

Liberating the NHS:

Greater choice and control

A consultation on proposals

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Foreword

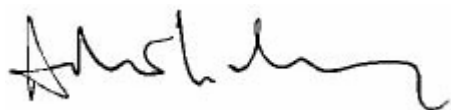
The NHS is a great institution. In *Liberating the NHS*, published in July, we described our ambition for it to excel in the future. Equity and excellence in the NHS will give the people of this country confidence in the quality and outcomes of the healthcare they receive, in addition to their confidence in access to healthcare based on need, not ability to pay.

We need to raise the quality of the patient experience. So, we will put patients at the heart of everything we do, free healthcare professionals to make the decisions that matter to patients, and focus on results rather than targets.

Giving people more choice and control is key to putting them at the heart of the NHS, giving them more say in making decisions about their care. It's about being sensitive to people's preferences and aspirations about their health, healthcare and treatment. It's about giving them the opportunity and support to make the choices that will make a difference to them. It's also about giving people the information they need to exercise control and the confidence to use it – this needs an '*information revolution*' and a change in culture in how clinicians relate to patients and carers.

Of course, often patients are already encouraged to exercise choice and to share in decision-making. But we know - from what patients tell us, from our own experiences, and from what has happened to people close to us - that it doesn't happen in every case. We know that the positive experiences are often the result of the positive attitudes of NHS staff, not the reliable result of quality in the design of services around patients' needs, choices and expectations. So we will push forward with reform.

That's why we have published this consultation document alongside *Liberating the NHS: An information revolution*. So that, together, we can work towards giving people the choices that matter to them and to provide the information and support needed to realise control of their health and healthcare.



Secretary of State for Health

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Executive Summary

1. The White Paper, *Equity and Excellence: Liberating the NHS*, sets out the Government's vision of an NHS that puts patients and the public first - where patients, service users, carers and families have far more influence and choice in the system, and the NHS is more responsive to their needs and wishes.
2. The proposals envisage a presumption of greater choice and control over care and treatment, choice of any willing healthcare provider, wherever relevant and choice of treatment and healthcare provider becoming the reality in the vast majority of NHS-funded services by no later than 2013/14.
3. We are seeking the views of patients, the wider public, healthcare professionals and the NHS about how we take forward these proposals. We want to know what sorts of choices you want to make, when you want to make them, what information and support you need to make the right choices for you, and how we make this happen.
4. In our introduction we set out why greater choice can be good for patients and the NHS. This first chapter introduces this consultation document and outlines why we are publishing it.
5. *Liberating the NHS* sets out a number of specific choice commitments around extending choice of provider and treatment in planned hospital care and, more specifically, in maternity, mental health, end of life care and long term conditions. Our proposals for offering more choice for patients and service users are outlined in chapter 2. We explore what extending choice could mean and how it could work in practice, using case studies to show what choice could look like. We also ask for views on whether the proposed choices are the ones that people would want.
6. Choice and shared decision-making ought to be the rule not the exception, and should be built into health professionals' everyday practice. In chapter 3, we talk about how shared decision-making can become the norm. Patients' experience should always be that no decision is made about them without them. Only then can the Government's ambition to achieve healthcare outcomes that are among the best in the world be realised. This would mean a cultural change in the NHS, with patients, service users, their carers and families being put in control. Of course, shared decision-making extends beyond choice, but wherever choice is relevant it should be available. We ask for your views on how we can make

shared healthcare decisions a reality, the support that is needed to help this happen and what can be done to get people involved in healthcare decisions.

7. Without the right information, support and infrastructure being in place, the vision of informed, empowered patients making choices over the things that matter to them is unlikely to be achieved. Chapter 4 is about making it happen. The ‘information revolution’ described in *Liberating the NHS* would ensure that people have the information they need to make informed choices, presented in a way that they can understand. A separate but related consultation document, *Liberating the NHS: An information revolution*, looks at information in more depth. Other things that may help to make choice a reality include:
 - The arrangements we need to support choice of any willing provider, such as pricing;
 - The technology, like Choose and Book, that people can use to make their choice;
 - Possible new duties on healthcare providers and professionals; and,
 - Personal health budgets.

We ask for your views on how these, and any other things you might want to suggest, could support choice.

8. The choices that people make should be safe and sustainable. In chapter 5, we look at how we can achieve this. There will be major challenges in making sure that everyone can exercise choices that do not cause problems for them or the NHS. From engaging with patients and professionals to making sure that services are properly joined up – we will need to tackle these challenges to give everyone an opportunity to make safe and sustainable choices. We ask for your views on issues such as whether there should be limits on choice, and how we can make sure services are joined up and that choice is offered to everyone.
9. This consultation document covers many different issues and therefore asks a large number of questions. The questions may not be relevant to everyone but you are invited to answer **any** question that you have a view on. You can respond online at <http://www.dh.gov.uk/liberatingthenhs>, by email to choiceconsultation@dh.gsi.gov.uk or by post to the Choice Team, 11th floor, New King’s Beam House, 22 Upper Ground, London SE1 9BW, making sure that your response reaches us by **14 January 2011**. After the consultation closes, we will publish our response, which will describe our detailed proposals and next steps.

1. Introduction

Equity and Excellence: Liberating the NHS

- 1.1 The White Paper, *Equity and Excellence: Liberating the NHS*, sets out the Government's vision of an NHS that puts patients and the public first - an NHS where patients, service users, families and carers have far more influence and choice, and an NHS that is more responsive to their needs and wishes.
- 1.2 There should be a **presumption that everyone should have choice and control** over their care and treatment, and choice of **any willing provider**, wherever relevant. We expect this to become the reality in the majority of NHS-funded services by no later than 2013/14.
- 1.3 We want the principle of **shared decision-making** to become the norm, where people can expect that no decision will be made about them without them. The Government's ambition is to achieve healthcare outcomes that are among the best in the world. This can only be realised by involving people in their own care, with decisions made in partnership with healthcare professionals.
- 1.4 *Liberating the NHS* makes clear the Government's policy intentions. Further work lies ahead to develop and implement detailed proposals. In progressing this work, the Department will be engaging with external organisations, seeking their help and wishing to benefit from their expertise. This document provides further information on proposals to extend choice reflecting the various commitments made in the White Paper on this issue. Many of the commitments made in the White Paper require primary legislation and are therefore subject to the approval of Parliament.
- 1.5 While these proposals apply to the NHS in England, we welcome views from across the UK and recognise that proposals have implications for patients who might live elsewhere in the UK but who use NHS-funded services in England.

Why will greater choice be good for patients and the NHS?

- 1.6 First, many people want and value choice. Over 95% of people feel that they should have choice over the hospital they attend and the kind of treatment they

receive.¹ People want to make choices for a number of reasons - to receive healthcare that gives them the best chance of better health outcomes, to access healthcare in a way that is most convenient for them, and others.²

- 1.7 Secondly, having greater choice and control may be particularly beneficial for some people, because it can help to build confidence and aid recovery. A review by the Sainsbury Centre for Mental Health and the King's Fund found that choice had a central role in improving the daily experience of people with mental illness and supporting their recovery.³ Shared decision-making is central to developing effective personalised care-plans for people with long-term conditions such as diabetes, building ownership of, and a shared responsibility for, managing their conditions, especially where life-style changes may be needed. We know that people with long term conditions who work together with clinical teams and openly share in discussions about responsibility and risk have better clinical outcomes.⁴
- 1.8 Thirdly, choice has an important role in promoting equality and reducing inequalities by helping people from different backgrounds to access the highest quality of services. For example, people living in some of the most deprived communities historically have the greatest health needs yet a poorer choice of GP practice.⁵ More about the impact of choice on equalities can be found in the initial Equality Impact Assessment accompanying this document.
- 1.9 Lastly, choice encourages healthcare providers to tailor their services to what people want and to improve their quality and efficiency. A recent report published by the London School of Economics found that choice has already led to an increase in the quality of hospital services,⁶ although a report by the King's Fund showed that there is still some way to go before choice is a real force for improving quality.⁷

¹ British Social Attitudes Survey, Natcen, <http://www.natcen.ac.uk/study/british-social-attitudes-25th-report/findings> (2009)

² A. Dixon et al, Patient choice - how patients choose and how providers respond, Kings Fund, <http://www.kingsfund.org.uk/publications/> (2010)

³ Our Choices in Mental Health, Care Services Improvement Partnership (2005)

⁴ J. Hibbard, Coaching To Patient Activation Levels Improves Disease Management Outcomes, <http://www.medicalnewstoday.com/articles/153469.php>

⁵ NHS Staff 1999-2009, <http://www.ic.nhs.uk/statistics-and-data-collections/workforce/nhs-staff-numbers/nhs-staff-1999--2009-general-practice>

⁶ Z. Cooper et al., Does Hospital Competition Save Lives? Evidence from the English NHS Patient Choice Reforms, LSE, eprints.lse.ac.uk/28584/1/WP16.pdf (2010)

⁷ A. Dixon et al, Patient choice - how patients choose and how providers respond, Kings Fund, <http://www.kingsfund.org.uk/publications/> (2010)

This consultation document

- 1.10 This consultation document tells you more about our plans to give people greater choice and control over their healthcare and asks you what you think. You are encouraged to answer any question that you have a view on. We use case studies to show what choice could look like - they describe best practice, but this could vary between individuals or regions. It is intended that the results of this consultation will help to develop further proposals for implementing greater choice and control. Further consultation on the detail of implementing those proposals will follow.
- 1.11 In this consultation document, whenever we refer to giving people choice, involving them in decisions and making sure they have information and support, it applies equally to adults and children who are patients, service users and carers, their families, and others who represent and support decisions and choices as appropriate. A separate consultation document, *Liberating the NHS: An information revolution*, has also been published which looks at information in more depth.
- 1.12 It is important to note that proposals in this document are subject to the outcome of the consultation. Some, especially those involving legislation, would also be subject to Parliamentary approval.

Responding to this consultation

- 1.13 This consultation will close on **14 January 2011**. You can respond online at <http://www.dh.gov.uk/liberatingthenhs>, by email to choiceconsultation@dh.gsi.gov.uk or by post to the Choice Team, 11th floor, New King's Beam House, 22 Upper Ground, London SE1 9BW, making sure that your response reaches us by **14 January 2011**. After the consultation closes, we will publish our response. This will set out an overview of your answers and emerging policy options, and will ask further questions about some of the detail of implementation.
- 1.14 In responding to this consultation, we would ask you to think about the possible costs, benefits and risks associated with giving patients and service users more choice and control as outlined in this document. Any evidence provided on the costs, benefits and risks associated with the proposals as set out will be taken into consideration and inform the impact assessment which we will produce and refine as policy options become clearer.
- 1.15 We would also welcome any comments on, or additional evidence for, the accompanying Equality Impact Assessment.

2. Greater choice and control

“We expect choice of treatment and provider to become the reality for patients in the vast majority of NHS-funded services by no later than 2013/14.”⁸

- 2.1 Everyone should have choice and control over their care and treatment, and choice of any willing provider wherever relevant. The only exception should be where it might be inappropriate clinically or impracticable to expect people to make choices - for example, where there is an over-riding need to access the right care very urgently.
- 2.2 Greater choice and control may mean something very different to different people, depending on factors like their personal preferences and their healthcare needs. It might mean that one person wants different choices from another person. Or, it might mean that some choices are more or less important to a person at different times or at different stages in their treatment or care. So, the choices that people should have over their care should not always be the same.

Q1. How should people have greater choice and control over their care?
How can we make this as personalised as possible?

Any willing provider: the basic presumption

“We will create a presumption that all patients will have choice of any willing provider...”

- 2.3 Whenever people need healthcare they should be able to choose from any organisation in England that offers a service that is clinically appropriate for them, meets the quality standards expected from providers of NHS-funded services, and can deliver services within NHS prices. This will also apply to all independent and voluntary sector healthcare providers. Many people are already able to choose their healthcare provider when they are referred for their first hospital appointment. We would begin to extend this to all healthcare services and at all stages along a person’s care pathway.

⁸ The quotes in *italics* are from the White Paper, *Equity and Excellence: Liberating the NHS*, 2010

- 2.4 The commitments listed in the following paragraphs are some of the ways that people who need particular types of healthcare would be able to choose the organisation that provides their healthcare. Sometimes, healthcare will have a broad meaning, like all of the various assessments, treatments and procedures that may be needed for a particular illness or condition (for example chronic diabetes). Other times, it will have a narrow definition applying to a specific treatment or procedure (for example hernia repair).
- 2.5 We are proposing that this would be a reality for most healthcare by 2013/14, but it will be possible to introduce a choice of any willing provider in some services before others. We have begun by looking at how to make sure people can choose any willing provider of healthcare delivered in the community, because these are important services supporting a large number of people, where we want to drive up quality and encourage innovation. This will mean that people who need some types of therapy, treatment or other healthcare will be able to choose any community service provider in England that offers a service that is clinically appropriate for them, meets the quality standards expected from providers of NHS funded services, and can deliver those services within NHS prices.

Sanjay recently had a fall and has a large wound on his leg which is being dressed three times a week. Unfortunately, this has now developed into an ulcer and requires more long-term treatment. Sanjay struggles to attend the surgery twice a week, having to book in advance. If he needs his leg to be seen to at weekends, he has to ring the district nurse and wait in for her visit. Sanjay would really like to see someone first thing in the morning and closer to his own home. His GP offers him a choice of seeing the practice nurse at the GP surgery, going to the hospital clinic, being treated at home by a district nurse or being treated by a twilight nurse - evening care or a regular appointment nearer his own home based in a local village hall which has been adapted into a leg ulcer clinic with skilled and specialist nurses.

Sanjay's choice

Sanjay would really like a more local approach to care, at regular times so that he is able to maintain his own lifestyle. He chooses the local village clinic.

Q2. Which healthcare services should be our priorities for introducing choice of any willing provider?

Q3. How can we offer greater choice of provider in unplanned care?

Choosing a healthcare provider when first referred for planned hospital care

*“We will increase the current offer of **choice of provider** significantly...”*

- 2.6 Most people who are referred by their GP, dentist or optometrist for their first outpatient appointment with a consultant-led team already have the right to choose their healthcare provider.
- 2.7 We want to make sure that people are actually offered this choice of any willing provider. Many people are still being sent to a hospital or other organisation without first being asked where they want to go. Our surveys and a report by the King’s Fund tell us that less than half of people recall that they were offered a choice of healthcare provider by their GP⁹ - and this figure has changed little for several years.

Brenda has had arthritis in her joints for several years. It makes movement very stiff and painful - particularly in her hips. Her GP recommends that she speaks to a consultant, or a member of that consultant’s team, about a hip replacement. He explains that she can choose where she goes for her first appointment from any willing provider of a clinically appropriate hip replacement service. Brenda’s GP looks on Choose and Book - the electronic referral and booking system - and gives her a shortlist of appropriate services. Brenda goes home and looks up information about them on the NHS Choices website.

Brenda’s choice

Brenda chooses a hospital that is a convenient location for her, has positive feedback from other people who have had a hip replacement there, and good outcomes.

⁹ Report on the National Patient Choice Survey, Department of Health, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_116958 (2010)

- 2.8 Making greater choice and control a reality will mean that many people will need to change their attitudes and behaviours. From health professionals, who might not be used to encouraging their patients and service users to be more involved, to patients, service users, their families and carers, who might be used to following health professionals' advice without question, and healthcare providers who might need to change the contracts they have in place. We say more about shared healthcare decisions in chapter 3 and about making it happen in chapter 4.

Q4. What would help more people to have more choice over where they are referred?

Choosing a named consultant-led team

*“We will introduce **choice of named consultant-led team** by April 2011 where clinically appropriate.”*

- 2.9 Current guidance to the NHS says that people can only be referred to see a named consultant if it is clinically necessary – for example, if a consultant is one of very few specialists in a patient's condition. Otherwise, they should be referred into a clinic, where they might be seen by any consultant-led team.
- 2.10 The Choose and Book electronic referral and booking system also allows some people to choose a particular team of health professionals, led by a named consultant. But in reality the choice is often made by the health professional who makes the referral.
- 2.11 We want everyone who needs to see a consultant to be able to make an appointment with a particular team headed by a named consultant. To make sure that all choices are safe and appropriate, the chosen consultant-led team must offer a health service that is clinically appropriate for the person making the choice. It will be for the healthcare professional making the referral to decide what is clinically appropriate. It may be that, in choosing a particular named consultant-led team, a patient needs to wait longer to be seen. The individual should be given the opportunity to make their choice, balancing up their wish to be referred to a specific named consultant-led team, with the information they have on how long they will need to wait.

- 2.12 Of course, some people will have no preference about the consultant-led team they see. In that case, they can choose to be referred to the clinic instead and it will be up to the clinic to decide which consultant-led team they see.

Jason has been feeling tired and noticed some swelling around his feet and ankles. His GP has run tests and suspects it was caused by a problem with his kidneys. She would like to refer him to hospital to see a kidney specialist. She explains that Jason can choose the healthcare provider that he goes to for his first outpatient appointment and also the named consultant-led team that he sees.

A friend at Jason's support group for people with hearing difficulties has recommended to him a team of healthcare professionals headed by Dr Johnson, because they are very experienced at treating deaf people. He talks to his GP about this, and she explains that Dr Johnson's team are very popular, so Jason would need to wait longer for his first appointment. A different hospital could see him earlier.

Jason's choice

Jason decides that he would still like to see Dr Johnson's team. He asks his GP for an appointment with them, knowing that, although he will be waiting longer for his first appointment than if he chose a different hospital, he will be able to see a team that understands his particular needs.

- 2.13 NHS providers use standard contracts to deliver their services. Those contracts refer to guidance in relation to choice that informs the providers' obligations under the contract. To make sure that some progress is made on delivering this commitment by April 2011, we propose to amend the choice guidance for the contracts that providers use to deliver their NHS funded services for 2011/12 - see paragraph 4.15.

Making choices about maternity services

"We will extend maternity choice and help make safe, informed choices throughout pregnancy and in childbirth a reality – recognising that not all choices will be appropriate or safe for all women – by developing new provider networks."

- 2.14 There is already guidance to the NHS which emphasises offering women choice throughout their pregnancy and after birth, including choice of how to access maternity services, the type of pregnancy care services they use, where they give birth, and how and where they access care after they have given birth. However, not every woman is offered choice in practice.
- 2.15 We propose that providers of maternity services will work together as networks to improve the quality of services whilst extending the range of choices available to women and their families. Providers of maternity services will ensure that every woman and her baby has access to the right level of care, with the right resources and staff with the right skills and experience.
- 2.16 Women would be able to make choices about the type of care and support they receive during pregnancy, labour and birth, and after they have given birth, and where they access that care and support. They would be able to make choices from the services offered by other providers, including voluntary and independent sector providers, so that their choices are not limited by where they live.
- 2.17 The choices offered could include:
- **For pre-conception care** (before pregnancy):
 - Information¹⁰ so that women can make choices about their preconception care - for example, healthy lifestyle choices to improve their overall health, choosing whether to take supplements like folic acid, and whether they should change their care and treatment for long term conditions like diabetes;
 - Choice of a range of services to improve women's health before and during pregnancy - for example, stop smoking services.
 - **For antenatal care** (during pregnancy):
 - Choice of who provides antenatal care and where this takes place - for example a health setting such as a hospital clinic, GP practice, or children's centre;
 - Opportunities to discuss and decide whether to access the scans and screening tests available to detect problems with the pregnancy or the foetus at an early stage;

¹⁰ The kind of information people would want and how they would prefer to receive it are issues covered in the related consultation document *Liberating the NHS: An information revolution*

- Choice of where to receive antenatal education, which may include workshops and classes. These could be near to where the woman and/or her partner and family live or work, or at any other location;
- Choice of where to plan to give birth - for example, at a hospital or midwifery unit or at home (although for some women a hospital will be the safer option);
- Choice of where to access services for women who have additional needs - for example, those who smoke, have diabetes, obesity or mental health problems, or experience domestic abuse.
- **For labour and birth care:**
 - Choice of where to give birth when in labour - women can change their planned choice at any time during pregnancy and when in labour;
 - Choice of pain relief during labour. The choices available will depend on where a woman has chosen to give birth - for example, epidural anaesthesia will only be available in hospitals with a 24 hour obstetric anaesthetic service.
- **For postnatal care (after birth):**
 - Choice of where to receive postnatal care for both mother and baby and who provides postnatal care;
 - Choice from a range of appropriate additional services - for example, breastfeeding support.

2.18 To make sure that all choices are safe and appropriate for both mother and baby, the choices available to each woman would be different according to her individual health and social care needs and those of her baby. There may be times when a woman is advised against proceeding with her preferred choices because of the risks involved. It would be for the woman, with appropriate support if necessary, to discuss with her maternity team and understand the risks and benefits of each option, so that she can come to an agreed solution that is in the best interests of her and her baby.

Mei is 10 weeks pregnant. Her local maternity services form part of a network and offer a range of services for pregnancy, birth and after birth. Since her first appointment with her midwife, they have been talking about her preferences for her maternity care.

Mei is now starting to think about where she would like to give birth. She speaks to her midwife about the choices that she has within her network and also some of the neighbouring networks. Mei decides that she would like to give birth at home, supported by her midwife. Mei's midwife explains what a home birth means for the sort of care Mei can receive during labour and birth, including the pain relief she would be able to have. She also explains that home birth might not be clinically appropriate if the pregnancy becomes more complicated.

Mei's choice

Mei and her midwife start to plan for a home birth, but Mei knows that she can change her mind at any time. Mei also knows that circumstances could change so that a different option would be safer for her and/or her baby, and is aware of the arrangements that may be put in place should this happen.

Q5. Which choices would you like to see in maternity services and which are the most important?

Making choices about mental health services

*“We will begin to introduce choice of treatment and provider in some **mental health services** from April 2011, and extend this wherever practicable.”*

- 2.19 The choices that mental health service users can make are increasing as new services develop. For example, a growing number of therapies and other services are available to people with mild to moderate depression or anxiety under the Improving Access to Psychological Therapies (IAPT) programme. IAPT guidance makes it clear that people should be offered choices about where, how and what services are provided and by whom.
- 2.20 However, we want mental health service users to have more choice: choice of how they access mental health services (including contacting the relevant

professionals directly, without speaking to a GP first); choice of the clinically appropriate healthcare professional or team that assesses them to determine their mental health needs (for example a mental health nurse or a psychiatrist); and access to a range of clinically appropriate therapies and/or medication available on the NHS.

- 2.21 Choice of any willing provider would extend to mental health services. This would mean that any person who needs treatment for their mental health needs would be able to choose any healthcare provider that is considered clinically appropriate by their healthcare professional.
- 2.22 We would work towards making sure that everyone can choose between a range of different treatments and therapies for mild to moderate anxiety and depression. These choices would be phased in from April 2011.
- 2.23 People with mental health problems should have access to personalised care planning so that they can plan how to meet their healthcare and social goals in a way that takes into account their choices and preferences. To ensure that everyone's preferences are taken into account, even at times when they are not able to make choices, people can be encouraged to make statements of their wishes and choices about their future care and treatment as part of their care planning. These care plans should be inclusive, covering both health and social care and linking to personal and social care budgets where relevant.
- 2.24 Of the one million people who use mental health services each year, a small fraction are detained or on supervised community treatment under the Mental Health Act. It may be necessary to restrict some choice for these individuals for reasons of safety or urgency, but nevertheless choices should be extended to them whenever practicable.

Richard is receiving ongoing treatment and support from his local community mental health team for his diagnosis of schizophrenia. He also receives support from his sister, Jessica, who lives 30 miles away. Richard has had an urgent admission to a mental health hospital in the past when his mental health deteriorated to such an extent that he needed intensive in-patient care. This hospital was too far away from Jessica's home for her to visit easily while he was in hospital and he missed her visits and support.

As part of his personalised care planning, Richard has discussed this with the nurse leading his care (his care co-ordinator) and has asked that if an admission to a mental health hospital is needed in future he is admitted to a hospital nearer to Jessica so that she can visit and support him more easily.

Richard's choice

With the help of his care co-ordinator, Richard finds information on NHS Choices and they jointly identify a mental health hospital near to Jessica, which provides the type of support he might need if an admission is needed. They also discuss what might happen if an urgent admission is necessary, and Richard understands that his choice of hospital might not be able to be met on that occasion if an admission to a hospital near to his home, rather than Jessica's home, is in the best interest for his safety at that time.

Q6. Are these the right choices for users of mental health services, and if not why not?

Making choices about diagnostic testing

*"We will begin to introduce choice for **diagnostic testing**... from 2011."*

- 2.25 There are different types of diagnostic testing, including: methods of looking inside the body, such as X-rays, MRI and CT scans, or endoscopy (using a camera on the end of a tube); measuring body functions such as hearing or breathing; and taking samples such as blood or tissue samples which are sent away to be examined.
- 2.26 We want people to be able to choose where they undergo some tests and have some samples and measurements taken, when their healthcare professional refers them to undergo tests or have samples and measurements taken.
- 2.27 It would be for the healthcare professional making the referral to ensure that choices are safe and appropriate. People would be able to choose to have their samples and measurements taken or to undergo tests at a place that is appropriate for their individual health needs.

Alice has been experiencing stomach pains for six weeks. She goes to her GP, who suggests that she should have an abdominal ultrasound - which would capture images of the inside of Alice's body - to investigate the cause of her pain.

Alice's GP explains that she can choose where to have her ultrasound. She can choose from a range of different healthcare providers, including NHS

hospitals and many independent providers.

Alice's choice

Alice's GP tells her about a local independent health and treatment centre, which provides ultrasounds for NHS patients and could see her at the weekend. Alice does not want to take time off work, so she chooses to go there for her ultrasound.

Q7. When people are referred for healthcare, there are a number of stages when they might be offered a choice of where they want to go to have their diagnostic tests, measurements or samples taken. At the following stages, and provided it is clinically appropriate, should people be given a choice about where to go to have their tests or their measurements and samples taken:

- At their initial appointment - for example, with a GP, dentist, optometrist or practice nurse?
- Following an outpatient appointment with a hospital consultant?
- Whilst in hospital receiving treatment?
- After being discharged from hospital but whilst still under the care of a hospital consultant?

Q8. Are there any circumstances where choice of where to go for diagnostic testing would not be appropriate, and if so what are they?

Making choices after a diagnosis

*“We will begin to introduce... choice **post diagnosis** from 2011.”*

- 2.28 After people have been referred to see a consultant by their GP, dentist or optometrist, and they have been given a diagnosis by that consultant (or a member of the consultant's team), they should not have to be treated by that same healthcare provider or consultant if they do not want to be. They should have the option to go elsewhere if they choose to do so, perhaps because they've had a poor experience or other treatment options are available

elsewhere. On the other hand, if people are happy to do so, they can choose to stay where they are.

- 2.29 It would be for the healthcare professional making the referral and the healthcare provider or named consultant-led team that a person wishes to move to, to ensure that people are offered a choice of services that are safe and appropriate for their health needs, and that any transfer between clinical teams and/or organisations is managed effectively and safely.

Fatima goes to her GP with a pain in her back which is getting worse. Her GP tells her that he thinks this is a problem with her spine and he suggests that she sees a consultant at hospital to discuss the diagnosis and options for treatment. They talk about where she should go, and Fatima chooses to see Mr Frasier's team at a local hospital. Her GP books an appointment for her while she is there using the Choose and Book electronic referral and booking system.

Mr Frasier confirms that Fatima has disc compression and explains that he could perform surgery to make it better. He says that afterwards, Fatima would need to rest for as much as several weeks. Knowing this, Fatima decides it would be better if she stays with a friend after the surgery, until she is more mobile. Her friend lives over 50 miles away.

Fatima's choice

Fatima tells Mr Frasier that she would like to have her surgery in a hospital closer to her friend, so that she would not need to travel far after the surgery. She speaks to her friend about the hospitals and reads the patient feedback on the NHS Choices website. She chooses a hospital close to her friend's home and a member of Mr Frasier's team arranges for her care to be transferred.

Q9. Would you like the opportunity to choose your healthcare provider and named consultant-led team after you have been diagnosed with an illness or other condition?

Q10. What information and/or support would help you to make your choice in this situation and are there any barriers or obstacles that would need to be overcome to make this happen?

Q11. Is there anything that might discourage you from changing your

healthcare provider or named consultant-led team - for example, if you had to repeat tests, wait longer or travel further?

Making choices as part of personalised care planning

*“We will introduce **choice in care for long term conditions** as part of personalised care planning.”*

- 2.30 We want everyone who lives with a long term condition to be able to make informed choices about their care and managing their condition. They should have an opportunity to discuss and ultimately agree a plan of how their care will be managed, expressing their preferences and making choices.
- 2.31 Personalised care planning is about engaging people in making choices about how they want to manage their care. It’s about setting personal goals and receiving appropriate support to achieve those goals as equal partners with health care professionals. It’s about treating a person as a whole, recognising that there are other issues in addition to medical needs that can impact on a person’s total health and wellbeing.
- 2.32 There are 15.4 million people in England who live with one or more long term conditions. Some have more than one condition such as both diabetes and heart failure, which means they need a lot of support from both health and social care. For them care planning should be led and coordinated by one professional and will take more time and be more detailed. Others may have one condition such as moderate asthma that needs support from a health professional only. For them care planning should still be about meeting their wider needs, supporting them to self care and making sure they have the information they need to understand their condition and prevent it from deteriorating, but the process will not be as lengthy or detailed and would not involve social care.
- 2.33 For people with more complex needs, good quality personalised care planning will support better joined up working across health and social care professionals. Having a single assessment and care planning discussion that is led by one professional such as a nurse, doctor or social care worker followed by an agreed joined up care or support plan can really make a difference to the way professionals share information and work together. It is much better for individuals, since they do not have to repeat their story over and over, and should reduce fragmentation of care.
- 2.34 Effective care planning is already being delivered by many health and social care professionals, for example community matrons, specialist nurses, allied

health professionals and social care workers. However, we need to ensure that high quality personalised care planning is standardised across the country and that it is delivered proportionate to need.

- 2.35 Personal health budgets also play a big part in choice and personalised care planning. Individuals who decide to take a personal health budget must be offered a care planning discussion and agree a care plan. This is discussed further on in this consultation at paragraphs 4.25 to 4.28.
- 2.36 Current data¹¹ suggest that around 70% of people with a long term condition have a care plan. To increase this so that everyone with a long term condition can benefit from care planning, and to make sure that care planning is genuinely inclusive and personalised, the Department of Health is rolling out a programme of support for all Primary Care Trusts (PCTs) as part of the wider Quality, Innovation, Productivity and Prevention (QIPP) programme. PCTs taking part are working in teams with their local partners in social care, the voluntary sector and patient representatives to ensure quality, planned, proactive and integrated care planning becomes mainstream across NHS and social care.

Lorna is 79 and lives alone. She's had diabetes for years, was diagnosed with skin cancer at 74, has arthritis and mild heart failure. Lorna is offered case management with a community matron, Andrea. At the first home visit, they talk about Lorna's daily life, the things she wants to do, can do for herself and what she finds difficult. Andrea gives Lorna a telephone number so that she can get help quickly if necessary. The different medications Lorna takes are confusing so they come up with a simple way of marking and colour coding the containers to make sure she takes the right dose at the right time. They discuss the different options that might support Lorna to stay at home, including blood sugar monitoring and devices that monitor falls. Andrea arranges to visit when Lorna's daughter (who is her main carer) is there. Andrea also arranges a visit from Claire, a social care worker. After Claire's assessment, Lorna gets a cash personal budget which means she can employ her neighbour to help with her personal care needs as well as getting to the bingo hall once a week. She also buys a laptop so that she can do her shopping on-line and keep in touch with family. Lorna's daughter is also offered an assessment of her own needs as a carer and is given a personal budget which she uses to go on two weekend breaks.

Lorna's agreed care plan is called a care/support plan to show that it covers the services she is receiving from both health and social care professionals.

¹¹ The GP Patient Survey July 2009 – June 2010

The plan records her goals for remaining independent, feeling less isolated, staying out of hospital, being able to control her diabetes and continuing to cook and enjoy her food.

Q12. What else needs to happen so that personalised care planning can best help people living with long term conditions have more choice and control over their healthcare?

Making choices at the end of life

“In end of life care, we will move towards a national choice offer to support people’s preferences about how to have a good death, and we will work with providers, including hospices, to ensure that people have the support they need.”

- 2.37 We want to give people more control over the care that they receive as they approach the end of their lives. People should be given a choice about where they die. Most deaths occur in hospital, but, when asked, most people say they would like to die at home in familiar surroundings, close to family and friends.¹² Therefore, we propose to establish a national choice offer for those people who choose to die at home (including a care home) to receive the support that they need. A lot needs to be done to improve end of life care services to make this possible, so we will undertake a review in 2013 to decide when this national choice offer could be introduced. In the meantime, commissioners and providers should seek to improve both the range and quality of end of life care services and the choices available to patients and their families. For example, the availability of 24 hour community nursing services is crucial in supporting people who choose to die at home.
- 2.38 The choices that people can make about their end of life care will depend on their individual health needs. Where someone has very complex health needs, for example, it may be necessary to use health equipment or services that can only be provided in a hospital, or a specialist centre such as a hospice. There will also be cases where the level of social care support required, including

¹² National Audit Office report, *End of Life Care*, http://www.nao.org.uk/publications/0708/end_of_life_care.aspx (2008)

any support needed by carers, may mean that some choices will not be possible.

- 2.39 Health and social care professionals will need to undertake good care planning and advance care planning with patients and their families to capture people's preferences about their end of life care, enabling services to be tailored around them. Carers often play a vital role in supporting people as they die, and their needs and feelings need to be taken into account when decisions about where someone would like to die are being made.
- 2.40 Services to support people at the end of life are currently delivered by a range of providers, such as hospitals, GP practices, community services and hospices. However, to support a more personalised and integrated service, and deliver on people's choices about their care, we also want to encourage more organisations and new partnerships to provide end of life care.

Gemma has been taken to hospital for the fourth time this year. Her chronic lung disease has been getting worse, and she again has a bad cough and is very short of breath. She asks her hospital doctor why the treatment no longer makes her feel much better, and he tells her that he does not think she will live for longer than a few months.

He asks Gemma to think about where she would like to be cared for now and into the future. He explains that she could decide not to keep coming back into hospital, and that her GP and the district nurses could look after her at home. They would be able to visit her regularly to help and support her and her family. He also explains that, if needed, they would be able to get help from specialist palliative care health professionals, who provide care for people at the end of life.

Gemma's choice

Gemma speaks to her partner, who is also her carer. It is important to them that Gemma is comfortable, in familiar surroundings, and that this does not put too many demands on her partner. They decide that Gemma should be at home when she dies. Her doctor will make sure that everyone who will be involved with caring for Gemma knows about the choice she has made.

Q13. What choices are most important to people as they approach the end of their lives? What would best help to meet these?

Q14. We need to strengthen and widen the range of end of life care services from which patients and carers can choose. How can we best enable this?

Q15. Carers may sometimes feel that they themselves have no choice when the person they care for chooses to die at home. How should the respective needs and wishes of patients and carers be balanced?

Choosing a GP practice

*“We will give every patient a clear **right to choose to register with any GP practice** they want with an open list, without being restricted by where they live. People should be able to expect that they can change their GP quickly and straightforwardly if and when it is right for them, but equally that they can stay with their GP if they wish when they move house.”*

- 2.41 People should be able to choose to register with any GP practice they want and be able to change GP. Equally, people should be able to stay with their GP when they move, should they wish. This will mean that your GP practice no longer has to be determined by where you live.
- 2.42 If you choose a GP practice further from where you live, it is important that you also have access to urgent medical care near home. We propose to develop a coherent 24/7 urgent care service in every area of England, which will incorporate GP out-of-hours services and provide in-hours urgent medical care where necessary for people who aren't registered with a local GP. We say more on the proposed 24/7 urgent care service in chapter 4.
- 2.43 Earlier this year, the Department of Health initiated a consultation on enabling people to register with the GP practice of their choice. The consultation, which closed on 2 July, attracted widespread interest from members of the public, healthcare professionals, NHS organisations and professional bodies. Over 5,400 responses were received, which shows how important an issue this is to so many people, patients and NHS staff.
- 2.44 The Department is currently looking at the responses in more detail and will publish a summary of the findings. It is clear that the overwhelming number of patients and public responding support proposals to give people the choice to register with any GP practice with an open list.
- 2.45 There are a range of issues to be worked through in more detail. The Department of Health will work with the NHS and with professional and patient groups to find sensible and pragmatic solutions to resolving these issues and will publish a policy framework by early next year.

Making choices about treatment¹³

*“We will consult on **choice of treatment** later this year...”*

- 2.46 People already have a fundamental right to decide whether they receive treatment. Without consent, supported by appropriate information, health professionals cannot provide treatment except in special circumstances. Also, many healthcare professionals do involve people in decisions about which treatment they have, and offer them a range of available and appropriate treatments, therapies and other services.
- 2.47 However, people should be offered a choice of treatment as a matter of course, except where this is clinically inappropriate or unfeasible. Healthcare professionals should include their patients and service users, with their families and carers, as equal partners in decisions about their treatment. This is not just about *whether* to have treatment, but also *which* treatment to have. Where there are a range of different, clinically appropriate and evidence-based treatments available on the NHS, we want people to be able to choose the treatment that is right for them, supported by information about the treatments, risks and any side-effects.¹⁴ This could mean patients being offered a choice of any clinically-appropriate treatment that has been approved by the National Institute for Health and Clinical Excellence (NICE)¹⁵. However, this would exclude many “tried and tested” treatments that have not been through the NICE approval process but that have been used by clinicians for some time - more on safe and appropriate choices is in chapter 5.
- 2.48 Also, it would not be appropriate to offer people a choice over the type of treatment they receive in all circumstances. For example, in an emergency healthcare situation, healthcare professionals may need to take decisions in their patients’ best interests and following their patients’ known preferences as far as possible.

Imran is 62 and is a carer for his wife. He has knee pain, which has been getting worse. He is finding that paracetamol does not relieve the pain any more. After seeing his GP, Imran goes to see a consultant, who confirms that he has osteoarthritis of the knee.

Imran’s consultant tells him that he has a number of different treatment options. He could exercise, see a physiotherapist, take medication stronger than paracetamol or ultimately have a knee replacement. The consultant

¹³ Treatment could mean therapy, support for self management, medication or a procedure like surgery

¹⁴ *Liberating the NHS: An information revolution*

¹⁵ NICE is the National Institute for Health and Clinical Excellence. One of its aims is to make recommendations to the NHS on new and existing medicines, treatments and procedures

recommends that he looks at a decision aid to help him to think about what he wants from his treatment, the pros and cons of the different treatment options and how they would fit with his life.

The decision aid shows him that a knee replacement could take 6-12 months to recover from. Imran is not sure that he could find someone to take over his caring responsibilities for that time. On the other hand, he is concerned about taking more medication. He is surprised to see that exercise could reduce the pain in his knee rather than increase it, and it might help him to lose weight.

Imran's choice

The decision aid suggests trying exercise as a first step, and think about a knee replacement if his symptoms get worse in the future. Imran chooses this option.

Q16. What sort of choices would you like to see about the NHS treatment that you have? Treatment could mean therapy, support for self management, medication or a procedure like surgery.

Taking responsibility for choices

“In return for greater choice and control, patients should accept responsibility for the choices they make, concordance with treatment programmes and the implications for their lifestyle.”

- 2.49 It is important that we take responsibility for the choices we make as patients and service users, for following the treatment programmes and care plans we have agreed to, and for the implications that those choices have for our healthcare and lifestyle.

Q17. How can we encourage people to take more responsibility for their health and treatment choices?

3. Shared healthcare decisions

“We want the principle of ‘shared decision-making’ to become the norm: no decision about me without me.”

- 3.1 The NHS Constitution states that everybody has the right to be involved in decisions about their healthcare, and to information to enable them to do this.¹⁶ Healthcare providers are also legally required to ensure that people are able to make or share in decisions relating to their care or treatment.¹⁷ Yet surveys tell us that not being told enough about their illness and the options for treatment is the most common cause of dissatisfaction, and many people feel that they do not yet have enough say in their healthcare.¹⁸
- 3.2 Children, those with learning disabilities and others who find it more difficult to make decisions may need additional support so that they can be more involved in decisions about their healthcare. People who help them with their decisions will also need to be involved.

Q18. How do we make sure that everyone can have a say in their healthcare?

Q19. How can we make sure that people’s choices can reflect their different backgrounds - whether ethnic, religious or any other background that could affect their healthcare preferences?

Q20. How can we make sure that carers and the families of patients and service users can have a say in decisions about the healthcare of the people they support, where appropriate?

A healthcare partnership

- 3.3 Many healthcare professionals and patients and service users are already working together in new ways to change the traditional “doctor-patient”

¹⁶ NHS Constitution, pages 7 and 8 (March 2010)

¹⁷ Health and Social Care Act 2008 (Registration of Regulated Activities) Regulations 2009, Regulation 17(1)(b)

¹⁸ National Patient Survey,

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_116958 (2009)

relationship and give more say to the patient or service user. But this is a significant shift in culture for many people: health professionals, who might be unfamiliar with encouraging people to take a more active role in their health; patients, service users, their families and carers, who might be used to following health professionals' advice without question; and healthcare providers, which might need to change the contracts they have in place.

- 3.4 Some people may want to take a less active role in making decisions about their care. In some circumstances (for example in a crisis or when they are very ill) patients may prefer the clinician to make more decisions for them. Others may need additional support, either from healthcare professionals or from carers or family members, to make informed decisions. Some people will also find it useful to have time to think things through or discuss options with their friends, family or carer, if appropriate.
- 3.5 People can also decide in advance whether they would wish to refuse treatment if it was offered to them at a time in the future when they were unable to make this decision. They can change this decision at any time.
- 3.6 An important skill of healthcare professionals should be gauging how much involvement their patient is comfortable with and how they can be supported to make informed decisions. However, research has shown that some GPs assume incorrectly that only young and middle-class people want choice.¹⁹

Q21. How can we support the changing relationship between healthcare professionals and patients, service users, their families and carers?

Q22. What needs to be done to ensure that shared decision making becomes the norm? What should we do first?

Q23. Should healthcare professionals support the choices their patients make, even if they disagree with them?

Making shared decision-making a reality: advice and information for providers of NHS care

- 3.7 Subject to consultation and Parliamentary approval of primary legislation, the new NHS Commissioning Board will take responsibility for making sure that people are given more choice and control over their healthcare. While the

¹⁹ A. Dixon et al, Patient choice - how patients choose and how providers respond, Kings Fund, <http://www.kingsfund.org.uk/publications/> (2010)

Board is being set up, the Department of Health will continue to provide advice and information to support the new healthcare partnership. In particular:

- We will provide advice and information about how healthcare professionals can ensure that everyone can make choices about their healthcare, whatever their background or personal characteristics and wherever they are along their care pathway. This could include advice and information about opening up choice to people with additional support needs.
- We will continue to promote personalised care planning and support people living with long term conditions to understand and exercise choice around the self care support they receive, so that they can manage their condition better and take more control over their health and wellbeing.
- We will consider how to encourage more people to talk with their healthcare professional about their preferences for the care and support they receive at the end of their life. Called ‘advance care planning’, this is particularly important for people who may be unable to make decisions about their care later on. If that happens, healthcare professionals will make decisions that they think are in their patients’ best interests, and advance care planning helps them to take their patients’ known preferences into account as far as possible.

Q24. What sort of advice and information would help healthcare professionals to make sure that everyone can make choices about their healthcare?

Q25. How can we encourage more people to engage in advance care planning about their preferences for the care and support they receive - for example, when they are approaching the end of their life?

Q26. Would you welcome a chance to engage in advance care planning before you become ill – for example, when you go for your mid-life Health Check – rather than after a diagnosis of a life-threatening condition?

Making shared decision-making a reality: education and training

- 3.8 Education and training could help existing and new healthcare professionals to involve people more in decisions about their care and offer them choices.

Q27. How could training and education make choice and shared decision-making a part of healthcare professionals' working practices?

- 3.9 Education for patients, service users, their families and carers is also very important, to help them to understand their health needs/condition and the treatment and other care that is available. There are courses for people with a specific condition, such as diabetes, and others are more general self-management courses for anyone with a long term condition, such as the Expert Patients Programme. There are also courses for carers. Many people have benefitted from participating in this kind of education/skills training and there is scope for increasing this across the country.

Q28. How can we help people to learn more about how to manage their health?

Support with shared decision-making

- 3.10 People will need different levels of support so that they can understand and use information to make decisions and choices. The kind of information people need and how they want to receive it is also being addressed as part of the work on the 'information revolution' announced in the White Paper. This begins with the relevant consultation document *Liberating the NHS: An information revolution*.

Q29. What help should be available to make sure that everyone is able to have a say in their healthcare?

Q30. Who would you like to go to for help with understanding information and making decisions and choices about your healthcare, or that of someone you support?

Carers

- 3.11 Many people are looked after or supported by a carer, who are often partners in choices and decisions. The choice that someone makes could have a significant impact on their carer - for example the choice to die at home.

Carers might need information and support so that they can help the person they care for with choices and decisions, and understand the impact that these choices and decisions could have for them.

Parents, guardians and those with powers of attorney or deputyship

- 3.12 Some people are not able to make some decisions by themselves - for example, those living with a condition which significantly affects their ability to understand and use information. This can include some people with learning disabilities or dementia. This might mean that they need help to make choices or decisions, or another person might have the legal authority to make decisions on their behalf.
- 3.13 Children and young people, and adults who lack the capacity to make some decisions, should be involved in decisions and choices about their healthcare as much as possible, even when they are unable to make decisions and choices by themselves. The level of involvement that they are able to have will depend on their individual circumstances and ability and how information is presented to them, and it may often be in partnership with their parents, family and other representatives as appropriate.
- 3.14 Those who are making decisions for other people may need additional support so that they can continue to do so.

Voluntary sector and patient-led support groups

- 3.15 There are already a wide range of voluntary sector, patient-led support groups and user led organisations which help people to understand information, make choices, and be more involved in decisions about their healthcare. These groups may need support to continue to do this as the information, choices and involvement available to people grows. There might be increased demand for their services, as more people need help with their new choices.

Q31. How can we make sure that carers' views are taken into account when the person they support makes a healthcare choice?

Q32. What information and support do carers, parents, guardians and those with powers of attorney or deputyship need to help others to make choices or to make choices on others' behalf?

Q33. What information and support do voluntary sector and patient-led support groups need so that they can continue to help people to make choices about their healthcare?

Getting people involved in healthcare decisions

- 3.16 It is also important to give people information and support to encourage them to get more involved in decisions about their care. The new healthcare partnership might be very different for some people, who are used to a different kind of relationship with their healthcare professional.
- 3.17 Decision aids can also support choice of treatment and provider. They are tools which can help people to think about what they want from their treatment and what their preferences are before they make a difficult decision. Decision aids can be used by an individual by themselves or in discussion with another person, for example a family member, carer, or a healthcare professional.

Q34. How can people be encouraged to be more involved in decisions about their healthcare?

Q35. Would decision aids be a useful tool for healthcare professionals and their patients and service users? Are there any barriers to their use?

4. Making it happen: information, “any willing provider” and other tools

“In implementing proposals for extending choice, the Department will consult widely. We will need to tackle a range of issues, including: professional and patient engagement; reform to payment systems so that money follows the patient and enables choices to work; information availability and accessibility to enable choice of treatment, including decision aids, particularly in mental health and community services; support to patients with different language needs and patients with disabilities to ensure that they can exercise choice; ensuring that local commissioners fully support rather than restrict choice; and maximising use of Choose and Book...”

Information to support choice

- 4.1 So that they know how to make the choice that is right for them, we want everyone to have easy access to reliable, user-friendly information on: their health; what they can make choices about and when; the treatment, healthcare providers and healthcare professional teams they can choose from; and the likely benefits and risks of their choices.
- 4.2 Healthcare professionals would be key to making sure that people know what they have choice over and when they can choose. But it is also important to make sure that people who do not speak to their GP first before using some healthcare services (for example, some counselling, physiotherapy and maternity services) know about how they can make choices.
- 4.3 We will encourage a range of different people and organisations to provide the information needed to support choice. This is a key aspect of the ‘information revolution’ announced in the White Paper. A separate consultation is taking place on this, which asks for views about the type of information people need to make choices and how it is presented. Further details are on the Department of Health’s website.²⁰
- 4.4 Some information is already available via information prescriptions, on the NHS Choices website and via independent information services such as patient organisations and health charities. We expect information gathered from patients themselves to be increasingly important. People can also access

²⁰ *Liberating the NHS: An information revolution*, October 2010

feedback from patients, service users, their families and carers on NHS Choices and via independent comment services such as *Patient Opinion* and *iWantGreatCare*. NHS Choices also has staff feedback from the national NHS staff survey. This includes information such as whether staff would recommend where they work to their own family or friends if they needed treatment.

- 4.5 We will consider how to build on these, to ensure that people get the information they need at the right time in a way they can easily access. For example, the information prescription service allows local NHS organisations and voluntary sector organisations to upload information in accessible formats such as audio, video and easy read. More on the importance of accessible information is in the accompanying Equality Impact Assessment, and a key function of an information strategy will be to address how information is made available.
- 4.6 We will also consider how to ensure that people can rely on the accuracy of information supplied by the range of different people and organisations, for example encouraging information producers to use The Information Standard, a certification scheme which helps people to identify trustworthy sources of information they can rely on when making decisions about their care.

Information about research studies

*“We will give patients more information on **research studies** that are relevant to them, and more scope to join in if they wish.”*

- 4.7 Everyone can choose to join in relevant, ethically approved research studies. We will make sure that people can access information about current research studies, search for clinical trials that are relevant to them, and be told when opportunities arise for them to join in relevant and ethically approved research.
- 4.8 Research is key to improving evidence and achieving better outcomes. People may decide to join in because of access to new treatments, or because they want to help others by contributing to the evidence that patients and healthcare professionals will use in the future. Making sure that people are aware of opportunities to participate in relevant research studies should help to open up these opportunities to different groups and communities, and make it easier for them to find out about research that could affect their own health outcomes.

Q36. How should people be told about relevant research and how should their preferences be recorded?

Choose and Book

- 4.9 Choose and Book, the electronic referral and booking system, allows people to choose to book an appointment for many NHS-funded healthcare services. Appointments can be made on the internet or over the telephone, by patients or by healthcare professionals on their patients' behalf. Choose and Book is not used for all referrals. Some people are still referred by letter or other electronic means, and some people self-refer where possible.
- 4.10 The King's Fund report on patient choice found that although some GPs thought that Choose and Book gives patients and service users greater control and certainty, others remain reluctant to use it.²¹ However, all healthcare professionals need to know how best to use Choose and Book in order to gain the most benefits for themselves and their patients. This should mean that more healthcare professionals use Choose and Book when they refer their patients to a healthcare provider.
- 4.11 Some GPs think that Choose and Book does not support referrals to named consultant-led teams. However, this is in fact possible if the service is listed appropriately by the healthcare provider. So we will make sure that wherever appropriate healthcare providers link their healthcare to consultant-led teams when they put them on Choose and Book.

Q37. How can we encourage more healthcare professionals to use Choose and Book when they make a referral?

Q38. How can we encourage more healthcare providers to list their services on Choose and Book?

Q39. How else can we make sure that Choose and Book supports the choice commitments in chapter 2?

GP contracts

- 4.12 The services delivered to patients by their local GP practice are known as primary medical services. These are delivered through a system of contracts, commissioned by PCTs from the relevant service provider (a general practice). General practices can hold one of three different contracts. Most of them hold general medical services contracts, the terms of which are consulted on with

²¹ A. Dixon et al, Patient choice - how patients choose and how providers respond, Kings Fund, <http://www.kingsfund.org.uk/publications/> (2010)

the British Medical Association (BMA) and are common to GPs across the country. The other contractual types (personal medical services and alternative provider medical services) contain a mixture of national requirements (to ensure that all patients registered with a general practice receive the same range of core services and standards) and local requirements, tailored to meet local priorities by PCTs in discussion with the individual general practices.

- 4.13 We are considering consulting the BMA on changes to the general medical services contract to require general practices to (1) offer their patients a choice of healthcare provider when they are referred for their first outpatient appointment with a consultant-led team and (2) register patients regardless of where they live if their registration list is open. Should these changes be introduced in relation to general medical services contracts we would also look to mirror these new terms in both personal and alternative provider medical services contracts as part of the range of national requirements.

Buying NHS services: contracts and commissioning

- 4.14 Healthcare providers that offer NHS care enter into contracts with commissioners. This contract sets out what services are being bought, plus standards or requirements about how these services are delivered. It has both fixed wording that applies to every healthcare provider and locally agreed elements to ensure that the requirements reflect the needs of the local population. The requirements in these contracts could be used to support greater choice in the NHS.
- 4.15 So that people are able to take up their extended choices, we propose to amend the 2011/12 choice guidance, which sets out the contractual duties that providers will have around choice, to require healthcare providers to support the extension of choice as proposed. The amended choice guidance will be published before April 2011. In particular, and so that we can meet the deadline of April 2011 on introducing named consultant-led team, we propose to require providers of NHS-funded healthcare to:
- Accept patients who are referred to a named consultant-led team, as long as the referral is clinically appropriate;
 - List their services on Choose and Book in a way that allows users to book appointments with named consultant-led teams as well as general clinics; and
 - Publish information about their services, so that people can use it to make choices about their healthcare, and support people to use this information.

Q40. Do you agree with the proposed approach to implementing choice of named consultant-led team? What else would you suggest needs to be done?

- 4.16 Commissioners take into account a lot of factors when they buy healthcare for their local population, including making sure that people have enough choice locally to meet their needs and preferences. The NHS Commissioning Board will be responsible for supporting commissioners to make the right decisions for their local population. The Board may decide to provide guidance, which could include choice considerations. The Board's role is discussed more in chapter 5.
- 4.17 There has been a separate consultation document looking at proposals for commissioning (*Liberating the NHS: Commissioning for Patients*). The Government's response to this consultation will be published in due course.

Implementing choice of “any willing provider”

- 4.18 In order to make choice of any willing provider a reality, we will need some other tools in addition to the ones mentioned above.
- 4.19 The NHS pays standard prices (the ‘national tariff’) for some healthcare, including most services provided by acute hospitals. These prices apply across England, but are adjusted to compensate for the unavoidable cost differences of providing healthcare in different parts of the country.
- 4.20 For some services, including community services and end of life care, there is no national standard pricing. To support choice of any willing provider, we will need to develop currencies (how healthcare activities are grouped for payment purposes) and, in some cases, standard NHS prices for the services that do not currently have them. National standard pricing could take considerable time to develop. In the meantime, prices will need to be agreed locally, within an appropriate national framework.
- 4.21 Subject to consultation, to ensure that all providers of NHS-funded services are safe and financially sustainable, they would be required to have a joint licence that covers both the quality of their care and their corporate structure (for example, finance). This joint licensing regime will be operated by the Care Quality Commission (CQC) and the economic regulator.
- 4.22 All providers of NHS-funded services will have to agree to the core terms of doing business with the NHS. By signing an NHS standard contract, providers

would agree to deliver healthcare to NHS standards and within the NHS standard price. They would be agreeing that commissioners will not guarantee them a minimum number of referrals nor a minimum amount of payment.

- 4.23 Commissioners would be free to commission services from any willing provider who is licensed under the joint licensing regime and had agreed to the NHS standard contract terms and conditions. Commissioners would have confidence that providers that meet these criteria are fit to deliver NHS care.
- 4.24 In order to make it easy for commissioners to establish that providers meet these criteria, we are considering establishing a central directory of any willing providers, which lists those providers that are licensed under the joint licensing regime and who have agreed to the NHS standard contract terms and conditions. By putting the information in one place, we would expect to avoid local commissioners having to repeat checks which would in turn free up resources for local commissioners to concentrate on specifying any local requirements.

Q41. Do you agree with proposed approach to establishing a provider's fitness to provide NHS services? What other criteria would you suggest?

Q42. Should this approach apply uniformly to all providers, no matter what size, sector and healthcare services that they provide? For example, should a small charity providing only one healthcare service to a very localised group of patients be subject to the same degree of rigour as a large acute hospital that delivers a range of services to a regional catchment of patients?

Q43. Do you agree that an "any willing provider" directory should be established to make it easier for commissioners to identify providers that are licensed and have agreed to the NHS standard contract terms and conditions?

Personal health budgets

"...[T]he Department will encourage further [personal health budget] pilots to come forward and explore the potential for introducing a right to a personal health budget in discrete areas such as NHS continuing care."

- 4.25 A personal health budget allows people to have more choice, flexibility and control over the health services and care they receive. It helps people to get the services they need to achieve their health outcomes, by letting them take control over how much money is spent on their care as is appropriate for them. Giving someone a personal health budget makes it clear to them how much NHS money is available for their care, and gives them greater choice and

control over how the money is spent. The aim of this is to improve the outcomes for the individual - both in respect of their health and for their satisfaction with services.

- 4.26 The personal health budget must be based on an agreed care plan. This is signed off by both the person using the budget and an NHS representative, to ensure it meets the person's health needs. The personal health budget is there to meet the person's entire health and wellbeing needs and cannot be topped up.
- 4.27 To understand the implications of personal health budgets, both for the individuals who hold them and for the rest of the NHS, there needs to be a robust evaluation. Personal health budgets are therefore being tested in a number of pilot sites. Most of the pilot sites are looking at one or more of the following: long term conditions, mental health, NHS continuing healthcare and end of life care. The pilot programme is being independently evaluated by the Personal Social Services Research Unit, looking at how effective personal health budgets are and how they should best be implemented. There may be significant potential for benefit from personal health budgets, but there will also be significant challenges in making personal health budgets effective for individuals while ensuring that wider NHS services are not undermined, hence the focus on innovation and piloting. The Department of Health will use the evaluation to inform the roll out of personal health budgets, and will explore the possibility of introducing a right to a personal health budget in discrete areas, such as NHS continuing healthcare.
- 4.28 Greater choice and control for social care users and carers through the wider introduction of personal budgets has been a feature of adult and children social care since 2008. Therefore there is already a lot of learning available to help with the local implementation of personal health budgets. Pilot sites are also thinking about how personal health budgets and personal budgets for social care may be linked up, where appropriate, so that services can be more joined-up and seamless. Where a person is eligible for both health and social care personal budgets, the longer term aim is that the care plan should be joined up to reflect all the services the individual needs and is accessing.

Q44. The White Paper indicates that the Government will explore the potential for introducing a right to a personal health budget in discrete areas. Which conditions or services should be included in this right?

Getting the right urgent care: 111

“We will develop a coherent 24/7 urgent care service in every area of England that makes sense to patients when they have to make choices about their care. This will incorporate GP out-of-hours services and provide urgent medical care for people registered with a GP elsewhere. ”

- 4.29 A new, easy to remember and free to call number - 111 - for urgent healthcare services is currently being piloted. People who need healthcare fast, but do not have a 999 emergency and do not know who to call, will be able to dial 111 and speak to an NHS adviser. 111 will help people choose the right service, first time, so they won't have to default to calling 999 or attending A&E, and it will be backed up by a more integrated non-emergency service, so the right response can be arranged directly through that call.
- 4.30 111 will provide a more comprehensive service than NHS Direct by delivering consistent clinical assessments of callers' needs and ensuring they are then linked up to the service that is best able to meet these needs, taking into account their location, the time of day at which they call and the capacity of local services. In developing the new service, our overriding aims will be to provide the best possible service for the public and deliver the best value for money.

Adeola's mother is anxious because Adeola has told her that it hurts when she urinates. They have not registered with a GP yet. Adeola's mother calls 111.

The 111 call adviser rules out any immediate threats to Adeola's life, but says that as she is a young child who has pain passing urine she needs to see a healthcare professional for further assessment (there is a risk that she could have a urinary tract infection). He finds a local out of hours centre that is open and books Adeola an appointment for later in the evening.

5. Safe and sustainable choices

- 5.1 There will be major challenges in making sure that *everyone* can exercise choices that do not cause problems for them or the NHS. From engaging with people to ensuring that services are properly joined-up – we will need to tackle these challenges to give everyone an opportunity to make safe and sustainable choices.

Making safe and sustainable choices

- 5.2 Our basic presumption is that everyone would be able to make choices about their healthcare – but these choices must be **appropriate** for their health needs, **safe**, and **financially affordable** for the NHS. Circumstances in which this might not be the case could include:
- Some providers may not be clinically equipped to receive referrals for specialist services and so may not be safe choices for all patients;
 - When a person has an urgent or critical healthcare need, accessing treatment quickly is the priority and this may limit the scope for choices. For example, there are guaranteed waiting times in place for people who need some cancer services. Accessing cancer services within guaranteed waiting times will be the priority;
 - Where treatments, therapies and procedures are not safe, appropriate, or financially affordable for the NHS, they will not be available to choose. Treatment options would need to be of proven clinical value - for example, being approved by NICE.

Q45. How can we make sure that any limits on choice are fair, and do not have an unequal effect on some groups or communities?

Choosing joined-up services

- 5.3 We will need to make sure that people who make choices about their healthcare still receive joined-up services. No matter what choices are made, health records should move between organisations and professionals quickly and securely so that healthcare is safe and appropriate. Healthcare should link

up with other types of service, such as employment, social care and other public services. Commissioners will need to be more flexible in how they look at services, making less of a distinction between health and social care. People with wide-ranging needs should be able to develop a care plan which covers the care they receive from different services – not just the NHS.

Q46. What do you consider to be the main challenges to ensuring that people receive joined-up services, whatever choices they make, and how should we tackle these challenges?

Financially affordable choices

5.4 We will make every effort to ensure that choices are financially affordable. Paying healthcare providers a standard price means that one choice about where to go for healthcare should not cost the NHS any more than a different choice. But there are a number of risks around the affordability of choice which we will need to mitigate. For example:

- If more people need and qualify for help from the NHS with travel to and from healthcare providers, travel and transport could cost the NHS more than it does now;
- If services aren't joined up then choosing a different healthcare provider could mean being asked to repeat some tests. This will be inconvenient for the patient or service user and could mean that the NHS pays twice for the same tests;
- If patients and service users choose services in relatively more expensive areas, this could cost the NHS more because services in more expensive areas cost proportionately more;
- If popular healthcare providers take on more staff or spend more on equipment or buildings but less popular providers don't spend less, overall costs could rise;
- If we do not have well structured, available, accessible information, more choice would be more difficult and probably more costly to deliver.

Q47. What do you consider to be the main risks to the affordability of choice and how should we mitigate these risks?

Making sure choices are offered to everyone

- 5.5 We want everyone to have an opportunity to exercise choice, irrespective of their circumstances. In extending the choices that are available to patients and service users, we would take steps to make sure that no one is disadvantaged by the way in which choices are offered, by the information that is available to support choice or by the choices they make.
- 5.6 A number of organisations and individuals will have a role in ensuring that all patients and service users get to make the choices set out in this consultation. Chapter 3 discussed the proposed role of healthcare professionals in helping patients and service users make informed decisions. Below we set out the roles and responsibilities of key organisations with respect to ensuring choices are offered.

The NHS Commissioning Board

- 5.7 Subject to consultation, the new NHS Commissioning Board is being created to take the lead on, amongst other things, promoting and extending involvement and choice, by:
- Championing effective involvement and engagement in decisions about healthcare, working with GP commissioners, local authorities, voluntary sector and patient-led support groups and HealthWatch;
 - Developing and agreeing with the Secretary of State the guarantees for patients about the choices they can make;
 - Promoting and extending information to support meaningful choice over the care and treatment that people receive, where it is provided and who provides it, including personal health budgets; and
 - Commissioning the information needed to support choice, including patient-reported experience and outcome measures.

Q48. How far should we extend entitlements to choice in legislation and hold organisations to account against these?

Q49. Where no specific right to choice applies, how can the Board best

encourage GP consortia to maintain and extend the choice offer?

GP commissioners

- 5.8 GPs would have the same responsibility as other healthcare professionals to offer choice and support their patients to make choices. However, as part of the proposed GP consortia, they would also be responsible for identifying the health services that their local people need and buying value for money services. Wherever possible, GP commissioners should commission services that enable people to make choices about their healthcare, and should make sure that people are not disadvantaged by their choices - for example, people who would find it difficult to travel to some healthcare providers.
- 5.9 There are a number of ways in which we can ensure that the proposed GP commissioners support rather than restrict choice. As well as being held to account formally by the NHS Commissioning Board for their performance in offering choice, we would expect GP commissioners to engage with oversight and scrutiny by local government and Healthwatch and respond to patient feedback.

Q50. What is the right mix of measures to encourage GP consortia to offer appropriate choices to their populations?

Q51. What is the best way to gather patient feedback about the extent to which commissioners have put in place choices?

HealthWatch

- 5.10 Subject to consultation, HealthWatch England will be the new national consumer champion. Local HealthWatch organisations would have a key role in supporting choice by providing information and advice for the users of local health and social care services. In addition, local HealthWatch organisations would make sure that feedback from patients, service users and the wider public is gathered and fed into local decisions about health and social care.

Secretary of State for Health

- 5.11 Subject to consultation outcomes, the choice guarantees developed by the NHS Commissioning Board would be agreed with the Secretary of State for Health, who will also hold the Board to account on its progress with extending patient and carer involvement and choice.

Local Government

- 5.12 Local Government would have a stronger role in supporting choice. For example, they will be able to task local HealthWatch organisations and others with providing complaints advocacy services for their local population and with supporting those who need help with their choices. They would also have a role in joining-up the NHS, social care and health improvement services delivered to their local population to enable more integrated care.

Q52. Are the responsibilities of organisations as outlined enough to:

- ensure that choices are offered to all patients and service users where choices are safe, appropriate and affordable?
- ensure that no-one is disadvantaged by the way choice is offered or by the choices they make?

Q53. If you do not get a choice you are entitled to, what should you be able to do about it?

Managing the impact of choice

- 5.13 The choices that patients and service users make will have consequences, which we will manage.
- 5.14 Some choices will inevitably be more popular than others, which could have financial and non-financial consequences. Increasing demand for particular services or treatment options could increase the time that people have to wait for them. Reducing demand for particular services or treatment options will reduce a healthcare provider's income. While this should provide an incentive for them to tailor their services to local needs and preferences, it may also make some services unsustainable.
- 5.15 Significant numbers moving to popular healthcare providers could put popular providers in a dominant position with respect to new or existing competing providers - particularly in areas where there have traditionally been few healthcare providers. We will need to make sure that dominant healthcare providers do not use their position unfairly to prevent competition.

Q54. What do you think are the main risks associated with choice and how should we best mitigate these risks?

Annex A. Consultation questions

Greater choice and control

Q1. How should people have greater choice and control over their care?
How can we make this as personalised as possible?

Q2. Which healthcare services should be our priorities for introducing choice of any willing provider?

Q3. How can we offer greater choice of provider in unplanned care?

Q4. What would help more people to have more choice over where they are referred?

Q5. Which choices would you like to see in maternity services and which are the most important?

Q6. Are these the right choices for users of mental health services, and if not why not?

Q7. When people are referred for healthcare, there are a number of stages when they might be offered a choice of where they want to go to have their diagnostic tests, measurements or samples taken. At the following stages, and provided it is clinically appropriate, should people be given a choice about where to go to have their tests or their measurements and samples taken:

- At their initial appointment - for example, with a GP, dentist, optometrist or practice nurse?
- Following an outpatient appointment with a hospital consultant?
- Whilst in hospital receiving treatment?
- After being discharged from hospital but whilst still under the care of a hospital consultant?

Q8. Are there any circumstances where choice of where to go for diagnostic

testing would not be appropriate, and if so what are they?

Q9. Would you like the opportunity to choose your healthcare provider and named consultant-led team after you have been diagnosed with an illness or other condition?

Q10. What information and/or support would help you to make your choice in this situation and are there any barriers or obstacles that would need to be overcome to make this happen?

Q11. Is there anything that might discourage you from changing your healthcare provider or named consultant-led team - for example, if you had to repeat tests, wait longer or travel further?

Q12. What else needs to happen so that personalised care planning can best help people living with long term conditions have more choice and control over their healthcare?

Q13. What choices are most important to people as they approach the end of their lives? What would best help to meet these?

Q14. We need to strengthen and widen the range of end of life care services from which patients and carers can choose. How can we best enable this?

Q15. Carers may sometimes feel that they themselves have no choice when the person they care for chooses to die at home. How should the respective needs and wishes of patients and carers be balanced?

Q16. What sort of choices would you like to see about the NHS treatment that you have? Treatment could mean therapy, support for self management, medication or a procedure like surgery.

Q17. How can we encourage people to take more responsibility for their health and treatment choices?

Shared healthcare decisions

Q18. How do we make sure that everyone can have a say in their healthcare?

Q19. How can we make sure that people's choices can reflect their different backgrounds - whether ethnic, religious or any other background that could affect their healthcare preferences?

Q20. How can we make sure that carers and the families of patients and service users can have a say in decisions about the healthcare of the people

they support, where appropriate?

Q21. How can we support the changing relationship between healthcare professionals and patients, service users, their families and carers?

Q22. What needs to be done to ensure that shared decision making becomes the norm? What should we do first?

Q23. Should healthcare professionals support the choices their patients make, even if they disagree with them?

Q24. What sort of advice and information would help healthcare professionals to make sure that everyone can make choices about their healthcare?

Q25. How can we encourage more people to engage in advance care planning about their preferences for the care and support they receive - for example, when they are approaching the end of their life?

Q26. Would you welcome a chance to engage in advance care planning before you become ill – for example, when you go for your mid-life Health Check – rather than after a diagnosis of a life-threatening condition?

Q27. How could training and education make choice and shared decision-making a part of healthcare professionals' working practices?

Q28. How can we help people to learn more about how to manage their health?

Q29. What help should be available to make sure that everyone is able to have a say in their healthcare?

Q30. Who would you like to go to for help with understanding information and making decisions and choices about your healthcare, or that of someone you support?

Q31. How can we make sure that carers' views are taken into account when the person they support makes a healthcare choice?

Q32. What information and support do carers, parents, guardians and those with powers of attorney or deputyship need to help others to make choices or to make choices on others' behalf?

Q33. What information and support do voluntary sector and patient-led support groups need so that they can continue to help people to make choices about their healthcare?

Q34. How can people be encouraged to be more involved in decisions about their healthcare?

Q35. Would decision aids be a useful tool for healthcare professionals and their patients and service users? Are there any barriers to their use?

Making it happen

Q36. How should people be told about relevant research and how should their preferences be recorded?

Q37. How can we encourage more healthcare professionals to use Choose and Book when they make a referral?

Q38. How can we encourage more healthcare providers to list their services on Choose and Book?

Q39. How else can we make sure that Choose and Book supports the choice commitments in chapter 2?

Q40. Do you agree with the proposed approach to implementing choice of named consultant-led team? What else would you suggest needs to be done?

Q41. Do you agree with the proposed approach to establishing a provider's fitness to provide NHS services? What other criteria would you suggest?

Q42. Should this approach apply uniformly to all providers, no matter what size, sector and healthcare services that they provide? For example, should a small charity providing only one healthcare service to a very localised group of patients be subject to the same degree of rigour as a large acute hospital that delivers a range of services to a regional catchment of patients?

Q43. Do you agree that an "any willing provider" directory should be established to make it easier for commissioners to identify providers that are licensed and have agreed to the NHS standard contract terms and conditions?

Q44. The White Paper indicates that the Government will explore the potential for introducing a right to a personal health budget in discrete areas. Which conditions or services should be included in this right?

Safe and sustainable choices

Q45. How can we make sure that any limits on choice are fair, and do not

have an unequal effect on some groups or communities?

Q46. What do you consider to be the main challenges to ensuring that people receive joined-up services whatever choices they make, and how should we tackle these challenges?

Q47. What do you consider to be the main risks to the affordability of choice and how should we mitigate these risks?

Q48. How far should we extend entitlements to choice in legislation and hold organisations to account against these?

Q49. Where no specific right to choice applies, how can the Board best encourage GP consortia to maintain and extend the choice offer?

Q50. What is the right mix of measures to encourage GP consortia to offer appropriate choices to their populations?

Q51. What is the best way to gather patient feedback about the extent to which commissioners have put in place choices?

Q52. Are the responsibilities of organisations as outlined enough to:

- ensure that choices are offered to all patients and service users where choices are safe, appropriate and affordable?
- ensure that no-one is disadvantaged by the way choice is offered or by the choices they make?

Q53. If you do not get a choice you are entitled to, what should you be able to do about it?

Q54. What are the main risks associated with choice and how should we best mitigate these risks?

Annex B. Words and phrases

Any Willing Provider	Any healthcare provider, including those in the independent and voluntary sector, that is registered with the CQC (or other body where / if appropriate), that has agreed to the Terms and conditions within the NHS Standard Contract and can offer services at NHS prices.
Carer	A carer spends a significant proportion of their life providing unpaid support to family or friends. This could be caring for a relative, partner or friend who is ill, frail, disabled, or has mental health or substance misuse problems.
Commissioner	A person, group of people or organisation that buys healthcare services for the local population.
Community services	Services that are provided in people's homes, clinics and other community settings
Consultant	A specialist who has been appointed to a medical consultant post. Consultants often work in hospitals, but not always.
Consultant-led team	A team of healthcare professionals headed by a consultant.
Diagnosis	Identification of the cause of symptoms - for example an illness or other condition.
Diagnostic testing	Taking samples, recording measurements and carrying out testing, supported by clinical opinion.

End of life care	Care that helps people with advanced, progressive, incurable illness to live as well as possible before they die. It enables the needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes managing pain and other symptoms and providing psychological, social, spiritual and practical support.
GP consortia	Groups of GP practices and other partners responsible for buying healthcare services for their patients and local population.
Long term condition	A disease, illness or other condition that cannot currently be cured but can be controlled with the use of medication and/or other therapies. People live with the condition(s) for the rest of their lives.
NHS continuing healthcare	A package of care that is arranged and funded by the NHS to meet the physical or mental health needs of adults with a disability, injury or illness over an extended period of time.
Pathway	The path that a patient goes along from their first contact with a healthcare professional to talk about symptoms, through to diagnosis, treatment, aftercare and their final follow-up appointment with a healthcare professional.
Palliative care	Healthcare aimed at helping with the symptoms caused by an illness or other condition, rather than curing the underlying illness or other condition. An example would be managing pain.
Provider	A person or organisation that provides healthcare services, whether by running a hospital, or an independent treatment centre, by providing services in the community, or in any other way.

<p>Referral</p>	<p>A healthcare professional transfers a patient’s care to a different healthcare professional or provider organisation. For example, a GP refers a patient if he or she asks the patient to go to hospital to speak to a consultant.</p>
<p>Research study</p>	<p>Scientists use medical research studies to build up knowledge about health and healthcare. Some research studies are to find out why people get ill. Others help to develop new treatments. Others test whether a treatment is safe, or whether it works better than other treatments.</p> <p>All medical research studies are reviewed by a research ethics committee before they start, to make sure that they will not harm anyone who joins them.</p>
<p>Voluntary sector healthcare provider</p>	<p>Local and national charities and other not-for-profit organisations that provide healthcare services - for example some local hospice services.</p>
<p>Voluntary sector and patient-led support group</p>	<p>Peer support groups, advocacy organisations, community networks and other groups that are run by local and national charities and other not-for-profit organisations and/or by patients, service users, their families and carers.</p>

Annex C. The consultation process

Criteria for consultation

C.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.

C.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

C.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

Please do not send consultation responses to this address.

Confidentiality of information

- C.4 We manage the information you provide in response to this consultation in accordance with the Department of Health's Information Charter.
- C.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).
- C.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.
- C.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

- C.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: Greater choice and control
A consultation on proposals
Department of Health
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October 2010