prefer to do so. In the past, they may have had to apply to be on the patient list with a new GP practice. Under new arrangements, there will be more opportunity for patients in this position to stay with their old practice. These new arrangements have been introduced and

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<sup>13</sup> [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_120284.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_120284.pdf)



will provide a strong foundation for giving patients greater choice of GP practice.

- 3.5 Information is already available on NHS Choices<sup>14</sup> to help people find and choose the right GP practice for them. We will build upon this to provide patients with more information about how practices are performing on delivery of care and services as part of the Government's Transparency agenda, so as to help patients make informed choices about their care.

## **Choice of Provider for Community Services**

- 3.6 We are committed to giving patients more say over who provides their community services. Where a commissioner offers patients a choice of any qualified provider it means that patients can choose from a range of providers that meet the necessary quality requirements and standards of the NHS. Although this is not a new policy, it is being extended to include a greater number of services. For 2012/13, commissioners were required to select at least three services as local priorities in which choice of any qualified provider will be offered<sup>15</sup>. These choices should be available by September of this year. The implementation will be phased with more choices becoming available over time as recommended by the Future Forum.
- 3.7 We published a full consultation response document, together with detailed guidance on the extension of choice of provider to any qualified provider on 19 July 2011. These are available on the Department of Health website<sup>16</sup>.
- 3.8 As part of the phased managed process to give patients more say over who provides their care, as recommended by the NHS Future Forum, the Department of Health identified eight service areas that national patient engagement told us were priority areas for any qualified provider policy:
- Musculoskeletal services
  - Adult hearing aid services
  - Continence services (adults and children)
  - Direct access diagnostic tests
  - Wheelchair services
  - Podiatry services

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<sup>14</sup> <http://www.nhs.uk/Pages/HomePage.aspx>

<sup>15</sup> [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_131428.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131428.pdf)

<sup>16</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_128455](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128455)

- Venous leg ulcer and wound healing
  - Primary care psychological therapies (adults)
- 3.9 The Department of Health has since been working to deliver an infrastructure to ensure the successful extension of choice of provider to any qualified provider. This includes working closely with a number of volunteer NHS commissioners to prepare implementation packs for each of the areas identified in our guidance. We are clear that competition will be on the basis of quality, not price. To that end, work has been undertaken to ensure that prices will be determined in advance by commissioners, using either a national tariff where it applies, or a locally agreed price.
- 3.10 For 2013/14, it is expected that more services will be offered under a choice of any qualified provider and the Department of Health will continue to support commissioners as they do this. It will remain for commissioners to decide which locally required services are priorities for extending choice to any qualified provider.

## **Personalised Care Planning**

- 3.11 People with long-term conditions engage mostly with primary care professionals and have their care, management and support organised by them. Whilst many of these people will have opportunities to inform and influence their care, treatment and management, we want this offer to be formalised for all patients being treated, cared for and managed in primary care. We know from the GP Patient Survey that 83% of people with a long term condition have had a discussion about their condition(s). Many of them also reported that they were given information about their condition(s) and felt the doctor or nurse took notice of their views. We see the care planning discussion as the main way in which patients will be able to participate in decisions about their care and to have greater choice of treatment, management and support where this is appropriate. Therefore, we will support personalised care planning, building on the work that is already happening at a national and local level.
- 3.12 More involvement in care decisions can be supported through the use of telehealth and telecare technology. This is about using electronic equipment to measure vital health signs that can be remotely monitored by health professionals and using telecare sensors to make the home environment safer. People who want to live independently are provided the opportunity to do so and can understand their own health needs using the same information to self care appropriately.

- 3.13 We have funded and run the Whole Systems Demonstrator (WSD) programme to evaluate the role of telehealth and telecare in helping people to manage their conditions. The headline findings from WSD have shown that unplanned admissions to hospital can be reduced along with reductions in mortality and have been instrumental in the development of the **3millionlives** initiative<sup>17</sup>. The aim of this initiative is to improve the lives of 3 million people with long-term conditions over the next 5 years using telehealth and telecare technologies, and help educate healthcare providers and patients on how these innovative items can best be used in health and care services.
- 3.14 The Quality, Innovation, Productivity and Prevention (QIPP) long-term conditions national work stream is looking at ways of reducing variation in the use of care planning for those with long-term conditions, of systematising self care and ensuring appropriate risk assessments are carried out to identify the people who will benefit from this approach. This includes making sure that the patient is at the centre of decision-making and a personal care planning approach delivers one integrated care plan focusing on the full needs of the individual. We recognise that proven good quality personalised care planning should be universally adopted and that the promotion of national standards, potentially through the development of a NICE quality standard, could support this. To help drive delivery of better care we are developing a year of care tariff approach for long-term conditions as part of the QIPP challenge so that the system of payments supports people receiving care in the most appropriate setting.
- 3.15 We are committed to publishing an updated long-term conditions compendium this year to promote and highlight existing good practice. Our aim is to reissue “Improving the health and well-being of people with long-term conditions”<sup>18</sup> as an information tool for clinical commissioning groups to ensure healthcare staff are better informed about the availability of local choices and the need for shared decision-making when developing personalised care plans.
- 3.16 The Government has also announced that we are developing a cross-government long-term conditions outcomes strategy. It will aim to identify shared or common issues that can help to prevent, delay and ultimately improve the management of long-term conditions. This in itself will help to promote patient and carer involvement but will also ultimately help to deliver better health outcomes. Recognising that long-term conditions affect far more than health, the strategy aims to improve quality of life and independence for people with long-term conditions, across all aspects of their lives, and to bring all parts of government together with a new focus to achieve this. We aim to publish the strategy later this year.

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<sup>17</sup> <http://www.3millionlives.co.uk>

<sup>18</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_111122](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111122)

## 4. Decisions before a diagnosis

### Choice of diagnostic test provider

- 4.1 We want patients to have more say before they receive a diagnosis. In future, the presumption should be that patients referred by their GP for the most common diagnostic tests would be able to choose the provider of these tests as well as where and when they are carried out, unless there are medical reasons not to. We would take steps, as set out here, to make this a reality, acknowledging some of the challenges that remain to be overcome.

### Any qualified provider: greater choice of diagnostic test provider in the community

- 4.2 We propose that a key mechanism for giving patients a choice of diagnostic test provider in the community will be through the use of the any qualified provider model. This model will allow patients who are referred for a particular service, to choose, where appropriate, from a range of providers that are qualified to provide safe, high quality care and treatment at NHS prices – and select the one that best meets their needs. ‘Diagnostics services closer to home’ is one of the eight priority areas for the implementation of any qualified provider in 2012/13.
- 4.3 A number of Primary Care Trust (PCT) clusters have chosen diagnostics services closer to home as a priority for implementation in 2012/13. We expect this to be focussed mainly upon Magnetic Resonance Imaging (MRI) and non-obstetric ultrasound in the first instance. An implementation pack has been developed to support commissioners to procure providers of these two diagnostic tests, including model service specifications. Some commissioners may expand any qualified provider into other diagnostic areas in 2012/13, for example, to include other community based tests such as cardiac and respiratory investigations. We will consider what, if any, further support would be needed for commissioners taking any qualified provider forward in diagnostics services not covered by the implementation pack.
- 4.4 We anticipate that the any qualified provider model will be used even more widely for diagnostics in 2013/14. We want the presumption to be that patients going for diagnostic tests in the community would have a choice over their test provider and we will continue to support the expansion of any qualified

provider for diagnostic services closer to home from 2013/14 and beyond, informed by any lessons learned from the first phase of implementation.

## **Choosing your secondary care diagnostic test provider**

- 4.5 Patients referred to a consultant-led first outpatient appointment for diagnostic tests are able presently to choose any provider in England that offers that service. This currently covers a broad range of diagnostic services and tests in the areas of imaging, endoscopy and physiological diagnostics. This will continue to be the case and will be confirmed in future guidance on both choice policy and the use of the Choose and Book system<sup>19</sup> and in further engagement with the service on the benefits of registering their services with Choose and Book.
- 4.6 We propose to go further to ensure that patients will have choices over their diagnostic test provider where the diagnostic test does not take place as part of a consultant-led first outpatient appointment, in other words, further extension of direct access to diagnostic tests for primary care. We know that some commissioners already offer patients a choice over where they may go to have common diagnostic tests and other services carried out. We want to build upon this to ensure that all patients across the country can make these choices.
- 4.7 In future, diagnostic tests which are not carried out as part of a consultant-led first outpatient appointment should be listed on the Choose and Book system and be directly bookable, provided this is clinically appropriate. This will permit people referred for a diagnostic test to choose who provides it and have more say and greater flexibility over when and where they have their test.
- 4.8 During 2012/13, we will set out which tests will be the priorities for comprehensive inclusion on Choose and Book from April 2013. We will work with the National Clinical Directors for Diagnostic Services to identify the priority areas, which could include high volume services such as audiology, non-obstetric ultrasound, gastroscopy and electrocardiograms (ECGs). We will also work with Choose and Book to ensure it is able to support these choices. Commissioners would be required to ensure that this choice is available to all eligible patients. New requirements on providers to list relevant diagnostic tests on Choose and Book and to provide information to support patients involved in making these choices would be set out in the Standard Contract.<sup>20</sup>

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<sup>19</sup> <http://www.chooseandbook.nhs.uk/>

<sup>20</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_111203](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111203)

- 4.9 A key obstacle to using Choose and Book as a means to give patients a choice of diagnostic imaging services is the incompatibility of the existing Radiology Information Systems (RIS) with Choose and Book. Work is ongoing to identify how best to improve the compatibility of the systems with a view to including imaging services on Choose and Book. During 2012/13, we will set out further detail on the timetable for giving patients more say in this area.
- 4.10 We acknowledge that enabling individuals to make decisions over who provides their diagnostic test is not appropriate at all stages of healthcare, for example, when a person is receiving inpatient hospital care or where diagnosis is needed urgently. For this reason we will exempt all direct access urgent referrals, such as cancer two week waits, although providers could continue to use Choose and Book to list these services and allow direct bookings to them. This year, we will explore the possibility of giving patients more choice over diagnostic test provider at other points along the patient pathway where appropriate, for example, in secondary care and aftercare stages.
- 4.11 We acknowledge that a choice of diagnostic test provider is not appropriate for some clinical support services, such as the carrying out of pathology tests. For clarity, we propose that patients would be able to make choices over patient facing elements of diagnostic tests, not of the provider of the analysis of samples.

### **Direct Access to Diagnostic Testing**

- 4.12 Direct access to diagnostics gives patients greater flexibility over when to have their diagnostic test. We are not proposing to replace or restrict existing direct access arrangements. Rather, we wish to add to this set of choices through the any qualified provider initiative.
- 4.13 In addition, we will work during 2012/13 to consider how tariff can best support greater choice of diagnostic test provider.

## 5. Decisions at referral

### Choice of provider

- 5.1 Since April 2008, patients have had the right to choose from any clinically appropriate provider in England when referred for their first outpatient, consultant-led appointment for acute elective care. This right is underpinned by legally binding Directions from the Secretary of State to PCTs, which were published alongside the NHS Constitution and took effect from 1 April 2009. The Directions require PCTs to ensure that patients needing an elective referral are offered a choice. The Directions also place duties on PCTs to publicise and promote patients' entitlement to choice and to publish and report to their Strategic Health Authority (SHA) the number of choice related complaints, and the action taken by PCTs.
- 5.2 We want to go beyond this to extend the principle of choice of any qualified provider from across the public, private and third sectors to other areas of healthcare in line with the *Equity and Excellence: Liberating the NHS* commitment to embed shared decision-making through more patient choice in the majority of NHS funded services.

### Choice of named consultant-led team

- 5.3 This year, NHS patients in England will have the freedom to choose not only where they are treated but also who provides their hospital care. Patients will be able to choose a specific named consultant-led team when referred to secondary care. Patients will be able to have more say over the named consultant-led team that delivers their care and treatment, providing them with more involvement at a time when they may wish to be in more control of their care.
- 5.4 Recently published guidance for providers and commissioners and a full response to the consultation questions on the choice of named consultant led team proposals, may be found on the Department of Health website<sup>21</sup>.

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<sup>21</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_130426](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_130426)

## Choice of provider for maternity services

- 5.5 We understand that each pregnancy is different and our vision is of all women, together with their midwives (and other clinicians where appropriate), being able to plan their care throughout the maternity pathway with the information they need to make informed choices and the confidence that the services they choose are safe, appropriate to their needs and available when needed. Providers of preconception, maternity and newborn care will help deliver this vision by working together in local networks.
- 5.6 Local networks will bring together all the services a pregnant woman or new mother might need, by linking together GPs, local hospitals, specialist units, Sure Start Children's Centres, charities and community groups so they can share information, expertise and services. When a woman becomes pregnant, she will access maternity care through a local provider. That provider can ensure women receive the services specified in their personalised care plan either directly or working with other providers in their local network. Local networks can also provide better access to specialist services such as midwives with special skills in providing care for women with disabilities, mental health or substance misuse issues, HIV, or for teenage mothers.
- 5.7 Nationally, work is progressing to determine which services will form Strategic Clinical Networks (SCN) and how they will work in terms of role and remit. This work has already proposed a single operating model and these networks will be accountable to the NHS Commissioning Board. If maternity is designated as SCN the Commissioning Board will expect all provider and commissioner stakeholders to be included in local networks. The Chief Medical Officer and other Directors of the Commissioning Board will make the decisions about SCNs later in the year. If maternity is not designated as an SCN, local networks will as now be locally established and resourced, but again the expectation would be that commissioners would want to see all provider stakeholders included.
- 5.8 We want to make sure that women and their partners have informed and safe choices about where to give birth. 'Birthplace', a study based on data from 65,000 births in England provides for the first time, evidence for those with 'low-risk' pregnancies about the risks and outcomes associated with different planned places of birth – at home, in a midwifery-led unit and in obstetric units.
- 5.9 The 'Birthplace' study was published on 25 November 2011<sup>22</sup> and its findings can help women make informed choices about where they feel most comfortable planning a birth, help healthcare workers in providing advice and

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<sup>22</sup> <https://www.npeu.ox.ac.uk/birthplace>



aid commissioners and providers in planning maternity services and clinical guidelines.

- 5.10 We have heard that parents to be and new parents can struggle to find information they can trust on the internet and elsewhere to help them through pregnancy, birth and beyond so that they can become more confident parents. The Government has launched the NHS Information Service for Parents – a new digital service. Parents will be able to sign up from early in pregnancy to receive regular free emails and SMS messages offering high quality NHS advice, and signposts to other quality assured information.
- 5.11 Together with the Family Nurse Partnership<sup>23</sup>, we have recently published “Preparation for Birth and Beyond: *a resource pack for leaders of community groups and activities*’.<sup>24</sup> The pack is a practical tool that aims to improve outcomes for babies and parents through a refreshed approach to antenatal education that moves beyond traditional models. The information and support provided through this pack enables participating groups to provide and explore possible choices that mothers and families may have, during and after the birth of a child. Recent engagement has highlighted that choice of provider may offer an opportunity to improve access and quality of services for expectant parents. There has been a call for a stronger understanding on the opportunities for extending patient choice in this area. Choice of provider may enable niche and voluntary sector organisations to offer targeted services to parents with higher health and social care needs or those who find it difficult to access traditional models of provision.
- 5.12 We know that it is important that service user experiences inform their choices. A new maternity user indicator was introduced as part of the NHS Outcomes Framework 2012-2013<sup>25</sup>, to measure a woman’s experience of care throughout the care pathway (antenatal, labour and birth and postnatal). In addition, to support the NHS in delivering improved outcomes, the National Institute for Health and Clinical Excellence (NICE) are developing a suite of quality standards.<sup>26</sup>

## **Choosing who provides your mental health services**

- 5.13 For too long the choices that are available for patients referred to secondary elective care services have not been available to those individuals referred to secondary care mental health services. This means, for example, that there has

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<sup>23</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_118530](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_118530)

<sup>24</sup> <http://www.dh.gov.uk/health/2011/10/preparation-for-birth-and-beyond-resource-pack-to-help-parenthood-groups/>

<sup>25</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_122944](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122944)

<sup>26</sup> <http://www.nice.org.uk/guidance/qualitystandards/qualitystandards.jsp>

been less involvement in decisions about care and less choice for people referred for assessment for depression over when, where and who provides their care.

- 5.14 We want there to be parity for users of mental health services with those receiving other forms of elective care, wherever possible. We acknowledge that there are some features of secondary mental health services that may place limits on shared decision-making and choice. The need for some services for some patients to be integrated across social care and NHS services may require their provider to be in the same geographical location as their local authority thereby limiting the scope for patients to choose secondary mental health service providers that are far from home. Equally, tariffs for mental health services will need to be developed further. Nevertheless, we want the principle to be that there are choices for service users unless there are good grounds not to have them. These will be limited to clinical grounds for limiting choices, because of the need for joined up services or because supporting arrangements such as tariffs and currencies are insufficiently developed to support choices.
- 5.15 To give mental health service users greater say and choice of who provides their services, we propose permitting service users to choose any named consultant-led team within their secondary mental health service provider, irrespective of where they live, provided that it is clinically appropriate. There may be some exceptions when care is needed urgently or where specific named consultant-led teams have highly specialised referral criteria. This will mirror the arrangements in place for other acute elective care services. This choice will be progressively implemented during 2012/13 with full coverage being achieved in April 2013.
- 5.16 We propose to go further and extend this choice to any team led by a clinically appropriate professional as defined in Schedule 1 of the MHA 1983 Approved Clinician (General) directions 2008<sup>27</sup> such as community psychiatric nurses, occupational therapists or clinical psychologists. We recognise that in mental health services, it is not always a consultant who organises and takes responsibility for the care of those receiving secondary care mental health services. Therefore, we will open up this choice to other professional-led teams in line with the proposed timing for implementing our proposals on choice of named consultant-led team.

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<sup>27</sup> 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.

- 5.17 We propose greater choice for those using services available under the Improving Access to Psychological Therapies (IAPT) programme<sup>28</sup>, and that these choices will be available on an equal footing whether offered in primary or secondary care. We have discussed, above, the use of the any qualified provider model and the Department of Health has worked with NHS Commissioners to develop an implementation pack for psychological therapies delivered in the community. Where these services are provided in secondary care, the choice of professional-led team will lead to more say over when, where and how these services are offered.
- 5.18 The benefits of more choice in this regard are clear. A survey carried out by the mental health charity MIND, in 2010<sup>29</sup>, shows that people who said that they had a choice of therapy were three times more likely to be content with their therapy, than those who wanted a choice but did not receive it.
- 5.19 More work remains to be done to increase choice for secondary care mental health service users. We have commissioned a study of mental health service provision with the aim of:
- providing policymakers with a clear, comprehensive analysis of the current landscape of NHS-funded mental health provision,
  - assessing, at a general and service-specific level, the barriers to provider movement into and within NHS-funded mental health service provision,
  - indicating possible future trends in market development and their implications for policy development.
- 5.20 In addition, the Implementing Recovery Organisational Change (ImROC) project<sup>30</sup> is aiming to help NHS mental health services, their local independent sector partners and service user and carer groups, to improve the quality of local services in order to support the recovery of those using mental health services and to lead meaningful and productive lives. We will evaluate and share outcomes from the project.
- 5.21 Nevertheless, commissioners should be thinking of ways of ensuring that mental health service users can have the same choices as those for other elective care services. We propose challenging commissioners to pilot and test new ways of extending shared decision-making, including through greater use of the any qualified provider model from 2013/14 (see chapter 7, below).

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<sup>28</sup> <http://www.iapt.nhs.uk/>

<sup>29</sup> [http://www.mind.org.uk/assets/0001/0027/Mind\\_We\\_need\\_to\\_talk\\_Report.pdf](http://www.mind.org.uk/assets/0001/0027/Mind_We_need_to_talk_Report.pdf)

<sup>30</sup> <http://www.nhsconfed.org/Networks/MentalHealth/OurWork/imroc/Pages/NMHDU-Implementing-Recovery-Organisational-Change-Project.aspx>

## Choice of self-referral

- 5.22 Self-referral to services permits people to have more choice. The report, *Self-referral pilots to musculoskeletal physiotherapy and the implications for improving access to other allied health professional (AHP) services*<sup>31</sup> supported the findings of earlier research carried out in Scotland. The pilots identified a number of benefits including earlier presentation and supporting self-care by empowering patients to be more actively involved in managing their condition. The report is available on the Department of Health website<sup>32</sup>.
- 5.23 Self-referral to improve access and to give patients more choice has already operated successfully in many NHS trusts and is often the norm in the independent sector. It is expected that self-referral would normally be available where there are benefits to patients of having it. It is for local NHS 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.

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<sup>31</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_089516](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089516)

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[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_089516?IdcService=GET\\_FILE&dID=175274&Rendition=Web](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089516?IdcService=GET_FILE&dID=175274&Rendition=Web)

## 6. Decisions after a diagnosis

- 6.1 Through the *Liberating the NHS: Greater choice and control* consultation we heard many respondents express the view that real informed choices can only be made after a diagnosis, once there is some certainty about the problem and potential treatment and management pathways are known or clear.

### Choice of treatment

- 6.2 We are clear that patients, their carers and families should be involved in decisions about their care along the patient pathway and this applies equally to decisions about their treatment, management and support once a diagnosis has been made. 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. For example, a patient with arthritis of the knee may decide to receive physiotherapy in the first instance rather than opt for more invasive tests or surgery, when the different treatments and expected results have been explained, possibly facilitated through the use of a patient decision aid<sup>33</sup> to explore their treatment options.
- 6.3 The presumption should be that patients make choices within the set of options that are clinically appropriate and financially affordable. There may be times when providing a choice of treatment is not appropriate, possibly due to the specialised nature of a condition or where urgent treatment is needed, however it is expected that any decision is agreed with the patient and that they remain involved throughout the care pathway.
- 6.4 As recommended by the NHS Future Forum's report, implementation of the Mandate by the NHS Commissioning Board will encourage providers and professionals to involve fully, patients and their carers and families, where appropriate, in looking at all treatment, management and support options and in all decisions about their care. Appropriate information about treatments that are approved by NICE will be made available, for example on NHS Choices<sup>34</sup> to support choice. Information about non-clinical issues, such as food, attitude of staff and cleanliness will also be available to inform patients' decisions.

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<sup>33</sup> [https://www.nhsdirect.nhs.uk/DecisionAids/PDAs/PDA\\_KneeArthritis.aspx](https://www.nhsdirect.nhs.uk/DecisionAids/PDAs/PDA_KneeArthritis.aspx)

<sup>34</sup> <http://www.nhs.uk/Pages/homepage.aspx>

## Choosing an alternative provider

- 6.5 Some respondents to the consultation said that they would prefer to be treated by the same provider or named consultant-led team after a diagnosis has been made. However, we recognise that others may want to change because of a poor experience, or where an alternative, more appropriate treatment or management option is available. This latter case is consistent with existing clinical practice, for example consultant-to-consultant referrals following diagnosis. For the avoidance of doubt, patients wishing to stay with the same provider after a diagnosis has been made should normally be able to do so unless this is not clinically appropriate.
- 6.6 The NHS Constitution<sup>35</sup> sets out a patients' right to access services within maximum waiting times, or for the NHS to take all reasonable steps to offer patients a range of alternative providers if this is not possible, and where patients request this. Further information within the handbook to the NHS Constitution states as from 1 April 2010, patients have the right to start their consultant-led treatment within a maximum of 18 weeks from referral for non-urgent conditions; and be seen by a cancer specialist within a maximum of two weeks from GP referral for urgent referrals where cancer is suspected.
- 6.7 Pilots will be carried out during 2012/13 to identify the best ways in which the NHS can offer patients the choice of being treated by a range of alternative providers where their non-emergency consultant-led treatment within the NHS Constitution maximum waiting time is at risk – this will include a particular focus on orthopaedics services. The lessons from these pilots will be available for full roll-out from April 2013.
- 6.8 The 'How do I get a second opinion?'<sup>36</sup> section on the NHS Choices website, advises patients about requesting a second opinion as well as signposting them to other pieces of useful information.
- 6.9 Where patients are not satisfied with their care or treatment they already have means of recourse and in some cases may request a second opinion<sup>37</sup>. However, we are clear that choice post-diagnosis will not mean introducing a formal right to a second opinion in all cases or introducing an automatic right to be referred elsewhere.

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<sup>35</sup> <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx>

<sup>36</sup> <http://www.nhs.uk/chq/pages/910.aspx?categoryid=68&subcategoryid=156>

<sup>37</sup> <http://www.nhs.uk/chq/pages/910.aspx?categoryid=68&subcategoryid=156>

## Research

- 6.10 We recognise that some individuals will have an interest in taking part in research or clinical trials relevant to their condition, but they often have little knowledge about how they may register their interest. We will look at the different ways that information about clinical trials can be made more easily available. Full details about how the UK Clinical Trials Gateway works are available at [www.ukctg.nihr.ac.uk](http://www.ukctg.nihr.ac.uk) where you can also find full details of how to search the site effectively.
- 6.11 The National Institute for Health Research<sup>38</sup> has developed the UK Clinical Trials Gateway. The Gateway provides information about clinical trials and will be accessible by patients, carers and the public.

## Personal Health Budgets

- 6.12 Personal health budgets are being piloted in the NHS in England. The pilots involve people with a range of long-term conditions such as chronic obstructive pulmonary disease, stroke, diabetes and neurological conditions and mental health needs. People receiving NHS Continuing Healthcare are also being offered personal health budgets as part of the pilot programme. Personal health budgets aim to improve people's health and wellbeing by giving them more say about how their healthcare needs are met. They offer the potential for greater integration of health and social care at the level of the individual.
- 6.13 At the heart of a personal health budget is a care plan. This sets out the individual's health (and social care) needs and includes the desired outcomes, the amount of money in the budget and how this will be spent. The care plan is developed in partnership and agreed between the individual and the healthcare professional. Once an individual's care plan has been developed it will be subject to clinical governance and sign off.
- 6.14 The pilots will run until October of this year when an independent evaluation report will be published. We have already set out that subject to the evaluation, by April 2014, everyone who is eligible for NHS Continuing Healthcare will have the right to ask for a personal health budget including a direct payment.
- 6.15 Like the any qualified provider model, personal health budgets are a potential means of giving people more say over the NHS-funded services they receive. They are a way of commissioning services at the level of the individual. Patients can make decisions on which services to commission based on their

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<sup>38</sup> <http://www.nihr.ac.uk/Pages/default.aspx>

personal needs and preferences. They will be able to buy services from a wide range of service providers, including those who are listed on the national directory of providers resulting from the extension of patient choice to any qualified provider. The services could range from traditionally core NHS services or non-traditional services such as hydrotherapy, acupuncture, or gym membership.

## **End of Life Care**

- 6.16 We remain committed to establishing a national choice offer for people and their families who choose to die at home, including care homes, to receive the support that they may need. The responses to the consultation supported the introduction of this right of choice, as one of the processes of supporting the delivery of high quality, patient-centred care. We will continue to implement the End of Life Care Strategy<sup>39</sup> to ensure that the right services are in place, particularly in the community, and to allow the right of choice to die at home to be introduced.
- 6.17 In 2013, we will review progress in implementing the End of Life Care Strategy, which will include looking at the feasibility and timescale for introducing this right. Following the review, we will be in a better position to assess if a right can be introduced and a realistic timescale.
- 6.18 Plans are in place to develop a per-patient funding system to support effective commissioning and delivery of end of life care through the generation of data about service costs and development of a national tariff. We expect to start a two-year pilot project this year, which could allow a standardised unit for pricing end of life care services to be introduced from 2015.

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<sup>39</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_086277](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277)



## 7. Making it happen: Shared decision-making to become the norm

- 7.1 We are committed to ensuring that these proposals will genuinely give patients more say and opportunities to make shared decisions about their care and treatment. We propose using the full range of means available now and in the future as set out in the Health and Social Care Act (2012) in order that we meet our commitment to making “no decision about me, without me” a reality for all patients. Where there are already well developed means of implementing the proposals we have set out details here, but these will continue to be developed.
- 7.2 Patients will continue to have the right to choice and information to support their choices as set out in the NHS Constitution. As set out in the handbook to the NHS Constitution, the right to choice and information is currently a free choice of provider where a patient is referred for a first consultant-led outpatient appointment for most elective care. Various exemptions apply which presently extend to mental health services and urgent referrals, for example. This right could be extended over time.
- 7.3 Under the Open Public Services agenda, there will be a number of initiatives that could support the implementation of the proposals set out in this document. Specifically, we will instigate an independent review of the barriers to choice in public services to identify the factors that prevent people from understanding and exercising the choices available to them. A call to evidence has been launched examining whether there is value in enshrining in legislation a right to choice across public services<sup>40</sup>. Steps will be taken to raise the profile of choice in public services through a ‘You have the right to choose’ campaign and foster a new Choice Champions Network<sup>41</sup>.

### Your choices

- 7.4 Regulations are one of the levers in the new system, which could be used to give effect to changes or extensions to choice policy. These regulations would be a set of legal requirements for the NHS Commissioning Board and clinical commissioning groups.

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<sup>40</sup> <http://consultation.cabinetoffice.gov.uk/ops-calltoevidence/>.

<sup>41</sup> [http://files.openpublicservices.cabinetoffice.gov.uk/HMG\\_OpenPublicServices\\_web.pdf](http://files.openpublicservices.cabinetoffice.gov.uk/HMG_OpenPublicServices_web.pdf)

- 7.5 The Government’s commitment to making “no decision about me, without me” a reality is also evidenced by the duty in the Health and Social Care Act (2012) on the NHS Commissioning Board and clinical commissioning groups to promote the involvement of patients and carers in decisions about their care and treatment and to act with a view to enabling patients to make choices with respect to aspects of health services provided to them.
- 7.6 We will use existing patient feedback routes to determine whether patients are having their say and we will develop mechanisms to address patient concerns where they are not given opportunities to make decisions about their care and treatment. HealthWatch England will enable the views of people who use health and social care services to influence national policy, advice and guidance. In addition, Local HealthWatch organisations will be able to advise the new clinical commissioning groups on the shape of local services to ensure they are informed by the views of the local community. They will champion patients’ views and experiences and be able to promote the integration of local services, especially through their seat on the local Health and Wellbeing Board, which will be responsible for preparing the local joint strategic needs assessment and local joint health and wellbeing strategy.
- 7.7 Local HealthWatch will also signpost people to information to help them make choices and be able to provide NHS complaints advocacy where the local authority considers it appropriate to arrange this (from April 2013). Seventy-five local HealthWatch pathfinders are testing plans ahead of the full establishment of HealthWatch England and local HealthWatch across the country in October of this year. HealthWatch England will be able to establish a Citizen’s Panel or equivalent arrangements to enhance shared decision-making for patients. It will be able to publish regular assessments on how well organisations have done on delivering the expectations for more patient involvement in decisions and choice as described in the Mandate.

## **The Mandate**

- 7.8 In line with the recommendations of the NHS Future Forum, we will publish a ‘Choice mandate’ as part of the Secretary of State’s Mandate to the NHS Commissioning Board. This will be used by the Board to develop its specific plans to make choice a reality where it is in the patients interest. The Board will publish a business plan at the start of each year setting out how it will achieve these objectives. The Mandate could constitute the Choice Framework for NHS Services as outlined in the Open Public Services call to evidence<sup>42</sup>.

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<sup>42</sup> <http://consultation.cabinetoffice.gov.uk/ops-calltoevidence/>

- 7.9 Under the Health and Social Care Act 2012, the Board and clinical commissioning groups will have a duty to act with a view to enabling patients to make choices. The Mandate will help to clarify expectations with respect to the Board’s duties concerning patient choice.
- 7.10 Our proposals to increase shared decision-making through more choice in light of the White Paper commitments would be set out in the Mandate. Where there are no specific proposals for how to increase choice in any given service area we would be asking commissioners to develop their own proposals to extend choice where it is in the patients interest, through, for example, use of the any qualified provider approach. The Department of Health could ask the NHS Commissioning Board through its Mandate to pilot and test new choice offers and to evaluate them in line with the NHS Commissioning Board and clinical commissioning groups’ duties with respect to choice.

## **The standard contract**

- 7.11 The standard contract<sup>43</sup> would be a key means of making shared decision-making: “no decision about me, without me” a reality by placing requirements on providers with respect to choice. Providers would be required to:
- list all services eligible for patient choice on the Choose and Book system,
  - list services against a lead healthcare professional (e.g. consultant) as and where appropriate, including on Choose and Book,
  - accept all clinically appropriate referrals made through Choose and Book,
  - publish the information needed to support these choices,
  - 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.

## **Choose and Book**

- 7.12 Choose and Book is an electronic referral and booking system, which allows patients to see the appointments available to them at different providers. As such it is a key means of ensuring that patients are offered a choice and have an opportunity to make one.

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<sup>43</sup> Primary medical services contracts must comply with the statutory requirements in accordance with Part 4 of the National Health Service Act 2006 and regulations and direction made under that Act.

- 7.13 We are working to maximise use of Choose and Book so that more referrals are made through it and more patients are given an opportunity to make choices over their care and treatment. We have already made a commitment as part of the Cabinet Office transparency agenda to publish the utilisation rates for Choose and Book by general practice. Publication of this data will allow GP practices to demonstrate continuing practice performance and enable patients and the local public to exert pressure in areas where Choose and Book utilisation needs to be increased to support greater choice for patients. Where Choose and Book is not being used, formal requirements to support greater choice for patients will have to be met by alternative, potentially labour intensive, methods.
- 7.14 We are also looking at the feasibility of developing Choose and Book and NHS Choices further to provide a combined information source and booking system that is directly accessible by patients. This would include a comprehensive directory of available diagnostics and treatments across the country. It would also include non-clinical information on different pathways, providers and consultant-led teams. Support will be available to patients to interpret outcomes data and other technical information.
- 7.15 This year, we will publish Referral to Treatment Times (RTT) information by specialty on the Choose and Book system, where applicable, so that patients will be able to make a more informed choice when referred to secondary care with an expectation of the likely waiting times for treatment at their chosen provider.

## **Supporting patient decisions**

- 7.16 Existing education and training guidance and requirements already contain references to shared decision-making, for example, as part of the General Medical Council's assessment criteria for trainee doctors. However, we will continue 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 will continue to develop a range of both 'long-form' and 'short-form' patient decision aids through the Right Care Shared Decision-Making programme<sup>44</sup>.
- 7.17 Some respondents to our consultation were concerned that more patient involvement in decisions about their care could potentially lead to more disagreements between patients and their clinicians. Existing guidance and professional standards address potential disagreements or differences of

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<sup>44</sup> <http://www.rightcare.nhs.uk/shareddecisions/>

opinion between clinicians and patients on clinical matters or clinically inappropriate choices. However, it is worth noting that the vast majority of decisions made about treatments do not involve any dispute between patient and clinician.

- 7.18 Empowering patients relies upon them having access to a wide range of appropriate information that is clear and accessible. We are aligning our proposals for giving patients more say with the development of the Information Strategy. This will mean that patients will increasingly have access to and control over a wide range of information, including their health and care records. This will promote a more balanced relationship between patients, healthcare professionals and providers, facilitating effective shared decision-making, giving patients more say and opportunities to choose their treatment or service provider, and will ensure patient safety particularly in more complex cases where there could be a risk of fragmentation in care.

### **Our information strategy**

- 7.19 We are working towards making sure that good quality, easily understandable, and timely information is available to support informed choice. This will be standardised and benchmarked to help people compare treatments, providers and named consultant-led teams. Information will include: treatment options, waiting times, hospital acquired infection rates, facilities offered and condition specific patient experience data. The Department of Health's Information Strategy, *The power of information - Putting all of us in control of the health and care information we need*, recently published, sets out our approach to providing patients with information to help them become more involved when they make shared decisions about relevant healthcare choices.

## **Annex A: The consultation questions**

### **No decision about me, without me.**

- 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 B. The consultation process

### Criteria for consultation

B.1 This consultation follows the ‘Government Code of Practice’. In particular, we aim to:

- formally consult at a stage where there is scope to influence the policy outcome;
- consult for at least 12 weeks with consideration given to longer timescales where feasible and sensible;
- be clear about the consultations process in the consultation documents, what is being proposed, the scope to influence and the expected costs and benefits of the proposals;
- ensure the consultation exercise is designed to be accessible to, and clearly targeted at, those people it is intended to reach;
- keep the burden of consultation to a minimum to ensure consultations are effective and to obtain consultees’ ‘buy-in’ to the process;
- analyse responses carefully and give clear feedback to participants following the consultation;
- ensure officials running consultations are guided in how to run an effective consultation exercise and share what they learn from the experience.

B.2 The full text of the code of practice is on the Better Regulation website at: [Link to consultation Code of Practice](#)

### Comments on the consultation process itself

B.3 If you have concerns or comments which you would like to make relating specifically to the consultation process itself please contact:

Consultations Coordinator  
Department of Health  
3E48, Quarry House  
Leeds, LS2 7UE

**E-mail**      [consultations.co-ordinator@dh.gsi.gov.uk](mailto:consultations.co-ordinator@dh.gsi.gov.uk)

**Please do not send consultation responses to this address.**

## **Confidentiality of information**

- B.4      We manage the information you provide in response to this consultation in accordance with the Department of Health's Information Charter.
- B.5      Information we receive, including personal information, may be published or disclosed in accordance with the access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).
- B.6      If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.
- B.7      The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties.

## **Summary of the consultation**

- B.8      A summary of the response to this consultation will be made available before or alongside any further action, such as laying legislation before Parliament, and will be placed on the Consultations website at

<http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/index.htm>



**Liberating the NHS: No decision about me, without me**  
*Further consultation on proposals to secure shared decision-making*  
**Department of Health**  
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**May 2012**