NHS

Liberating the NHS:

Greater choice and control

A summary of responses

Department of Health

DH INFORMATION READER BOX

Policy	Estates
HR / Workforce	Commissioning
Management	IM & T
Planning /	Finance
Clinical	Social Care / Partnership Working

Document Purpose	Policy
Gateway Reference	17331
Title	Liberating the NHS: Greater choice and control - A summary of responses
Author	Department of Health
Publication Date	23 May 2012
Target Audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads, Directors of Children's SSs
Circulation List	
Description	The White Paper, Equity and excellence: Liberating the NHS, set out the Government's vision of putting patients and the public at the heart of the NHS. The Department of Health consulted widely to gain views on how to implement the commitments to give patients greater choice and control as set out in the White Paper. This document summarises those responses.
Cross Ref	Liberating the NHS: No decision about me, without me. Further consultation on proposals to secure shared decision-making
Superseded Docs	N / A
Action Required	N / A
Timing	**N / A**
Contact Details	The Choice Team Department of Health 2nd Floor Richmond House 79 Whitehall London
For Recipient's Use	

Contents

Executive summary

1. The White Paper, *Equity and excellence: Liberating the NHS,*[1] set out the Government's vision of patients and the public being at the heart of the NHS - 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. Our consultation document *Liberating the NHS: Greater choice and control*[2], sought the views of patients, the wider public, healthcare professionals and the NHS about how the White Paper commitments might be implemented and how the presumption of choice could be achieved. The questions sought views on:

   - proposals on the specific choice commitments to extend choice of provider and treatment in planned hospital care, maternity, mental health, end of life care and long term conditions;
   - what needs to be done to achieve the necessary culture change and make shared decision-making the norm;
   - the information, support and infrastructure needed to achieve the vision of informed, empowered patients making personal choices;
   - how we can ensure that the choices people make are safe and sustainable, and, that their preferences do not cause problems for them or the NHS;
   - how to ensure informed choices on care and treatment are available for all.

3. The consultation ran for thirteen weeks from 18 October 2010 until 14 January 2011. In total, 617 unique responses were received from stakeholders.

4. We have already published a summary of the responses received and our resultant proposals on extending patient choice of provider (any qualified provider) (July 2011) and on implementing choice of named consultant led

---

[1] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

[2] http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_119651

team (October 2011). These documents may be accessed from the Department of Health's website[3].

5. The purpose of this document is to summarise the responses received to the remaining elements of the consultation exercise. It is accompanied by a separate document: *Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared decision-making*, which sets out our response and detailed proposals. Relevant equality analysis and impact assessment documents are also available.

6. The responses received to the Greater choice and control consultation suggested that the broad proposals for extending choice and control in line with the White Paper commitments to give patients more choice and control were supported by the majority of respondents.

7. Respondents broadly supported the concept of shared decision-making between patients and professionals to become the norm and generally welcomed the chance for patients to have more involvement through a partnership with their healthcare professional.

8. Respondents also generally agreed with the proposals to encourage and extend advance care planning and personal care planning, though the ability to change one's mind at any time was emphasised as being important.

9. A recurring theme of the responses was the need to give patients appropriate information in order to make informed choices. Respondents wanted information to be accessible via the internet but also wanted provision of suitable information for those who cannot or do not have access to the internet, ensuring equitable access for all.

10. Another identified theme was support for patients making a choice. Suggestions to support patients included formal advocacy services and decision aids, the latter being an area where we are already making significant investment in developing tools to support patients and clinicians in making choices about different interventions and treatments.

11. For patients and patient groups, a key theme was the need for the healthcare professional culture to change so that shared decision-making and "*no decision about me, without me*" became a reality. Some respondents stated that the proposals for shared decision-making would require a significant change in the way that patients view and engage with their healthcare professionals.

---

[3] http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_130425
http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_125442

12. Ensuring that time was made available for patients to spend with their healthcare professionals was identified as a key element to this. A general concern was that there would not be sufficient time during the consultation process for a truly shared decision with a fully informed patient to become a reality. Some respondents recognised that investment of time upfront could save time overall.

13. Only a minority of respondents provided responses to the ‘making it happen’ section of the consultation. The following key points emerged from the responses which have been taken into account in developing our policy proposals:

    - The plan to use the existing Choose and Book[4] system to support an extended choice offer was welcomed, although there was a view that the system needed to be easier to use and local implementation should be promoted. Some also felt that the use of Choose and Book should be mandated, with many respondents suggesting that incentives and penalties be used;

    - Some respondents wanted the local HealthWatch groups and the NHS Commissioning Board to have a formal role in ensuring choice and shared decision-making becomes the norm for all;

    - Penalties, incentives and disincentives could be used to ensure that the clinical commissioning groups continue to offer choice appropriately.

14. More generally, respondents raised a number of important points about implementation of the choice proposals, which we agree with and have taken on-board in developing the more detailed proposals in the accompanying document “*Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared decision-making”*. These include the following points:

    - The introduction of choice would be unsuitable for some diagnostic testing, for example, the option to change diagnostic provider whilst in hospital receiving treatment, or the choice of diagnostics in an emergency. Our proposals for extending choice over diagnostic test provider acknowledge this;

    - Making choices should not be mandatory and patients should be able to delegate decision-making partly or completely to their healthcare professional at any time. We endorse this as a key principal of choice: *that you are not obliged to make choices*;

---

[4] http://www.chooseandbook.nhs.uk/

- In general, the provision of information, around providers, outcomes and patient experience, needs to improve to enable patients to make informed choices and everyone needs to be able to access information to support choice, using different formats and approaches where required. This point is recognised in the document " *Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared decision-making*;

- Choice of treatment should be between treatment options that are recognised as clinically appropriate, effective and safe and equally, choice over services should always be clinically appropriate. We agree with this point.

15. Respondents identified a number of potential risks to equality from the broad proposals to give patients greater choice, which we have also considered in developing further our proposals. Respondents told us that risks could include:

- rural areas may have less choice of providers;

- patients with specific support needs or those needing help with information, such as children, elderly patients or people with learning disabilities, may not receive the necessary support to engage fully in shared decision-making;

- some conditions are too rare to grant any real choice of provider;

- implementing the proposals to give patients more say over their care and treatment could be costly at a time when the NHS is required to make savings;

- the transfer of patients from one provider to another may not be seamless, possibly leading to duplication of work and incurring extra cost for the NHS;

- additional transport costs may be incurred if patients choose non-local providers;

- fragmentation of care pathway and a loss of continuity of care could result if patients choose to see different providers;

- independent providers may identify only the most cost effective services, and 'cherry-pick' patients from the local provider;

- possible loss of local services, if closure occurs due to patients choosing independent providers.

16. In developing our proposals, we have given due consideration to any potential risks identified. Our proposals are designed to mitigate any risks. We have published alongside our response documents an equality analysis and an impact assessment, which consider economic impacts and impacts on equalities in more detail.

1. Introduction

1.1 The purpose of this document is to summarise the responses received to the Government's consultation document *Liberating the NHS: Greater choice and control*. The Government response including more detailed proposals is set out in the accompanying document: *Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared decision-making.*

Why focus on giving patients greater choice and control?

1.2 The White Paper, *Equity and excellence: Liberating the NHS*, set out the Government's vision of patients and the public being at the heart of the NHS – 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.

1.3 The White Paper stated that, "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." Choice would also be extended so that shared decision-making becomes the norm: "no decision about me, without me".

Consultation process

1.4 The Department of Health undertook to consult widely to gain views on the best ways to implement the commitments to give patients greater choice and control as set out in the White Paper. The first round of the consultation, *Liberating the NHS: Greater choice and control*, ran for thirteen weeks from 18 October 2010 until 14 January 2011, following Cabinet Office protocol.

1.5 This consultation document set out broad proposals to implement the choice commitments and sought the views of patients, the wider public, healthcare professionals and the NHS about how this might best be achieved. 54 questions were asked that covered:

- proposals on choice commitments to extend choice of provider and treatment in planned hospital care, maternity, mental health, end of life care and long term conditions;

- what can be done to achieve the necessary culture change and make shared decision making the norm;

- how we can ensure that the choices people make are safe and sustainable, and ensure that their preferences do not cause problems for them or the NHS;

- how to ensure informed choices on care and treatment are available for all.

1.6 The consultation document was available on the Department of Health's website and responses could be returned online, by email or by post.

1.7 To reach the widest audience possible, summaries of the consultation document were made available in various accessible formats, including easy-read, alternative language and large print. A summary presentation of the proposals, the consultation questions and a guide to running a consultation event were produced for organisations to use when engaging with their members to inform their responses to the consultation.

1.8 Responses were logged and analysed by the Department of Health.

1.9 During the consultation period, a number of engagement events and activities were carried out around the country to promote the consultation document and encourage people to put forward their views:

- key messages about the consultation were inserted into events where appropriate and relevant;

- Strategic Health Authorities (SHAs) conducted local engagement;

- presentations were given at events run by organisations with an interest (eg the Race Equality Foundation and the Mental Health Providers Forum).

1.10 The NHS Future Forum ran a Listening Exercise between 6 April and 31 May 2011, and their recommendations were published in June in their report *Choice and Competition: Delivering real choice*[5]. The NHS Future Forum's report and the Government's response[6] to their report have been taken into account in this consultation process.

1.11 The *Liberating the NHS: Greater choice and control* consultation questions are set out in Annex A along with the percentage of respondents who answered each question. Annex B contains selected quotes taken from the consultation returns. A list of organisational respondents is included as Annex C and a list of the engagement events and activities attended during the consultation period is recorded at Annex D.

---

[5] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_127541.pdf

[6] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127444

1.12 The accompanying document, *Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared decision-making,* sets out the Government's response including detailed proposals and a small number of additional questions around the overall concept of the proposals. A full impact assessment and equality analysis will be published alongside the response and further proposals.

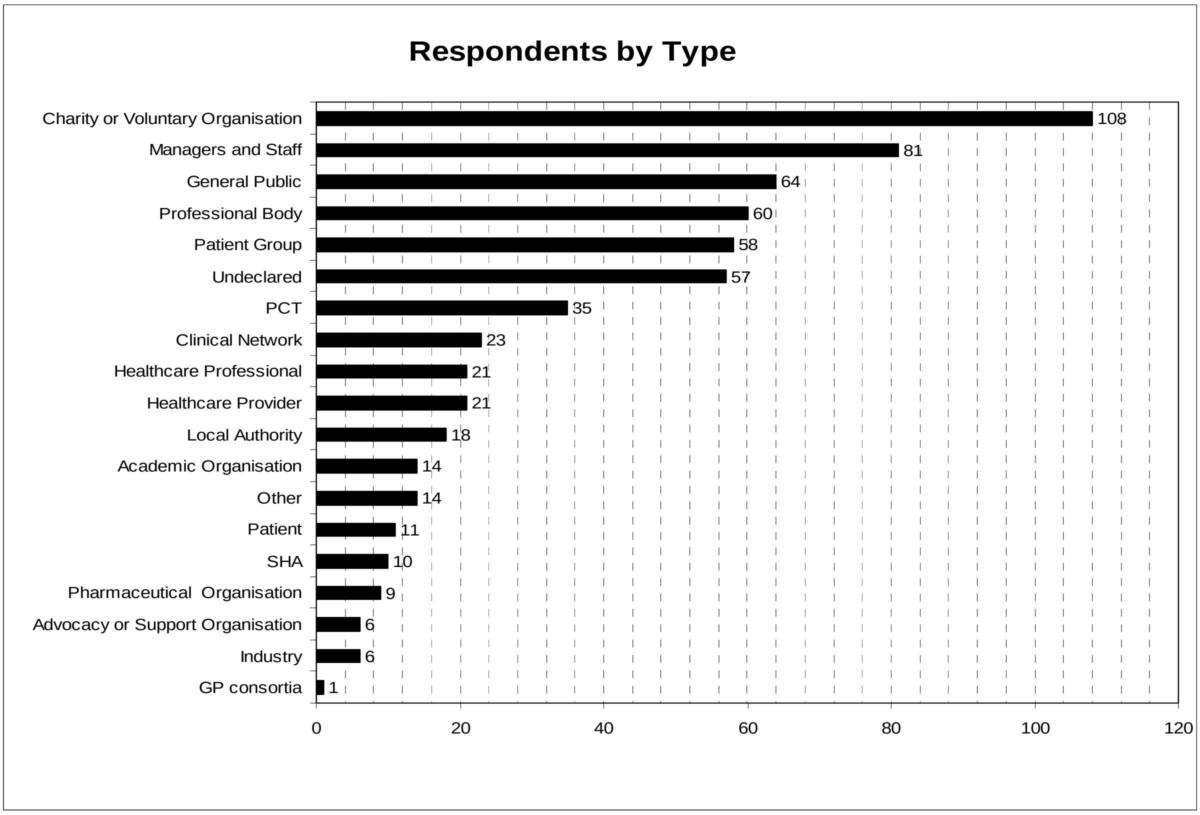
Consultation responses

1.13 617 unique responses[7] were received from stakeholders, including patients, members of the public, clinicians, voluntary organisations, patient representative groups, carer organisations, local authorities, local involvement networks (LINks), NHS organisations and staff, independent providers, pharmacists, academics, professional bodies and Royal Colleges, think tanks and trade unions. A breakdown of respondents is demonstrated below.

1.14 Given the huge scope of the content, we did not expect every respondent to answer all 54 questions. An indication of the proportion of responses to each question is included within the table at Annex A.

---

[7] The total number of responses received was 834, but 219 of these were on one of three templates from individuals or their carers with ME/Chronic Fatigue Syndrome. Two of the three templates were identical; the third differed very slightly. For our calculations, we therefore subtracted 219 from the total number of responses, and added two to represent the slightly different templates.


Respondents by Type
Charity or Voluntary Organisation 108
Managers and Staff 81
General Public 64
Professional Body 60
Patient Group 58
Undeclared 57
PCT 35
Clinical Network 23
Healthcare Professional 21
Healthcare Provider 21
Local Authority 18
Academic Organisation 14
Other 14
Patient 11
SHA 10
Pharmaceutical Organisation 9
Advocacy or Support Organisation 6
Industry 6
GP consortia 1
0
20
40
60
80
100
120

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. The Government has said that everyone should have more say over their care and treatment and choice of any qualified provider wherever relevant.[9] The exception to this will be when it is considered clinically inappropriate or impracticable to expect people to make choices – for example, where there is a need to access the right care urgently.

2.2. Many of the questions not only invited responses about specific health areas but also raised broader issues around how best to involve patients in all aspects of their care. In an attempt to reflect accurately the responses, we have provided headings for the emerging themes as well as identifying the more specific issues.

Choosing a healthcare provider when first referred for planned care

> *"We will increase the current offer of choice of provider significantly…"*

What we asked

2.3. We asked:

- (question 1): "How should people have greater choice and control over their care? How can we make this as personalised as possible?" and,
- (question 4): "What would help more people to have more choice over where they are referred?"

---

[8] White paper, *Equity and excellence: Liberating the NHS* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

[9] At the time of publication of the consultation document, this was referred to as "any willing provider", However, although the meaning of "any willing provider" and "any qualified provider" is the same, the terminology has changed to reflect the rigorous qualification process providers will be expected to meet before they can provided NHS services. The term "any qualified provider" is used within this document except where referring to direct quotes from previously published documents or from responses to the consultation.

What we heard

2.4. **Choice must be supported by appropriate information**, which should be accessible, easy to understand and up-to-date. More appropriate data is required about providers' clinical outcomes, waiting times, mortality rates, previous patient experiences and greater use should be made of Patient Reported Outcome Measures (PROMs).

2.5. **Appropriate interaction with the healthcare professional is critical,** with some respondents noting that a cultural shift is needed by some healthcare professionals to increase the offer of choice and facilitate shared decision-making.

2.6. **Some education of patients would be necessary,** to ensure patients assume responsibility for their healthcare needs and to ensure that they are aware of the opportunities to make choices.

2.7. **Changes in GP behaviour would be needed**, with some respondents recommending more time is made available for patients to spend with their healthcare professional. One suggestion was to penalise GPs who did not offer sufficient time or offer incentives to ensure that they discuss choice options with patients.

2.8. **Availability of formal support.** Respondents wanted improved support structures to allow patients easier access to advocates or support workers. Some believed healthcare professionals were best placed to provide this support and the provision of help with travel costs was also suggested.

2.9. **Use of Choose and Book.** Many views were received around Choose and Book, including suggestions that its use be mandated for referrers and providers. Chapter 4 deals with this issue in more detail.

2.10. **Personalised care planning would facilitate choice.** A few respondents noted the complicated nature of some long-term conditions, and suggested that patients should be able to choose between packages of care, as opposed to having discrete choices at all the different stages of the care pathway.

2.11. **Personal health budgets would facilitate control.** Respondents supported personal health budgets as a means of giving individuals more say when choosing between treatment options.

2.12. Other points made by respondents included:

- patients should be able to opt-out of making a choice if they wished;
- local services should not be allowed to suffer;

- there should be equality of opportunities to make choices;

2.13. A few respondents questioned whether patients wanted more choice, with the majority of these stating that priority should be given to the provision of good local services rather than looking to give patients more say over their care and treatment.

Our response

2.14. We agree that a shift in culture of both referrers and patients will be required to achieve the vision of shared decision-making as the norm and more choices all along the patient pathway. We also acknowledge that patients need varying levels of support in making decisions and that access to appropriate information is essential to help patients exercise informed choice. We say more about how we expect to achieve our vision in the *making it happen* section of the accompanying further consultation document *Liberating the NHS: No decision about me, without me.*

Greater choice of provider in unplanned care

What we asked

2.15. We asked (question 3): "How can we offer greater choice of provider in unplanned care?"

What we heard

2.16. The most common response, made by around a quarter of respondents, was that it would be very difficult and/or undesirable to implement choice of provider in unplanned care. Reasons given for this included:

- the public do not want choice for unplanned care.
- the risk of duplicating provision of care, and associated costs.

2.16 In contrast, a few respondents noted that choice in unplanned care already exists through the provision of A&E, Walk-In Centres, pharmacists etc.

2.17 Ensuring provision of suitable information to support extension of choice in unplanned care was the second most popular theme amongst responses. A few respondents suggested specific ways in which information about participating providers should be organised, with some form of central database, accessible by the GP.

Our response

2.18 Although this question was included to enable respondents to state which choices they would expect or require when needing urgent or unplanned care, it is clear from the majority of views that it is felt that more choice for unplanned care at this time is inappropriate. As many respondents noted, there are a number of existing choices for people requiring unplanned or urgent care and the main concern was around the provision of suitable and accessible information that allows people to know of existing choices within their area, when it is appropriate to access these facilities and how they can be reached.

Priorities for introducing choice of any qualified provider

> *"The Government will create a presumption that all patients will have choice and control over their care and treatment, and choice of any willing provider wherever relevant (it will not be appropriate for all services – for example, emergency ambulance admissions to A&E)."*

What we asked

2.19 We asked:

- (question 2): 'Which healthcare services should be our priorities for introducing choice of any willing provider?'
- (question 41): "Do you agree with the proposed approach to establishing a provider's fitness to provide NHS services? What other criteria would you suggest?"[10]
- (question 42): "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?"

---

[10] The proposals in the consultation document covered currencies and standard national NHS pricing of services, joint licensing of providers and, contractual and commissioning issues.

- (question 43): “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?”

What we heard and Our response

2.20 The Government response to the “*Greater choice and control*” consultation on implementing choice of any qualified provider was published on 19 July 2011 along with “*Operational Guidance to the NHS : extending patient choice of provider*” to give guidance to providers and commissioners on implementing the Government commitment to extend patient choice, this is accessible on the Department of Health website.[11]

Choices in 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.”*

What we asked

2.21 We asked (question 5): “Which choices would you like to see in maternity services and which are the most important?”

What we heard

2.22 Just under half of respondents felt that decisions about how and where maternity and newborn care is provided as being the most important choices within maternity services.

2.23 Around a tenth of respondents suggested that all relevant choice options should be available; however, slightly more respondents felt that some choices should be limited depending on a woman’s state of health, circumstances and risks. A minority said the NHS should only offer core maternity services.

---

[11] http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_125442

2.24 Respondents were split over whether care should be provided by a single provider, with some having the view that women should be able to choose to have elements of care provided by different maternity services. Others said that all required care should be provided by a single maternity service, and just under a quarter said that most maternity services should be available locally.

2.25 About a quarter of respondents commented on the importance of information and support to help women and their families understand the interdependencies between their choices for care (e.g. epidural anaesthesia is not available for births at home or in midwife-led units).

2.26 About 20% of respondents felt that having a few options that were consistent with equitable access, took priority over providing a large number of choices, some of which may not be available when women wished to access them.

2.27 For some respondents, specific choices were important, such as choice of a lead health professional, access to support with lifestyle, parenting or breastfeeding support, pain management/relief, antenatal education, screening and having an elective caesarian section.

2.28 The maternity and newborn service providers and professional bodies who responded were mostly supportive of maternity networks as a mechanism for extending choice.

Our response

2.29 The majority of responses confirm the importance for women and their families to have choice about where and how pre-conception, maternity and newborn care is provided. To support the NHS in delivering improved outcomes, a suite of quality standards – antenatal, intrapartum (birth) and postnatal care – are being developed by NICE during 2011/12. These proposals and others are set out in the accompanying further consultation document *Liberating the NHS: No decision about me, without me.*

Choices for users of 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.”*

What we asked

2.30 We asked (question 6): “Are these the right choices for users of mental health services, and if not why not?”

What we heard

2.31 The majority of respondents thought the choices set out in the consultation document were broadly the right ones. There was general support in principle for the development of the any qualified provider model for mental health services, although an appropriate governance and regulation framework to ensure all provision is safe and evidence based was expected. A small number of respondents urged proportionality on any regulation and support for smaller organisations.

2.32 Around 7% of respondents identified a need for good information on the quality and availability of services and the requirement of information systems for support. Also highlighted was the critical role of the third sector, carers, families and advocates in supporting patient choice and information.

2.33 A few respondents said that speed of treatment was more important than choice, with others suggesting that the provision of more choice could reduce waiting times.

2.34 A small number of respondents wanted the government's approach to adopt a more gendered view when tackling mental health and ensure that choice extends to children and young people's services.

2.35 Around 8% of respondents commented on the necessity to restrict some choice for patients detained under the Mental Health Act. Some highlighted the need to consider forensic settings and prisons; the need to take account of the proximity of the patient's local community networks; and the importance of structured care planning. The British Medical Association (BMA) and the Royal College of Speech and Language Therapists requested detail on how choice could work in relation to imposed treatment under the Mental Health Act.

Our response

2.36 We are content that there is general support for the proposed choices in mental health and we noted the support in principle for extending choice of provider through the any qualified provider model in mental health services. Future plans and more detail on how we propose to take forward choice for mental health services are included within the accompanying further consultation document *Liberating the NHS: No decision about me, without me.*

Choice of diagnostic provider

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

What we asked

2.37 We asked:

- (question 7): “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?”
- (question 8): “Are there any circumstances where choice of where to go for diagnostic testing would not be appropriate, and if so what are they?”

What we heard

2.38 The majority of responses were supportive of introducing choice of diagnostic test provider especially at referral but with recognition that there were some points during the patient pathway where it might not be in the best interest of the patient. The proportion of responses against any choice of diagnostic provider was less than 3%.

2.39 A third of respondents agreed with offering more choice for diagnostic testing at all of the proposed stages. Some respondents linked this question with the proposals for extending choice of treatment, whilst a further 14% welcomed all of the choices except ‘whilst in hospital receiving treatment’ as they had doubts about how this would benefit the patient.

2.40 The most common suggestions for when diagnostic testing should not be allowed was if a patient was in some way unable or incapable of making a decision, or where it was not clinically appropriate.

2.41 Patients raised concerns and issues on:

- the patient's ability to make a fully informed and supported choice of diagnostic test provider;
- the potential impact on the continuity of care of a patient choosing different providers at different stages of the pathway;
- the potential for wasting NHS time and resources by duplicating work;
- the potential for wasting patients' time;
- ensuring that choice of diagnostic test provider is available to all.

Our response

2.42 We are pleased to note that the majority of respondents support greater choice of diagnostic test provider and we have set out our proposals for implementing this in the community and in secondary care in our consultation document " *Liberating the NHS: No decision about me, without me*. We have taken on-board the points raised by respondents. Choice of diagnostic test provider will be facilitated where possible through the Choose and Book system and there will be new requirements for providers to supply information to support these choices. We accept that enabling individuals to have greater choice of diagnostic test provider is not appropriate at all stages of healthcare, for example, when a person is receiving inpatient hospital care or where diagnosis is needed urgently and we have acknowledged this limit on choice in our proposals document.

Choice of healthcare provider and consultant-led team post diagnosis

"We will begin to introduce… choice post diagnosis from 2011".

What we asked

2.43 We asked:

- (question 9): "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?"
- (question 10): "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?"

- (question 11): “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?”

What we heard

2.44 Around 75% of respondents indicated that they would like the opportunity to choose their healthcare provider and consultant-led team after their diagnosis, although there were concerns that this could lead to differences in referral patterns and possibly fragmented patient pathways.

2.45 There were also concerns that if choice was not managed well, patients choosing different providers at different points in the pathway could ‘fall between the gaps’ as records may not be shared between providers. This could result in patients not being called for treatment or getting appropriate support.

2.46 One way to mitigate these concerns could be to embed choice of provider more clearly within the care pathway so that practical elements of record keeping and handover may be managed properly, avoiding potential issues such as:

- problems with follow up management of complications if a distant provider supplies treatment;
- a GP is less likely to know the track record of ‘distant provider’ and therefore less likely to be in a position to advise patients about that service;
- matters of legal responsibility and where concerns about appropriate treatment arise between first consultant and second consultant;
- the risk of poor communication if relevant details about allergies, drugs or investigations, for example, are not effectively communicated from first to second provider,
- the risk of poor communication if no correspondence is received due to secretarial issues / staff sickness / maternity leave, for example.

2.47 Another recommendation was that commissioners should have access to specialist advice, to plan and commission pathways across clinical commissioning group boundaries, so as to enable choice of provider where possible.

Our response

2.48 We note that many respondents indicated that they would support more choice over provider or clinical team after a diagnosis has been made. Patients may wish to change provider or consultant-led team if they have had a poor experience, or where an alternative, more appropriate treatment or management option is available.

2.49 We also noted the concerns that respondents had about possible fragmentation of pathways and of patients "falling between the gaps". For these reasons, we consider that choices post-diagnosis should be made jointly with the patient's clinician, and / or with their GP. It is also recognised that some conditions require extremely specialised care, which only a few providers can offer. In the accompanying further consultation document *Liberating the NHS: No decision about me, without me,* we set out how patients can exercise choice once a diagnosis has been made.

Personalised care planning and long term conditions

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

What we asked

2.50 We asked (question 12): "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?"

What we heard

2.51 The responses indicated overwhelming support for care planning to help engage people in decisions about their care. Supported self-care, shared decision-making and structured education and information were given as essential components of good care planning.

2.52 However, the general view was that for quality care planning to be implemented, a number of whole system changes need to occur, together with supporting the workforce with the right skills, approaches and capacity to undertake care planning.

2.53 Key themes that emerged were:

- the quality of care planning as described in the government's vision and illustrated in the consultation as a case study example, is still not universally adopted;

- the workforce needs education and training to work more effectively in partnership with individuals and their families and carers;
- workforce was an issue raised by a significant number of respondents, not just around training, but also for staff to undertake care planning discussions, particularly nurses, allied health professionals, other support staff and better use of pharmacists to support medicines management and self-care;
- integration between primary, secondary, social care and the voluntary sector with more multidisciplinary team working is viewed as being crucial for successful care planning. Joint needs assessments for those with the most complex needs as part of care planning is also vital;
- time, resources and capacity to undertake care planning. Communication needs to be recognised and applied, and there needs to be a clear definition of what a care plan should include, to promote national consistency;
- developing national standards for care planning would drive up quality. The NHS Commissioning Board and clinical commissioning groups would have an important role in modelling best practice and setting the parameters for local commissioning arrangements;
- NHS staff should know of the wider local choices available to meet holistic needs.

Our response

2.54 We are pleased that there is support for the personalised care planning as an integral component of a generic Long Term Conditions (LTC) model for the NHS. To help make care planning a reality, we have produced a range of guidance documents and actively promote the concept.

2.55 In addition, we have established a specific long-term conditions work stream as part of the Quality, Innovation, Productivity and Prevention (QIPP) programme to improve the quality of care for patients. Future plans and proposals are set out in the accompanying consultation document, *Liberating the NHS: No decision about me, without me.*

Choice in end of life care

> *“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.”

2.56 Several questions on end of life care were asked within the consultation document. As each question concerned specific issues we have listed them separately as themes.

What we asked

2.57 We asked (question 13): “What choices are most important to people as they approach the end of their lives? What would best help to meet these?”

What we heard

2.58 The majority of respondents confirmed that choice of where to die was a key component for good end of life care. Only a small minority said that this was not necessary, instead identifying high quality care as the most important thing, regardless of care setting.

2.59 A number of respondents sounded a note of caution on placing too much emphasis on gearing services towards meeting choices around place of death. They put forward the view that people sometimes change their minds about where they would like to be cared for, and that consequently, services needed to be flexible to respond to changing wishes.

2.60 Having choices around treatment and care was a clear theme in the responses. Linked to this, some respondents stressed the need for effective pain control and management of symptoms, and the importance of having a say over how this was managed. Choices about the environment in which care was given were also identified as being important.

2.61 In terms of what would best help meet these choices, a number of topics emerged:

- the need for shared discussions about care and treatment options between people approaching the end of life and clinicians or other care staff to take place early, ensuring that there was time to plan care effectively, and talk through the individual’s care preferences with the individual and their families or carers;
- support for the development of care plans, and the need to make these easily available to health and social care staff involved in the individual’s care;

- providing individuals and carers with clear information about the prognosis, where possible and the choices available to them;

- improved training for staff, in relation to end of life care;

- improved co-ordination of care, through more integrated working between health, social care, and the voluntary sector and ensuring individuals are provided with a named contact, or key worker;

- help and support available in the community 24/7. Most often highlighted was the availability of community nursing services.

- the importance of considering, and responding to the needs of carers and the provision of respite care, training and support for the family in their caring role.

2.62 Enhancing care provision in the community was highlighted as a key requirement to support greater choice and quality of care, particularly in relation to supporting people to die at home, or in a care home. Views given, included 24/7 nursing service coverage, better co-ordination of care and effective support for carers.

What we asked

2.63 We asked (question 14): “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?”

What we heard

2.64 A small number of responses specifically endorsed the need to widen the range of end of life care services; although others felt existing services are broad enough but could be strengthened.

2.65 Some other routes to expand the range of service provision were suggested:

- encouraging the development of less clinically based services and greater use of personal health budgets;

- improving training for health and social care staff;

- 24/7 community nursing provision, the importance of respite care and the need for better co-ordination of care were also highlighted;

- the new commissioning arrangements were identified by some respondents as a means to stimulate service provision and address gaps in services;
- training for commissioners in end of life care;
- the important role of hospices and the further development of hospice outreach services, such as Hospice at Home. The reliance of hospices on voluntary funding was raised and the possible need for increased funding for hospices;
- the need to address existing inequalities in access to specialist palliative care services for different condition groups was mentioned by some respondents, as was the need for services to be responsive to the needs of different groups in society, such as lesbian, gay, bisexual and transsexual people and black and ethnic minority communities.

What we asked

2.66 We asked (question 15): “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?”

What we heard

2.67 The responses revealed a range of opinions about balancing the wishes of the dying person and the carer. Some expressed the view that as long as sufficient care was in place, both for the patient and carer, difficulties should not arise. In addition, care packages should take account of the level of involvement in the individual’s care that the carer is willing, and able, to take on.

2.68 A minority felt that sometimes a place other than home would need to be considered, as providing care within the home may not always be appropriate, particularly for those with very complex needs.

2.69 Some responses stated that the wishes of the person approaching the end of life were paramount. However, a more consistent theme was that both the individual and the carer are important, and that any difficulties should be resolved through discussion. Also highlighted was the important role of professionals, such as GPs, in facilitating these discussions and ensuring all parties had a clear understanding of what options and support were available.

2.70 A clear message from those responding, was that individuals and carers should be actively engaged in the decision-making process right from the start, and address issues through the advance care planning process. Carers should be able to have discussions away from the patient, providing freedom to speak in confidence.

2.71 Respondents gave clear support for the provision of effective support for carers, through counselling services as well as undertaking and implementing, assessments and care plans for carers.

Our response

2.72 We acknowledge the points raised by respondents. We remain committed to establishing a national choice offer for people and their families who choose to die at home, including care homes, to receive the support that they may need. The responses to the consultation supported the introduction of this right of choice, as one of the processes of supporting the delivery of high quality, patient-centred care. We will continue to implement the End of Life Care Strategy[12] to ensure that the right services are in place, particularly in the community, and to allow the right of choice to die at home to be introduced. The Strategy addresses many of the points made.

2.73 In 2013, we will review progress in implementing the End of Life Care Strategy, which will include looking at the feasibility and timescale for introducing this right. Following the review, we will be in a better position to assess if a right can be introduced within a realistic timescale

Choice of treatment

"We will consult on choice of treatment later this year…"

What we asked

2.74 We asked (question 16): "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."

What we heard

2.75 Overall, respondents favoured choice for all types of treatment. Approximately 15% of respondents identified a limited range of treatments

---

[12] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

that could be offered under choice. Within this group, some said that treatments offered should be those approved by the National Institute for Health and Clinical Excellence (NICE), although others did not see NICE [13]guidelines and local commissioning practice as suitable limits for the choice offer.

2.76 Many respondents felt that medication and surgery were the main areas where choices could be made. Around 7% of respondents suggested expanding the offer of treatments to include non-clinical or non-traditional therapies. However, others felt that only clinically proven treatments should be available as part of the choice offer.

2.77 Some respondents suggested that they would like to have choice of when and where to have treatment, with choices being largely influenced by location and practicality for the individual. For some, this meant being able to choose an appointment time at their or their carers convenience, whilst for others, this meant more flexibility in the treatment pathway.

2.78 As with most of the choice commitments, many respondents felt that choice of treatment should be supported with information or advice from their healthcare professional, including relevant details such as side effects. A few suggested that choice of treatment should include facilities to support greater self management or self help and that these be offered within a community setting.

2.79 A potential risk raised by a small number of respondents was that people might make treatment choices that have a negative effect on their healthcare. Suggestions to mitigate this risk included the possibility of providing patients with decision aids.

Our response

2.80 We were encouraged by the responses, which indicated that the majority of people favoured choice for all types of treatment. Choice of treatment in the NHS will be strengthened through the provision of information and implementation of shared decision-making. This will ensure dialogue between patient and clinician becomes stronger as both parties are more informed about the treatment options. There will necessarily be limits on the treatment choices available to ensure that treatments are clinically appropriate and affordable. We say more on this in our consultation document “ *Liberating the NHS: No decision about me, without me.*

---

[13] www.nice.org.uk/

.Taking responsibility for health and treatment 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."*

What we asked

2.81 We asked (question 17): "How can we encourage people to take more responsibility for their health and treatment choices?"

What we heard

2.82 In terms of encouraging people to take more responsibility for their choices, there were a number of recurring themes:

- Around a third of respondents stated that better provision of information was required, with the most popular suggestion being through the education system. Also suggested was the need for better education or training for people once they had been diagnosed with certain conditions. Others recommended advertising or public health campaigns. Many respondents also held the view that patients would be more likely to take personal responsibility for their choices if they were more aware of the consequences on both themselves and the health service. Suggestions given to encourage people to take more responsibility included:
- involving patients in decision-making about their healthcare;
- using incentives and/or penalties;
- the use of personal health budgets;
- the offer of choice in itself and emphasising the benefits to the patient;
- the suggestion of a "contract" or 'personal care plan' that could be drawn up between the NHS and patient when treatment is agreed.

2.83 A concern raised by some respondents was that encouraging people to take more responsibility for their choices represents a fundamental culture shift in both the minds of healthcare professionals and patients. The main risk associated with this was that not everyone would want to, or be able to, take more responsibility for their choices.

Our response

2.84 We noted the importance that respondents attached to information, shared decision-making and personal budgets as a means of helping patients to become more responsible and aware of their health needs. These themes are picked up throughout our accompanying further consultation document, *Liberating the NHS: No decision about me, without me.*

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 consultation asked a range of questions about making shared decision-making the norm throughout the NHS. The responses provided views on what could be done for, or by, patients, carers, healthcare professionals, voluntary, community and Social Enterprise Sector organisations and patient-led groups. Questions on patient decision aids, encouraging people to be involved in healthcare decisions, advance care planning and healthcare professionals support for the choices patients make, are addressed under relevant headings.

What we asked

3.2 We asked:

- (question 18): "How do we make sure that everyone can have a say in their healthcare?"
- (question 19): "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?"
- (question 20): "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?"
- (question 21): "How can we support the changing relationship between healthcare professionals and patients, service users, their families and carers?"
- (question 22): "What needs to be done to ensure that shared decision making becomes the norm? What should we do first?"
- (question 23): "Should healthcare professionals support the choices their patients make, even if they disagree with them?"
- (question 24): "What sort of advice and information would help healthcare professionals to make sure that everyone can make choices about their healthcare?"

- (question 27): “How could training and education make choice and shared decision-making a part of healthcare professionals’ working practices?”

- (question 28): “How can we help people to learn more about how to manage their health?”

- (question 29): “What help should be available to make sure that everyone is able to have a say in their healthcare?”

- (question 30): “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?”

- (question 31): “How can we make sure that carers’ views are taken into account when the person they support makes a healthcare choice?”

- (question 32): “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?”

- (question 33): “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?”

- (question 34): “How can people be encouraged to be more involved in decisions about their healthcare?”

- (question 35): “Would decision aids be a useful tool for healthcare professionals and their patients and service users? Are there any barriers to their use?”

Making shared decision-making the norm

What we heard

3.3 Whilst respondents felt that there was no single solution to achieving a changed relationship between patients and professionals, suggestions were made around roles and actions that could be taken by strategic, commissioning, provider, professional and other organisations to support improved shared decision-making. These fell broadly into two major themes:

- **develop a clearer vision of shared decision-making** involving healthcare professionals, patients and their representatives and other key organisations and incorporate these across the health system;

- **greater and more intelligent use of information for patients and information about patient experience**. The former included ensuring greater use of up to date, trustworthy and accessible information about symptoms, conditions and treatments. Regarding the latter, respondents suggested that this would include greater transparency around complaints and could be used to hold healthcare providers to account;

3.4 Responses from patients clearly indicated that patients should actively request and seek greater involvement in decisions around their healthcare. Other views included:

- encouraging greater public and patient awareness, through the promotion of their existing rights and responsibilities. For example, the NHS Constitution includes the patients right to 'be involved in discussions and decisions about (their) healthcare, and be given information to enable (them) to do this'.[14] Ideas on how to generate public and patient awareness and understanding, included the use of mass media and television publicity, and working with schools;

- respondents highlighted the importance of providing opportunities for individuals to become involved in decisions around their care and treatment;

- allowing patients greater control over their own health information, including having access to their own records and being the prime recipients of letters about them, for example regarding their diagnosis or test results;

- using information prescriptions;[15]

- access to useful, accurate and up-to-date healthcare information, from reliable sources was viewed as being very important. GPs were often considered to be the trusted first port of call;

- independence of information providers, with voluntary groups being considered impartial. Some referred to the value and potential of the Information Standard[16], although it was noted that the accreditation process could be cumbersome.

3.5 Respondents raised a number of concerns about shared decision making from a patient's perspective:

---

[14] NHS Constitution (March 2010) p.11

[15] The Information Prescription Service, hosted by NHS Choices is at http://www.nhs.uk/IPG/Pages/IPStart.aspx

[16] http://www.theinformationstandard.org/

- not everyone wishes to be included in a shared decision-making process but everyone should be able to make their views known;

- engaging seldom heard and vulnerable groups in decisions about healthcare can be challenging and some healthcare professionals may overlook them or perhaps view some individuals as not having the ability to become involved in decisions about their healthcare;

- it is not always possible to develop good relationships with healthcare professionals, which may prevent some individuals becoming fully involved and informed about their care and treatment.

3.6 Responses from carers and families highlighted their involvement in healthcare decisions as a complex area, with the majority keen to stress that the patient's needs and patient confidentiality were paramount. Respondents also wished the patients' views and decisions to be given priority unless they were unable to make informed decisions or understand the implications of those decisions. There were a number of suggestions around how carers and families could best be supported in contributing to decisions:

- ensuring the early identification of a carer/family member, their expected responsibilities and prospective level of involvement. This information should be confirmed with all parties at an early stage. Patients to be able to nominate a carer or relative to be kept informed and involved in relevant decisions;

- proactively involving carers and families in decisions as appropriate, at all stages of the care pathway;

- making carers aware of existing rights and responsibilities – both theirs and the patients'- referencing existing documents such as NICE guidance on dementia[17] and the Mental Capacity Act 2005;[18]

- considering the impact of patients' decisions on the carer and involving carers when a patient's decision impacts upon them. For example, where a carer is required to provide more support to the patient;

- an extension of personal budgets for people with long term conditions.

3.7 Respondents raised a number of concerns about shared decision making from the perspective of carers and families:

- the difficulty of sharing health records was raised as a potential barrier to carer involvement in decision-making. Respondents noted that access to patient

---

[17] http://www.nice.org.uk/CG42

[18] http://www.dh.gov.uk/en/SocialCare/Deliveringsocialcare/MentalCapacity/MentalCapacityAct2005/index.htm

records was not always dealt with as part of the process of taking power of attorney;

- some respondents noted that although the vast majority of carers act in the best interest of the person they care for, there would be exceptions. In addition, some carers feel unable to be completely honest with healthcare professionals due to concerns that views given in confidence may be recorded and inadvertently disclosed to the patient.

3.8 The majority of respondents felt that the attitude and openness of healthcare professionals was central to make shared decision-making the norm.

3.9 Whilst a number of respondents felt that healthcare professionals already practised shared decision-making and that there was sufficient coverage of shared decision-making and related skills in some existing curricula, others were clear that they wanted healthcare professionals to receive specific education and training around shared decision-making.

- Some respondents wanted this training to be included in pre-registration education, but many others wanted it within postgraduate or continuing professional education and suggested it be made an explicit competence. It was also suggested that shared decision-making should be included within professional revalidation.

- Specific ideas on how best to embed patient involvement within healthcare professional education and training included:

  - communication skills training;

  - greater involvement of patients within training programmes for healthcare professionals;

  - a wider use of video-based and e-learning material featuring facilitative consultations;

  - engaging organisations who invest in continuing professional education to look at the development of shared decision-making training resources.

- If healthcare professionals actively support patient access to records and test results, it would be a significant step towards improved shared decision-making.

- Healthcare professionals to have information relating to patient feedback on providers and up-to-date outcomes. Increasing the use of patient and carer feedback was suggested as a way of ensuring that healthcare professionals know how their patients, and their carers, feel about their care experience, including whether they are involved as much as they would like to be. This includes ensuring sufficient time within consultations to allow for shared decision-making.

- Providing healthcare professionals with a concise and complete list of what options are available to patients would facilitate patient choice.

- Respondents felt that healthcare professionals have a significant role in providing or signposting patients to information about their condition to help them to make informed decisions. Some respondents saw GPs as the first source of information, referring to other sources only when necessary. However, in recognising time pressures, other respondents argued for a bigger information-provision role for non–statutory organisations and for other members of the wider healthcare team.

3.10 Some reservations were expressed about the reluctance of some healthcare professionals to engage in relevant training unless there was the time and/or incentive to attend.

3.11 Respondents identified a number of key areas for the involvement of the voluntary sector and patient groups:

- the provision of relevant support, information and advocacy through voluntary organisations;

- patient groups could help people to navigate services and to make choices**,** but may need access to the same information about services, performance and treatments as their statutory counterparts;

- patient groups could provide leadership and help develop a vision for shared decision-making with clinicians, managers and other organisations;

- patient and voluntary organisations could encourage people to become more involved with their healthcare through awareness and promotion activities;

- local HealthWatch could remind commissioners and providers that shared decision-making is expected normal practice.

3.12 Some respondents questioned whether the voluntary sector would be able to fulfil its potential in supporting shared decision-making due to funding level concerns.

Patient Decision Aids

What we heard

3.13 Decision aids, both specific and generic, were highlighted by respondents as useful tools to encourage and support patients to become involved in healthcare decisions:

- there was overwhelming support for patient decision aids as a tool for healthcare professionals and patients to use together when discussing treatment and care;
- for decision aids to be embedded successfully in the healthcare professional and patient dialogue they must be accessible on well used and recognised online platforms like NHS Choices, Choose and Book, and in a range of formats and languages. Respondents stated that a simple, generic decision aid would be useful;
- many respondents expressed the view that healthcare professionals would need to support the use of patient decision aids and have the right skills to make the best use of them with patients and their carers. Some thought that a degree of culture change, assisted by education and support packages for individual healthcare professionals and clinical teams, would be required for this to happen;
- respondents said that decision aids would have to be kept up to date, easy to understand and evidence-based. Patients and carers, as well as healthcare professionals, would need support to use the aids effectively and ensure that they are used at the right point in the patient pathway.

3.14 Respondents raised a number of concerns:

- decision aids are no substitute for a proper consultation with a healthcare professional. Additional consultation time may be needed to ensure healthcare professionals and patients are able to consider a decision aid together and agree an outcome or course of action;
- decision aids may not be accessible for some, for example, those who are unable to access the internet, those with limited English language skills and those whose circumstances make the use of certain aids difficult, such as children or people suffering from certain mental health problems;

- lack of awareness with some respondents stating they were unclear what patient decision aids were, suggesting there is a need for raising awareness of such tools;
- decision aids would need to be quality assured, evidence-based and accessible if they were to be of use.

Encouraging people to be involved in healthcare decisions, and ensuring that people's choices can reflect their different backgrounds

What we heard

3.15 As well as themes that have been described elsewhere, a number of specific responses provided views on how people can be encouraged to learn more about managing their health. There was general support for:

- the Expert Patient Programme;[19]
- time within clinical consultations to enable full consideration of decisions;
- condition-specific management courses such as those for pain, diabetes and similar conditions;
- provision of condition-specific information and support, particularly by voluntary organisations;
- public programmes of health education and awareness, via the media;
- a greater number of referrals by healthcare professionals to voluntary sector resources to support patients in decision-making;
- lifestyle and health education on subjects such as exercise and nutrition, with the emphasis for these to start at school-age;
- community pharmacists as they could have a particularly valuable role to play.

3.16 Ensuring that everyone has the opportunity to take part in shared decision making, if they wished, was another common theme.

---

[19] www.nhs.uk/Conditions/Expert-patients-programme-/Pages/Introduction.aspx

- A number of respondents felt that full and proper involvement and engagement between patient and healthcare professional would be sufficient to ensure that relevant background, and other factors, were taken into account.

- Some respondents pointed out the need to ensure that healthcare professionals, and possibly GP practice and other non-medical staff, had appropriate communication training that was tailored to the needs of their local community.

- References were also made to the role that patient records could play in recording patients' preferences and values. It was suggested, that electronic records should be able to accommodate this type of information and that giving patients greater control over their health records could allow them to directly record relevant preferences, thus improving decision quality.

- Many respondents wanted personalised care planning, with a number saying that voluntary and patient groups could play a key role in supporting people from diverse and hard to reach backgrounds in making choices.

3.17 Respondents raised a number of general concerns.

- A number said that the growing diversity of the public could prove a barrier when encouraging people to learn how to manage their health.

- Healthcare commissioners and providers do not fully understand the needs of their wider community and will therefore be less open to individual preferences and sensitivities.

3.18 Care should be taken to ensure decisions are made on a case-by-case basis and not on the assumptions about the preferences of particular groups of people, or individuals, because of their perceived background. Background may only be one factor relevant to the choices made and it was felt that there was no substitute for genuine patient engagement to ensure patients backgrounds are taken into account when arriving at decisions.

Healthcare professionals' support for the choices their patients make

What we asked

3.19 We asked (question 23): "Should healthcare professionals support the choices their patients make, even if they disagree with them?"

What we heard

3.20 The majority of respondents felt that doctors should support the choices[20] their patients make even if they disagreed with them, although many qualified this answer by saying that support could not be forthcoming in every case because it depended on the nature of the situation, the decision and how it was reached.

3.21 There was general agreement that the patient is responsible for their actions and therefore must be responsible for the consequences, and that healthcare professionals have an advisory role, but the ultimate decision must rest with the patient. Again, there may be exceptions, for example, where a patient lacks the capacity to make decisions, in which case the healthcare professionals should work with those close to the patient and other members of the healthcare team.

3.22 Many respondents said that most circumstances concerning disagreements or differences of opinion between healthcare professionals and patients were covered in existing guidance and professional standards[21]. For example, the General Pharmaceutical Council quoted their professional standards, *"You must make sure that if your religious or moral beliefs prevent you from providing a service, you tell the relevant people or authorities and refer patients and the public to other providers"*.

3.23 Responses consistently referred to a number of themes or principles:

- a healthcare professional should not be expected to support a patient's choice to have treatment that they believe to be clinically unsafe, would cause harm or has no benefit;
- where disagreement occurs, the healthcare professional should justify and explain why they do not support a particular patient choice where this is on clinical grounds. This should include an explanation of the risks, benefits and side-effects of the chosen treatment, as well as alternatives;
- disagreements should be documented;
- where a healthcare professional does not feel able to support a patient's choice they should either inform them about, or refer the patient to, a different healthcare professional for either a second opinion or for the chosen treatment;

---

[20] Almost all responses considered 'choice' in this question to refer to choice of treatment rather than other choices.

[21] The Nursing and Midwifery Councils professional standards and the General Medical Council's 'Care towards the End of Life: Good Practice in Decision Making' (2010)

- there was some concern (mostly among healthcare professionals respondents), that with an increased emphasis on greater patient involvement, patients might expect their healthcare professional to agree in every circumstance. This was considered potentially dangerous and it was noted that there is a lack of clarity about what happens in situations where the issue of disagreement related to the cost of a treatment or whether it had been approved by NICE. .

Our response

3.24 The large numbers of responses received about shared decision-making are very encouraging and we are pleased that so many wish to be involved when it comes to making personal healthcare choices. We acknowledge that in order to truly achieve shared decision-making, action needs to be taken at both strategic and the system level. For this reason we have placed shared decision-making at the heart of our involvement model as set out in the accompanying further consultation document *Liberating the NHS: No decision about me, without me.*

3.25 We are pleased to acknowledge the strong support for patient decision aids, which reflects the Government’s commitment to making shared decision-making the norm, and we will be looking to the QIPP Shared Decision Making programme to identify and promote a number of patient decision aids.

3.26 We strongly believe that patients who receive appropriate encouragement and support can take greater control of their health and healthcare. Ensuring everyone can access appropriate support and advice is an essential part of this and we are determined to reduce inequalities around access to healthcare.

3.27 Shared decision-making is the product of a partnership between clinicians and patients and as we continue to develop our proposals and later as we implement policy, we will seek to clarify the position of patients, clinicians and others when there is disagreement over decisions. This would include the degree to which clinicians can or should be expected to support a patient’s decision

Advance care planning

What we asked

3.28 We asked:

- (question 25): “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?”
- (question 26): “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?”

What we heard

3.29 An underlying theme of many of the responses was that an increase in shared decision-making would encourage more advance care planning. However, respondents were also broadly supportive of more joint working between healthcare professionals and the voluntary sector.

3.30 Over half of respondents agreed that they would welcome a chance to engage in advance care planning and that advance care planning removes emotion and stress from difficult decisions, although it was noted that plans should be open to review.

3.31 For the third of respondents who felt they did not want to engage in advance care planning, there were two broad themes:

- primarily, respondents felt that personal decisions about healthcare could only be made at the time of diagnosis;
- secondly, some respondents felt the process of drawing up an advanced care plan would be a waste of resources.

3.32 It was also noted that people require different approaches if they are to be engaged in advance care planning. Methods put forward included:

- raising the issue of advance care planning at an earlier stage in the pathway, such as at the time of diagnosis as it was agreed as being the best time to raise this topic;.
- large-scale public health campaigns and advertising within surgeries, as a means to provide greater public awareness of advanced care planning.

3.33 There were suggestions from some respondents that attempting to engage people in advance care planning was too much of a risk, because the culture change necessary was too great.

Our response

3.34 We acknowledge the point made by respondents that advanced care planning is part and parcel of genuine shared decision-making. As set out elsewhere in this document and in our accompanying consultation *Liberating the NHS: No decision about me, without me,* shared decision making is central to ensuring that patients / service users have more say over their care and treatment. We also acknowledge the need for a change in culture to allow people to be more comfortable undertaking advance care planning.

4. Making it happen: How the system can support implementation of Choice

The availability of information on relevant research

What we asked

4.1 We asked: (question 36): “How should people be told about relevant research and how should their preferences be recorded?”

What we heard

4.2 The majority of respondents agreed that people should be made aware of opportunities to take part in appropriate clinical trials. A variety of suggestions included information to be made available on posters and leaflets within waiting rooms and greater use of the internet.

- **Information and support**. It was noted that people could need additional information and/or support to determine whether a trial would be suitable for them to take part.
- **Role of GPs.** A small number of responses suggested that this could be a role for GPs as the commissioners of healthcare services.
- **Risks.** There were some concerns around patients being encouraged to enter into a clinical trial against their wishes.

Our response

4.3 We agree that more people should be made aware of appropriate clinical trials and believe that the development of a UK Clinical Trials Gateway is an important step forward in the efforts of the National Institute for Health Research (NIHR) to improve access to information about clinical trials taking place in the United Kingdom.

Choose and Book

What we asked

4.3 We asked:

- (question 37): “How can we encourage more healthcare professionals to use Choose and Book when they make a referral?”
- (question 38): “How can we encourage more healthcare providers to list their services on Choose and Book?”
- (question 39): “How else can we make sure that Choose and Book supports the choice commitments in chapter 2?”

What we heard

4.4 In terms of encouraging healthcare professionals and providers to use Choose and Book, a number of key themes emerged from the responses:

- **local implementation issues.** The use of Choose and Book is significantly influenced by local implementation issues and IT infrastructure. More specifically, availability of clinic slots for some specialties, the quality of the IT available locally and its effect on the use of Choose and Book, interoperability with other systems and consistency of implementation;
- **mandating the use of Choose and Book**. Some suggested mandating through GP contracts to encourage system usage, although this did not have universal support. The idea of giving priority to electronic referrals was also suggested;
- **incentives and penalties.** Another strong theme was the use of incentives and penalties for referrers and providers, with a small number of respondents suggesting additional payment to encourage healthcare professionals to use Choose and Book.

4.5 A number of respondents felt that optometrists, dentists, pharmacists and all other relevant healthcare professionals should be able to refer through Choose and Book. Also, self referral by patients, thereby reducing the impact on GPs was suggested.

4.6 Allowing patients access to PCs and the internet in health centres and GP surgeries, was an idea to support and encourage use of Choose and Book.

4.7 The importance of providing quality information to patients and healthcare professionals at referral was emphasised by respondents, especially in relation to Choose and Book supporting the wider choice commitments.

4.8 In addition, the provision of proper training and provision of national technical support for providers were mentioned, and the perception that some GPs do not tell their patients about the choices available to them through Choose and Book.

4.9 Some respondents suggested the need to monitor and measure the use of Choose and Book, both from the point of view of providing information on usage and for formal performance monitoring.

4.10 Some felt that system improvements are needed to make Choose and Book quicker and easier to use, and to enable independent providers to list their services on Choose and Book.

4.11 A small number of respondents had significant reservations about the use of Choose and Book.

Our response

4.12 The number of positive responses received around Choose and Book are welcomed and show that when implemented correctly, Choose and Book delivers a better patient and professional experience than traditional referral methods. Comments about system improvements have been noted and addressed. As we set out in our further consultation document "*Liberating the NHS: No decision about me, without me,* we see Choose and Book as being a key enabler for greater patient involvement. We will be working to increase the range of services listed on Choose and Book and the number of professionals able to refer through it.

Personal health budgets

What we asked

4.13 We asked: (question 44): "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?"

What we heard

4.14 Over half of respondents supported the use of personal health budgets, although a small minority felt that personal health budgets should not be rolled out and others said they were awaiting the results of the independent evaluation of the pilot programme. There was clear recognition about the importance of the independent evaluation to inform wider rollout. In addition, three key themes emerged:

- **eligibility.** There were a range of views about who should be eligible for personal health budgets;
  - specific groups mentioned, included people with long-term conditions, those with mental health needs, those in receipt of NHS Continuing Healthcare and those in receipt of end of life care;
  - some respondents argued that all possible conditions should be included;
- **services to be excluded.** Very few respondents suggested specific services which should be excluded although there were mixed views about whether personal health budgets were appropriate for maternity services;
- **risks.** A number of practical issues were raised, including the question of what would happen if someone ran out of money, their needs changed or treatments became more expensive. In addition, the need for quality information and support for people as they developed and managed their budget, was highlighted.

Our response

4.15 We recognise that the success of personal health budgets is dependent upon the availability of good quality information and support. Established pilots will run until October 2012 and an independent evaluation report will be published. We have already set out our aim for everyone who is eligible for NHS Continuing Healthcare to have the right to ask for a personal health budget, including a direct payment, by April 2014, subject to the evaluation report.

5. Safe and sustainable choices

Making sure that limits on choice are fair

What we asked

5.1 We asked: (question 45): “How can we make sure that any limits on choice are fair, and do not have an unequal effect on some groups or communities?”

What we heard

5.2 The most popular suggestion for ensuring fairness was to be as inclusive as possible in developing choices for local populations. Other respondents suggested that the implementation of choice be informed by local equality impact assessments.

5.3 **National standards.** A few respondents felt that a central set of standards would ensure equality of access to choice, together with the monitoring of commissioning.

5.4 **Equality risks.** A small number of respondents felt that choice would in itself always result in some inequalities

5.5 **Financial implications**. Some respondents suggested that clinical outcomes should take priority over financial considerations when setting the limits of choice. However, others stated that financial limitations would play a significant role in deciding the limits of choice of treatment.

5.6 **The role of NICE.** A similar number of respondents focussed on the role of NICE in setting the limit on choice of treatments. A minority suggested that NICE should be abolished, but a greater number felt that it should take greater responsibility for setting out the choices available to patients.

5.7 **Information and support.** Ensuring that people have appropriate information on their options, the limitations of their choices, and the evidence to help them make a decision was highlighted, with some respondents feeling it is essential to enable a greater role for advocacy in order to ensure fairness.

Our response

5.8 We remain committed to ensuring that access to, and choices over, health services are tailored to the needs of the local population and are fair. We consider equalities issues in the associated equality analysis document.

Ensuring integration of services

What we asked

5.9 We asked: (question 46): “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?”

What we heard:

5.10 The most common concern, raised by around a quarter of respondents, was that the proposals for any qualified provider may encourage or contribute towards fragmentation of services.

5.11 Other potential challenges to integration of services raised by respondents were:

- **communication and information transfer between providers.** Times when information transfer may create a barrier to joined up services. Suggestions included: different IT systems, inconsistent ways of working, inconsistent staff training measures;
- **financial issues.** Inconsistent payment processes across providers, especially between health and social care;
- **equality issues**. Possible loss of representation in the new system structure.

5.12 Suggestions to prevent potential fragmentation fell into three broad themes:

- establish better communications between providers, particularly between health and social care;
- introduce more care co-ordination across new care pathways;
- implement common standards and governance.

Our response

5.13 We welcome the comments received around the establishment of better communications and co-ordination across new care pathways and these will serve to inform future policy proposals. We have published separately our response on proposals to extend choice (any qualified provider).

5.14 Additional information is included within the accompanying consultation *Liberating the NHS: No decision about me, without me.*

Legislative entitlements to choice and accountability

What we asked

5.15 We asked (question 48): "How far should we extend entitlements to choice in legislation and hold organisations to account against these?"

What we heard

5.16 Just over a third of respondents were broadly in favour of extending entitlements to choice in legislation. The following opinions on the extent of legislative entitlements to choose were put forward:

- **uncertainty about extent of legislation.** A number of healthcare professionals who responded favourably to legislation preferred delaying its introduction until details of how the proposals to give patients more say over their care and treatment would work in practice. Others were neutral about legislation, with several attaching greater importance to the awareness of choice whilst some were unsure of how legislation would work in practice;

- **prefer use of non-legislative methods.** Around a quarter of those who responded preferred non-legislative methods such as strengthening the provisions in the NHS Constitution, including choice responsibilities in GP contracts and having codes of good practice that could be monitored by NHS organisations such as the proposed NHS Commissioning Board.

5.17 **Total opposition to legislation.** Respondents completely opposed to legislation were primarily concerned about the potential for lack of flexibility.

Our response

5.18 We noted a range of views expressed on this point. While there is a lack of consensus on the use of legislation, we noted that the majority of respondents felt that some form of accountability was desirable.

Encouraging clinical commissioning groups to maintain and extend the choice offer

What we asked

5.19 We asked: (question 49): “Where no specific right to choice applies, how can the Board best encourage GP consortia to maintain and extend the choice offer?”

What we heard

5.20 Suggestions put forward by respondents included:

- **introduce incentives or disincentives.** About a quarter of respondents suggested using incentives, mainly financial, to reward those who offer patients more say over their care and treatment and penalise those who fail to do so. Various mechanisms were proposed, including using the Quality and Outcomes Framework[22] (QOF) and mandating choice through GP contracts;

- **encouraging local patient participation.** Some respondents believed empowering patients and patient groups as being the most effective way to encourage clinical commissioning groups to extend choice offers;

- **encourage flexibility for patients.** A few respondents suggested giving patients choice over their GP practice. Patients dissatisfied with the offer of choice at their practice would be able to move to a practice where it was better;

- **expand membership of clinical commissioning groups.** A small number of respondents wanted clinical commissioning groups to be encouraged to include other healthcare professionals and representatives from the local HealthWatch in their membership;

---

[22] http://www.nice.org.uk/aboutnice/qof/qof.jsp

- **limit expansion of choice.** Others believed there should be no additional encouragement of choice if a right to choice does not already exist.

Our response

5.21 The accompanying further consultation *Liberating the NHS: No decision about me, without me,* discusses in more detail how the choice proposals may be implemented.

Encouraging GP consortia to offer appropriate choices to their populations

What we asked:

5.22 We asked: (question 50): "What is the right mix of measures to encourage GP consortia to offer appropriate choices to their populations?"

What we heard:

5.23 The responses fell into a broad number of themes:

- **monitor clinical commissioning groups.** Some suggested giving the NHS Commissioning Board and local HealthWatch organisations the ability to monitor the availability of choice and hold clinical commissioning groups to account, in the event of choice not being offered;

- **incentivise the introduction of choice.** A similar number suggested the use of incentives and penalties for clinical commissioning groups to encourage them to offer appropriate choices;

- **information and Support.** Others stated the need to provide information on the availability of choices locally;

- **encourage local consultation.** Some members of the public, NHS organisations and local authorities believe that public scrutiny is essential to ensure GPs offer appropriate choices;

- **concern over specialist services.** Concerns were noted around geographical accessibility of specialist services, the need for GPs to be aware of such services and giving patients the choice to travel to gain access to these specialist services if required;

- **legislation.** The remainder of responses included using legislation to make sure appropriate choices are offered to patients and increasing the availability of choice so that GPs had appropriate choices to offer;
- **no action needed.** A few believed no additional action was necessary.

Our response

5.24 Our further consultation document *Liberating the NHS: No decision about me, without me*, discusses in more detail how the choice proposals may be implemented.

Collecting patient feedback on choice

What we asked

5.25 We asked: (question 51): "What is the best way to gather patient feedback about the extent to which commissioners have put in place choices?"

What we heard

5.26 **Patient surveys.** Nearly half of respondents advocated the use of patient surveys with most stressing the need for these surveys to be simple and to support the inclusion of all patient groups.

5.27 **Patient participation groups.** About a quarter of respondents, mainly members of the public, wished for feedback on the choices available to be provided via patient participation groups. The majority suggested using Local HealthWatch organisations; consortia based patient and public involvement groups or Health and Wellbeing Boards.

5.28 **Informal feedback.** A few suggested a less formal localised approach to gathering feedback, taking into account a large variety of sources such as face-to-face interviews, complaints and online discussion forums.

Our response

5.29 We welcome the various suggestions about how best to receive patient feedback on choice and plan to use existing routes to determine where choice is being offered. The responses received will help shape thinking as we implement proposals in due course, subject to the further consultation.

Ensuring that choice is offered where appropriate, safe and affordable

What we asked

5.30 We asked: (question 52): " 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?"

What we heard

5.31 Just over half of those who responded, broadly agreed that our proposals for the responsibilities of organisations were sufficient to ensure that choices are offered to all patients where appropriate, safe and affordable, and that no-one is disadvantaged. A number of additional key themes also emerged:

- **ensuring local integration.** Several respondents qualified this by saying the proposals needed to ensure local enforcement, perhaps using the Local HealthWatch organisations;
- **further detail needed.** Of those who disagreed with our proposals, a number were concerned about choice being limited by GPs who have a conflict of interest between their role as commissioner and provider of some services. Others felt current proposals were not strong enough to ensure patients were offered appropriate choices;
- **ensuring equalities.** There were differences in opinion about whether our proposals would ensure that no-one was disadvantaged by the choices they make. Many of those who disagreed believed that inequality was an inevitable outcome of choice, with patients actively involved in choice benefitting more than patients who are not.

Our response

5.32 We will make every effort to ensure that choices are financially affordable. An Impact Assessment with estimated costs is published alongside our further consultation, *Liberating the NHS: No decision about me, without me.*

When choice is not offered

What we asked

5.33 We asked: (question 53): “If you do not get a choice you are entitled to, what should you be able to do about it?”

What we heard

5.34 The majority of respondents believed there should be a complaints process whilst some believed patients should have a right of appeal. The range of proposals enabling the complaints and appeals processes included:

- **balance between local and national processes.** Most respondents supported the use of local organisations to receive complaints, as opposed to others who advocated the use of national organisations. Some respondents opted for a multi-tiered complaints process where patients could complain to higher authorities if dissatisfied with the decisions of local organisations whilst others believed that any organisation that received complaints should go directly to an independent health ombudsman;

- **role of GPs.** Some of those who answered this question felt that GPs would need to be a central part of the complaints process, as they could explain why they offered certain choices. A similar number mentioned the need for patients to know what choices they are entitled to, thus allowing them to compare them to the choices actually offered to them;

- **process of appeal.** The respondents who supported the use of an appeals system, believed that the process ought to be quick and locally based . A small number of respondents took the view that patients should be able to change their commissioner in cases where they are denied choice;

Our response

5.35 It is recognised that there is a requirement for a complaints process to be established and recognised. We set out in the accompanying document, *Liberating the NHS: No decision about me, without me*, how the proposals could be implemented. We will take the points raised by respondents on-board in developing further the proposals.

Main risks associated with Choice, and mitigating these risks

What we asked

5.36 We asked:

- (question 47): "What do you consider to be the main risks to the affordability of choice and how should we mitigate these risks?"

- (question 54): "What are the main risks associated with choice and how should we best mitigate these risks?"

What we heard:

5.37 **Financial and resource related risks** Some respondents suggested that providers would need to create extra capacity in order to accommodate any additional referrals to them made as a result of patients' choices with a risk that this could not be used and end up redundant. Respondents suggested mitigations including:

- placing restrictions on new service providers;

- phasing in introduction of choice for individual services.

5.38 Other risks identified included:

- patients would not make effective choices for themselves, and that 'rectifying' bad choices would place a burden on the health system;

- patients' expectations driving up the costs to the system over time;

- patients who become more involved in their care planning would result in higher transport costs for the NHS; though some suggested that patients should meet any transport costs arising from choice.

5.39 **Equality risks.** Equality was also a strong concern, with respondents suggesting that the introduction of choice could discriminate against those with learning difficulties, those who do not access the internet, and those who do not have English as a first language. In these instances, it was felt that health inequalities could increase.

5.40 Suggested mitigations included regular impact assessments of choice by commissioners, robust regulation of providers, and performance management by commissioners to ensure all providers offering choice adhered to national guidelines, for example, those provided by NICE.

Our response

5.41 In developing our proposals we have given due consideration to any potential risks identified. Our proposals are designed to mitigate any risks. We have published alongside our response documents an equality analysis and an impact assessment which consider the economic and equalities impacts in more detail.

Annex A. The consultation questions

Choosing a healthcare provider when first referred for planned care - Q1 & Q4	**Approx. percentage of respondents commenting**
Q1. How should people have greater choice and control over their care? How can we make this as personalised as possible?	77%
Q4. What would help more people to have more choice over where they are referred?	47%

Greater choice of provider in unplanned care - Q3	**Approx. percentage of respondents commenting**
Q3. How can we offer greater choice of provider in unplanned care?	31%

Choices in maternity services – Q5	**Approx. percentage of respondents commenting**
Q5. Which choices would you like to see in maternity services and which are the most important?	26%

Choices for users of mental health services – Q6	**Approx. percentage of respondents commenting**
Q6. Are these the right choices for users of mental health services, and if not why not?	32%

Choice of diagnostic provider – Q7 & Q8	**Approx. percentage of respondents commenting**
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 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?	42%
Q8. Are there any circumstances when choice of where to go for	32%

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

Choice of healthcare provider and consultant led team post diagnosis Q9 – Q11	**Approx. percentage of respondents commenting**
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?	38%
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?	38%
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 or travel further?	33%

Personalised care planning and long term conditions – Q12	**Approx. percentage of respondents commenting**
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?	45%

Choice in end of life care - Q13	**Approx. percentage of respondents commenting**
Q13. What choices are most important to people as they approach the end of their lives? What would best help to meet these?	35%

Expanding the range of end of life care services – Q14	**Approx. percentage of respondents commenting**
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?	28%

End of life care: Balancing the needs and wishes of patients and carers – Q15	**Approx. percentage of respondents commenting**
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?	28%

Choice of treatment – Q16	**Approx. percentage of respondents commenting**
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.	37%

Taking responsibility for health and treatment choices - Q17	**Approx. percentage of respondents commenting**
Q17. How can we encourage people to take more responsibility for their health and treatment choices?	39%

Making shared decision-making the norm **Patient Decision Aids** **Encouraging people to be involved in healthcare decisions** **Ensuring that people's choices can reflect different backgrounds Q18 – 22, 24 & 27 - 35**	**Approx. percentage of respondents commenting**
Q18. How do we make sure that everyone can have a say in their healthcare?	42%
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?	32%
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?	32%
Q21. How can we support the changing relationship between healthcare professionals and patients, service users, their families and carers?	35%
Q22. What needs to be done to ensure that shared decision making becomes the norm? What should we do first?	36%
Q24. What sort of advice and information would help healthcare professionals to make sure that everyone can make choices about their healthcare?	35%
Q27. How could training and education make choice and shared decision-making a part of healthcare professionals' working practices?	32%
Q28. How can we help people to learn more about how to manage their health?	33%
Q29. What help should be available to make sure that everyone is able to have a say in their healthcare?	32%

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?	30%
Q31. How can we make sure that carers' views are taken into account when the person they support makes a healthcare choice?	26%
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?	24%
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?	30%
Q34. How can people be encouraged to be more involved in decisions about their healthcare?	26%
Q35. Would decision aids be a useful tool for healthcare professionals and their patients and service users? Are there any barriers to their use?	29%

Healthcare professionals' support for the choices their patients make - Q23	**Approx. percentage of respondents commenting**
Q23. Should healthcare professionals support the choices their patients make, even if they disagree with them?	38%

Advance care planning - Q25 & 26	**Approx. percentage of respondents commenting**
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?	27%
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?	24%

Choose & Book – Q37 – Q39	**Approx. percentage of respondents commenting**
Q37. How can we encourage more healthcare professionals to use Choose and Book when they make a referral?	**24%**
Q38. How can we encourage more healthcare providers to list their services on Choose and Book?	**20%**
Q39. How else can we make sure that Choose and book supports the choice commitments in chapter 2?	**19%**

Personal health budgets – Q44	**Approx. percentage of respondents commenting**
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?	28%

Making sure that limits on choice are fair – Q45	**Approx. percentage of respondents commenting**
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?	41%

Ensuring integration of services – Q46	**Approx. percentage of respondents commenting**
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?	36%

Legislative entitlements to choice and accountability – Q48	**Approx. percentage of respondents commenting**
Q48. How far should we extend entitlements to choice in legislation and hold organisations to account against these?	23%

Encouraging GP consortia to maintain and extend the choice offer – Q49	**Approx. percentage of respondents commenting**
Q49. Where no specific right to choice applies, how can the Board best encourage GP consortia to maintain and extend the choice offer?	19%

Encouraging GP consortia to offer appropriate choices to their populations – Q50	**Approx. percentage of respondents commenting**
Q50. What is the right mix of measures to encourage GP consortia to offer appropriate choices to their populations?	20%

Collecting patient feedback on choice – Q51	**Approx. percentage of respondents commenting**

Q51. What is the best way to gather patient feedback about the extent to which commissioners have put in place choices?	26%

Ensuring that choice is offered where appropriate, safe and affordable – Q52	**Approx. percentage of respondents commenting**
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?	22%

When choice is not offered – Q53	**Approx. percentage of respondents commenting**
Q53. If you do not get a choice you are entitled to, what should you be able to do about it?	24%

The main risks associated with choice, and mitigating these risks - Q47 & Q54	**Approx. percentage of respondents commenting**
Q47. What do you consider to be the main risks to the affordability of choice and how should we mitigate these risks?	27%
Q54. What are the main risks associated with choice and how should we best mitigate these risks?	36%

Relevant consultation questions, respondents returns and proposed implementation relating to: Choice of named consultant-led team and Any qualified (willing) provider (AQP), are include within previously published documents listed below.

- Choice of named consultant-led team,
  question 40, *Do you agree with the proposed approach to implementing choice of named consultant-led team? What else would you suggest needs to be done?*

  Liberating the NHS: Greater choice and control. Government response: Choice of named consultant –led team. Published 11 October 2011. Available from the Department of Health website: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_130448.pdf

- Extending patient choice of provider (Any qualified provider), Question 2, *Which healthcare services should be our priorities for introducing choice of any willing provider?*

Question 41, D*o you agree with the proposed approach to establishing a provider's fitness to provide NHS services? What other criteria wold you suggest?*

Question 42, *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 pf patients be subjected to the same degree of rigour as a large acute hospital that delivers a range of services to a regional catchment of patients?*

Question 43, *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?*

Liberating the NHS: Greater choice and control. Government response: Extending patient choice of provider (Any qualified provider)
Available from the Department of Health website:
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128539.pdf

Annex B. Quotes from consultation responses

Specific views received

Choosing a healthcare provider when first referred for planned care

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

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

Choice must be supported by appropriate information,

- *People require the appropriate information and knowledge of services in order to make a considered and informed choice.* **Shropshire LINk**
- *To help people to have more choice over where they are referred, they must have access to information, which is unambiguous and describes available resources and the optimal outcome.* **Royal College of Obstetricians and Gynaecologists**

Appropriate interaction with the healthcare professional is critical

- *Clinicians, especially GPs need training in listening to patients and entering into shared decision making rather than making decisions and assumptions on their behalf.* **Medical Technologies Group**
- *Through partnership with medical professionals, patients need to be fully engaged in both the prevention and management of their conditions. They need to be involved, empowered and enabled to participate in their own care, with close family members and carers where appropriate.* **Royal College of Physicians**

Some education of patients would be necessary

- *Patients shifting from being passive recipients of care to taking responsibility for their health and care.* **Health Foundation**
- *Ensuring that the public knows that we all have a right to choose our provider and consultant where possible – public information campaign, press articles, information leaflets at GP surgery, NHS choices.* **Medical Technologies Group**

A change in GP behaviour would be necessary

- *Unbiased discussion of choice should be built into each and every consultation even if some services would necessarily have more choice options than others.* **Member of the public**
- *The way people can have greater choice and control over their care is to have GPs offer more consultation time.* **NHS Leicester City Patient Survey**

- *Incentivise GPs to ensure they discuss referral options and objectively highlight or signpost the patient towards information about choices they make when choosing one provider over another.* **Medical Technologies Group**
- *…the choice and control agenda would require a fundamental change of behaviour in GPs and unless this is written into the contract it won't happen.* **South East Coast SHA**

More formal support should be made available

- *[There is a] need to ensure there is a provision for advocates to work with people.* **Inclusion North**
- *Sometimes, this [enabling choice] will require additional support, as for example an advocate or support worker to help people to navigate complex care pathways or to use information. This support will need to be timely and easy to access.* **Age UK**
- *Patients overwhelmingly want more time with healthcare professionals to discuss options over where they can be referred.* **Breast Cancer Care**
- *Support structures - including better integration of systems such as Choose and Book, NHS Choices and HealthSpace.* **Capita Health**
- *Choice to attend treatment at far-off centres could be supported by provision of additional travel costs.* **The Royal College of GPs**

Use of Choose and Book

- *Moving to full implementation of Choose and Book would help in that Choose and Book would become seen as the standard referral method, rather than just a referral method as it is now.* **Berkshire Local Pharmaceutical Committee**

Personalised care planning would facilitate choice

- *The personal health plan could become a 'ticket' to services when they are required and a commitment to provide those services. So, for example, if someone has a condition that flares up…they should not have to ask their GP for a referral and then wait, but should be able to contact their choice of service directly and make an appointment.* **East of England SHA**
- *For long term conditions, choice may in practice be limited to which 'package of care' patients prefer.* **Royal College of Pathologists**

Personal health budgets would facilitate control

- *At an individual level, personal health budgets will give patients increased choice, control and improved outcomes. Personal budgets allow people to have control over resources and to secure their preferred treatment options.* **ADASS**

Potential risks and concerns

Choice opt-out

- *There needs to be acknowledged that in some circumstances people do not want choice.* **Voluntary Sector North West**

- *Choice and control and how to go about them differ for each individual.* **National Centre for Independent Living**
- *It is important to acknowledge that not everyone finds it easy to make choices, particularly if they are ill and /or vulnerable…These people need both clear and consistent information and importantly support and also the right not to choose.* **The British Association for Counselling and Psychotherapy**

Impact on local services

- *It is our concern that some of the proposals outlined in this consultation…will lead to a reduction in local service quality for communities as a whole.* **Royal College of GPs**

Equity of access

- *Unless adequately supported, choice and control may leave some people behind.* **RAISE**
- *The provision of information will also be important in facilitating choice, but the assumption that most of this will be done on the internet is dangerous as there are still a significant number of people who do not or cannot use it.* **The Kidney Alliance**

Conflict of Interest

- *…there was concern about potential conflict of interests of GPs as both providers and commissioners of services.* **South East Coast SHA**
- *GPs may have a conflicting interest in choosing a service which provides personal profit.* **British Association of Dermatologists**

Why provide Choice

- *It's not choice I'm bothered about but good quality local services.* **Member of the public**
- *What evidence is there that people want more choice, rather than increased satisfaction with outcomes.* **The NHS Suffolk Community Reference Group**

Greater choice of provider in unplanned care

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

The difficulties of implementing Choice in unplanned care

- *What is needed is greater availability, shorter waiting times, and decent quality. I would prefer to be able to ring just one number and get an appointment in an emergency, rather than having to choose between different services.* **Member of the public**
- *What evidence is there that people want more choice, rather than increased satisfaction with outcomes.* **The NHS Suffolk Community Reference Group**

- *[We are] concerned that this adds to costs by duplicating services… We would therefore question extending choice further into unplanned care.* **BMA**

Some Choice in unplanned care already exists

- *To some extent choice already exists in unplanned care (GP out of hours services, A&E, walk in centres, minor injury units, urgent care centres etc).* **Capita**
- *In the event of unexpected illness while away from one's registered practice, people basically need to understand where to go when they have a problem – this can be provided via the Internet, in local practices and chemists, and at walk-in centres.* **The Royal College of GPs**

Providing information to support choice in unplanned care

- *Centralised databases with menus of providers and star ratings from previous users and referrers to enable informed choice.* **Elders Voice**
- *Paramedics should offer alternatives…The nearest A&E may not be the best option for all patients.* **Member of the public**
- *The choice older people wish is to see their GP at home in a crisis.* **British Geriatric Society**
- *…there needs to be a diverse and thriving local voluntary and community sector, which works in partnership and on a level-playing field with statutory health and social care services.* **The Women's Resource Centre**

Choices in maternity services

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

Provision of maternity & newborn care

- *Women should 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. The most important choices are where they access that care and support.* **North Tyneside Council**
- *The choice should be home birth, community birth or local hospital birth.* **Member of the public**
- *…while these choices should be available, maternity commissioners and providers should not adopt an 'anything goes' approach but should rather set out some default positions as to when choice is and is not appropriate.* **Royal College of Midwives**
- *…we believe that services should be based at community level and that apart from specialist services, access to services should be as local as possible.* **Nottingham City Local Involvement Network**

Information and support

- *Pregnant women should be made aware of all the services available to them at prenatal, birth and postnatal stages and the implications of making particular choices.* **Senior Council for Devon**
- *A menu of choices would make it clear what the options are. If women and their families don't like what is on the menu they can choose another hospital where the menu may be different.* **South East Coast SHA**
- *We fully support that women have choice in services, however, we would want to feel as a profession and service provider that we offer these choices…e.g. we say we offer home birth to all but if all 'low risk' women took up the offer, would we be able to deliver it?* **Head of Midwifery**
- *Support for women who are vulnerable such as women with learning difficulties who are parents or parents-to-be so that they can make the same choices as other women.* **Bedford Borough Council**
- *The lack of support and access to 'choice' for teenage women, Black, Asian, Minority Ethnic and Refugee (BAMER) women, and women who experience great disadvantage in accessing these services must also be included and addressed to ensure their choice.* **The Women's Health and Equality Consortium**

Networks

- *We see networks as an important vehicle for ensuring that local services are available to cover the entire maternity pathway from pre-conception through pregnancy …to childbirth and neonatal services through to access to health visitors and early years services. As such, maternity networks could promote choice within these services and work with all providers to increase the range and quality of services while at the same time ensuring an efficient and effective health system where there is not duplication.* **Royal College of Midwives**

Choices for users of mental health services

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

Outlined Choices

- *We support the direct involvement of patients with mental health problems in shaping the treatment approach.* **NHS South Gloucestershire and South Gloucestershire GP Commissioning Consortium**
- *There is not yet an agreed national tariff model for mental health services and so they are still reliant on local reference costs.* **North West SHA**
- *Choice should be given at the initial appointment, this is probably the point at which there is the most scope for choice.* **Northamptonshire LINk Members**
- *Mind believes that choice should be offered at the initial appointment with a GP.* **MIND**

Information of choice and services

- *Service users wanted to know how people would know what treatment options were available.* **Outreach worker from North Staffs user group**

Equalities

- *[We] would like to see the government's approach to tackling mental health adopt a more gendered view … and to see more on the specific mental health issues women face and how they would be addressed through greater choice.* **Women's Health and Equality Consortium**

Choice of diagnostic provider

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?

Availability of Choice at different stages

- *All these stages are relevant and people should be allowed to choose where and when to access the services. They should be considered in terms of close to home, quality and cost and that the 'work up' of a patient is clinically acknowledged across boundaries.* **SHA leads for long term conditions**
- *As an ME patient, if I could elect to have quick accurate biomedical diagnostic tests…my prognosis would be better.* **Member of the public**
- *It is unclear what would be the benefits for patients from enabling them to choose another diagnostics provider while in hospital or under the care of a hospital consultant.* **NHS South Gloucestershire and South Gloucestershire GP Commissioning Consortium**
- *Choice should be available throughout the process of care, with the patient fully engaged in making choices or in choosing not to do so… Except in an emergency situation.* **NHS Cumbria Patients Voice Group**

Concerns and issues

- *Choice for people should be given at the earliest possible opportunity but information regarding the possible options at each stage would be needed.* **Nottingham City LINk**
- *Appropriate support for individual patients is key.* **Age UK**
- *Continuity of treatment is desirable in most cases and frequent change in professional can be detrimental to a course of treatment.* **Member of the public**
- C*onsideration must be given to the potential transaction costs of such arrangements*. **South of Tyne and Wear PCT**
- *The level of choice needs to be balanced with affordability.* **Southampton City Council**
- *Choice of test provider should not be provided if it comes at the expense of:…Rapid access to diagnosis*. **Roche Products Limited**
- *While it might be desirable to give greater choice of diagnosis at each stage… Currently, there remains a level of distrust of diagnostic results from other providers, and tests are often repeated*. **The Kings Fund**
- *People with learning disabilities can be afraid of diagnostic procedures…There is a need to have a standard set of information to help people with learning disabilities to make choices – especially around reasonable adjustments such as if the hospital provides acclimatisation visits, or if they have had good customer feedback on interpersonal interaction.* **Newcastle City Council**

Choice of healthcare provider and consultant led team post diagnosis

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?

Choice

- *It is important that patients can choose their healthcare provider or consultant led team post diagnosis.* **Royal Pharmaceutical Socie**ty
- *[We] are increasingly hearing from patients who want to choose their healthcare provider and named consultant-led team with the best results.* **The Patients Association**
- *Choice of location for treatment should also occur not only at the beginning of the patient journey, but at any point*. **Arthritis Care**

- *It may be that people would like to make choices, of a hospital for example, based on areas such as food, cleanliness and the attitude of staff – areas where they do feel comfortable making a judgement – rather than on medical issues.* **South East SHA**
- *The choice of provider after a diagnosis has been made will itself be greatly influenced by the initial choice of treatment, including non-medical or self-care options.* **Alliance Boots**

Provision of information

- *Timely and appropriate choices can only be provided if up-to-date and accurate information is accessible instantly whenever it is requested.* **British Geriatric Society**
- *Provision must be made to engage with those patients who do not have access to the internet, have special needs or who require information in another language.* **British Dental Association**

Referrals

- *Consultants now work together in multidisciplinary teams with a group of other health professionals.* **British Society for Rheumatology**
- *In a given area there is only likely to be one consultant-led team with expertise in Motor Neurone Disease [MND], if there are any at all; very often this will be based in the nearest MND Association care centre, which have tended to be set up by and around expert clinicians.* **Motor Neurone Disease Association**
- *It should be up to the patient, with the support of an appropriate healthcare professional, to determine which criteria is important to them when exercising their choice.* **Astrellas Pharma Ltd**
- *Prejudice of Consultant who has just seen you could be a barrier.* **University Hospitals Birmingham NHS FT - PPI Group**
- *Communication skills of doctors are a huge barrier to patients understanding their healthcare and treatment choices.* **The Patients Association**

Barriers to Choice

- *Those patients with more critical conditions are likely to choose the team with the shortest wait while those with less serious conditions may be more likely to wait but choose the 'better' consultant.* **Regional Voices**
- *Providers will need to closely monitor demand across consultants and be able to flex their appointment systems appropriately and report back to referrers in a timely manner to mitigate any negative effects.* **NHS East Midlands**
- *…rurality means that there may not be the range of expertise within easy access.* **Department of Health Long Term Neurological Conditions Delivery Support Team**
- *The barrier is having time to talk. 10 minutes [with professionals] is not long enough.* **Herefordshire Council Staff**
- *If not managed carefully, there is the potential for patient care to be delayed and/or diagnostic and other tests to be unnecessarily repeated.* **Royal College of Surgeons**
- *There are continuity of care issues [with] one consultant accepting another's diagnosis and treatment plan.* **Kirklees PCT**

- *Choice has the potential to improve services, but safeguards need to be put in place to ensure that quality is not allowed to deteriorate.* **Royal College of Surgeons**

Factors discouraging patients from changing provider

- *Waiting longer to be seen and begin treatment is the biggest barrier to patients changing their team or healthcare provider.* ***Breast Cancer Care***
- *The potential for unnecessary additional costs would need to be considered. For example, to avoid repeat first outpatient appointments and tests at another provider.* ***NHS South Gloucestershire***
- *Usually with wheelchair users an inability to travel due to their condition, lack of transport, an over complicated method of claiming travelling expenses which discourages people from asking for them or giving up travelling to a different provider.* **Milton Keynes Wheelchair User Group**
- *Travel times and waiting times are both major barriers to changing providers for mental health service users.* **MIND**
- *For people living with specialised conditions, the incentive to change healthcare provider may be limited by factors such as a desire for continuity of care.* **Specialised Healthcare Alliance**
- *Patients do not often rate care on clinical aspects alone; relationships with the physicians and 'bedside manner' are also extremely important.* **National Rheumatoid Arthritis Society**
- *Myth plays a large part here, such as the widely held belief 'I can't complain because that will affect my future care.* **Cambridgeshire LINk**
- *Fear of being seen to be a problem or nuisance.* **Elder's Voice**
- *Our research has shown that loyalty to local hospital provider, and previous positive patient experience, are the dominant 'pull' factors influencing choice of hospital provider.* **The King's Fund**

Personalised care planning and long term conditions

Q 12 "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?"

- *We support the vision of long term condition management described in greater choice and control where people are able to make informed choices about their care and self management decisions, underpinned by shared decision making with professionals.* **Asthma UK**
- *Pleased to see the emphasis on the importance of personalised care planning for those with long term conditions. The integration of services within the care pathway is crucial as there needs to be a heightened focus on the preventative methods and sustainable care pathways.* **Fitness Industry Association (FIA)**

Areas for improvement

- *[There is a need for a general culture change, identified as] a hearts and minds campaign to raise awareness.* **National Voices**

- *Pharmacists should be more closely involved in helping to draw up patients' personal care plans. With access to this information, pharmacists will better be able to provide patients with information and advice, arrange specialist forms of support (such as monitored dosage systems) and make recommendations about treatments in order.* **Allied Boots**
- *Personalised care planning is obviously an ideal to aspire to and one which the College would support, but will require additional human resource to support a far greater coordination and communication between services if it is to achieve its potential.* **Royal College of General Practitioners (RCGP)**
- *…does not want to see the number of care plans being measured as this promotes a tick box approach. The Health Foundation believes the NHS should stop measuring whether care plans exist and measure the effectiveness of care planning at activating and supporting people with a long term condition.* **Health Foundation**
- *There needs to be a step change in the availability of self management courses. A rapid expansion of self management programmes is likely to be one of the most high impact changes the government could make.* **Health Foundation**

Choice in end of life care

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

What matters most

- *In the experience of most of our respondents, patients approaching the end of their lives are often most concerned about the place of their treatment and death, generally choosing to be where there are familiar and trusted people, whether family and carers or supportive staff.* **RCGP**
- *They must have privacy and dignity – for example having their own room if in hospital during their care.* **Birmingham Sandwell and Solihull Cardiac and Stroke Network**
- *I think that the well-quoted statistics showing that most people want to die at home, but most actually die in hospital, are actually unrepresentative, as, like in maternity, many people do change their minds as the time draws nearer.* **Anonymous**
- *When we spoke to people with dementia and their carers about the choices that were most important to them at the end of life they included: where they spend their last months/weeks/days; who looks after them (personal care); who they spend time with (social and emotional needs); what everyday activities they are supported to do; what medical treatment they receive.* **The Alzheimer's Society**
- *Access to information about what is available or possible is vital. People cannot make choices if they are not aware of the possibilities open to them.* **National Council for Palliative Care**
- *Whilst the wishes of the patient should be paramount, the carers' needs have to be recognised and healthcare professionals will need to have the skills to sensitively facilitate discussions about the best treatment package to meet all*

the needs of both the patient and the family or carers. **Chartered Society of Physiotherapists**

What needs to happen

- *All organisations need to work together – social services, health, voluntary organisations – so that if a choice is made about care or treatment then the organisations responsible can make them happen.* **Norfolk LINk**
- *We know that 24/7 community care helps to avoid emergency admissions to hospital and can enable more people at the end of their lives to be cared for and die in the place of their choice.* **Marie Curie Cancer Care**
- *Adequately funded staff community nursing teams and more support for local (often charitable) hospice care is important. Respite provision within the community to allow carers at home to rest is also needed.* **NHS South Gloucestershire and South Gloucestershire GP Commissioning Consortium (Pathfinder)**

Expanding the range of end of life care services

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?

What needs to happen

- *There is an urgent need to stimulate, expand and diversify the market of providers in end of life care, particularly in view of the projected increase in the numbers of people dying.* **The King's Fund**
- *Strengthen the existing systems without dismantling by interference. Private providers could not provide the continuity of care, which already exists in end of life care.* **NHS worker**
- *Pharmacists currently play a role in signposting to services and this could be expanded so that they can assist patients and carers in making choices***. Royal Pharmaceutical Society**
- *…more needs to be done to improve post registration training and education to raise standards. Importantly more could be done to improve the level of understanding about the specific needs of patients reaching the end of their life amongst the general health and social care workforce.* **Royal College of Nursing**
- *GP consortia will need training and development to support them in commissioning end of life care for end-stage heart failure patients. In particular, they will need an understanding of the needs and wishes of heart failure patients at the end of life, and an understanding of the trajectory of heart failure.* **British Heart Foundation**
- *By providing proper funding for organisations such as hospices and palliative care physicians and nurses. Although the charitable element and independence of hospices are vital they should nevertheless have proper NHS funding.* **Epilepsy HERE**
- *There needs to be a better approach to explaining the range of end of life options to different communities as there are misunderstandings as to what different options actually involve. At the same time an understanding of the*

different expectations and perspectives of growing older. **Race Equality Foundation.**

End of life care: Balancing the needs and wishes of patients and carers

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?

Balancing the wishes of the patient and carer

- *If sufficient skilled back-up is available this question is redundant.* **Anonymous**
- *Caring for someone who is dying is one of the greatest responsibilities anyone can take on, and it's not for everyone. The default position needs to be made that a hospital death is normal (just as a hospital birth is normal). A home death needs to be negotiated both with family and medical professionals.* **Member of the public**
- *In this case carers do not make choices for the person. It's for the person to decide where they choose to die. The carer can only be supportive.* **Member of the public**
- *Choosing to die at home should, where possible, be a joint decision involving the patient, clinicians and the family and/or carers. The decision needs to be based on a realistic approach to what level of support is needed, both for the person dying and their carers and family members.* **Multiple Sclerosis Society**
- *Proactive advance care planning can identify tensions between carer and cared for wishes and allow discussion and decision making to be made prior to end of life care commencing.* **Southampton City Council**
- *Firstly, we must ensure that all carers are offered the assessment of their needs as carers that they are entitled to by law, and that they are then supported in meeting their needs.* **East of England SHA**
- *Carers have given feedback that in front of the cared-for they cannot always be as honest as they would like. Carers' needs should be discussed in their own right and not as an add on to the cared-for's treatment package.* **Plymouth LINk**

Choice of treatment

Q 16 '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.'

Types of treatment

- *All the choices available and appropriate to the treatment.* **Shropshire LINk**

- *Patients need to have a choice about the treatment they receive …they should be offered…the full range of therapies recommended by NICE.* **British Association for Counselling and Psychotherapy.**
- *I would like to see a full choice of treatments which take into account current peer reviewed research (in the case of ME, bio-medical research) and patient feedback. This full choice of treatments should not be confused with those that local commissioners think are appropriate.* **Member of the public**
- *Choice of which medicines to take and being able to try them and change them easily if they don't suit you, choice of what type of surgery - open or minimal so long as all risks are explained.* **Member of the public**
- *Alternatives to medication/surgery e.g. therapeutic treatments.* **York People First**
- *Further interventions should be added – in part because they will offer cost savings. Examples include: Exercise prescriptions / gym membership…Art therapy*. **MIND**
- *No alternative therapies without an evidence base on the NHS.* **Royal College of Anaesthetists**
- *Choice of time for appointments to fit in with peoples' access to transport and/or peoples' working lives or other commitments.* **South Central SHA**
- *Timing of treatment can be important…it may be in the patient's best interest to delay giving them time to organise their personal life before undertaking intensive drug therapy*. **The British Liver Trust**

Information

- *Where choices of treatment are available and patients want to make a choice…patients need information, and support to interpret that information.* **Macmillan**
- *Many of the patients we spoke to wished to have access to information of the full range of treatment available, …including the potential outcomes and side effects of the different treatments so that they could choose the approach that was best for them.* **Norfolk LINk**
- *It is important for patients and for the NHS and wider society for people to have access to a self management programme appropriate to their disease so that they can learn at a relatively early stage how best to self manage*. **The National Rheumatoid Arthritis Society**
- *We would like to see more imaginative commissioning of community based support for prevention, early intervention and to support lifestyle changes. Local voluntary organisations and community groups are well placed to deliver this kind of support.* **NAVCA**
- *Often what the patient may choose when presented…may have worse implications.* **Community provider**
- *There is good evidence that people respond positively to properly researched decision aids which empower them to make informed decisions where the choice is complicated.* **BUPA**

Taking responsibility for health and treatment choices

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

- *Education, which starts at a young age, at home, in school.* **Thyroid Patient Advocacy**
- *Local and national publicity about the benefits of self management strategies…More national campaigns about healthy living/eating/benefits of exercise.* **The National Rheumatoid Arthritis Society**
- *People should be encouraged to take more responsibility for their health by being made aware of the impacts of their lifestyle decisions on their health.* **LighterLife**
- *Maybe making the costs more visible would help them take more responsibility.* **Member of the public**
- *The process of shared decision making between patient and GP, backed up by ongoing support is the most likely route to achieving this goal.* **RCGP**
- *The Government too needs to take a role in ensuring that these practices can be easily achieved e.g. keeping the cost of healthier foods low.* **Breast Cancer Care**
- *Financial penalty for non attendance as happens with dental practitioners.* **British Association of Dermatologists**
- *Personal Budgets also foster responsibility as individuals realise the costs of their decisions.* **Turning Point**
- *People could be encouraged to take responsibility for their health and treatment choices by emphasising the choice process so that people are aware they have the option to choose and that they have played a large part in deciding on their care.* **MIND**
- *A 'contract' could be drawn up between the patient and the NHS when treatment is agreed.* **Bedford Borough Council**
- *If care plans are drawn up in the context of real partnership it is more likely that patients will follow the care plan.* **Royal College of Psychiatrists**

Concerns

- *This is a broad cultural issue, which will take time to evolve and develop.* **Hampshire Partnership NHS Foundation Trust**
- *It is important to recognise that many patients (across all generations and backgrounds) may prefer to rely on professional opinion and expertise for decisions that directly affect their health outcomes – and that this is not necessarily a problem.* **Community Action for Health**

3. 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?

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?

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 shared decision-making the norm

- National Voices' said that *"the most effective contribution that the government and the centre of the NHS could now make would be to fund and support a sustained 'hearts and minds' campaign, working with leaders and champions from within the medical profession"*.

Patients

- *People must be able to see clearly how their involvement will impact positively on their own health and the healthcare services they receive. Our research has shown that seeing the benefits of their involvement is the greatest motivation people need to become more involved.* **Community Action on Health**
- *We are keen to see the national roll-out of information prescriptions as soon as possible, since we believe they will greatly enhance patients' feelings of control over the treatment.* **British Specialist Nutrition Association**
- *A voluntary sector or patient led support group, as they are in the best position to offer impartial advice and will be able to advise on where the most appropriate treatment centre is.* **Children Living with Inherited Metabolic Diseases**
- *[We] strongly support the NHS Information Standard as an effective marker to reassure patients and the public about the trustworthiness of information providers.* **Parkinson's UK**

Concerns

- *Continuity of professionals is very important to young people. They have told us that being able to develop relationships is critical if they are to feel able to trust them, and therefore to ask more questions and communicate more easily with them.* **Council for Disabled Children**

Carers and families:

- *There should be a responsibility to record the views of carers (where one exists). This would help ensure that their perspective is known. In order to do this, healthcare professionals need to actively seek out carers and to support this statutory guidance could require this of them.* **Richmond Council for Voluntary Services**
- *Acknowledging the importance of carers and families by encouraging their presence in consultations, allowing enough time with healthcare professionals for carers and families to take part in the discussion, and healthcare professionals being open to carer and family involvement and investing time*

in building relationships with them as well as the patient. **Breast Cancer Care**

- *[We advocate] a legal framework which enables people approaching the end of life to ensure that their carers are involved in decision-making about them, if they wish that to happen.* **National Council for Palliative Care**
- *[Patients] should be referred to local sources of support such as carers centres and advocacy services. This is particularly important for vulnerable and 'seldom-heard from' carers, such as young carers, carers from BME communities, and carers with physical and mental health problems of their own.* **Macmillan**
- *[Personal budgets have]been shown to be helpful in enabling patients and carers to manage services that enable them to purchase care that is suitable for their needs, this potentially gives greater opportunities for choice but many need to have some quality assurance built in to provide a safeguard for vulnerable people.* **SHA Leads for Long Term Conditions**
- *[We felt that carers]with the appropriate consent, to view the care records of the people they care for, would enable them to help the person they care for to negotiate the healthcare system and make decisions about their care that ensure they get the most appropriate treatment. It will also help carers perform their caring duties.* **The Federation of Irish Societies**

Clinicians:

- *[We] would support the inclusion of the theory and practice in the curricula of all medical and care education, including where appropriate in revalidation.* **Royal College of Nursing**
- *The most important source of encouragement for greater patient involvement in decisions is likely to come from healthcare professionals.* **Specialised Healthcare Alliance**
- *Training for health professionals should include discussion about the changing roles of the patient and the professional, and should ensure that they have the skills to support patients to be as healthy as possible, which will include helping them to self-care and self-manage.* **The Kings Fund**
- *GP training already incorporates shared decision-making thoroughly into the curriculum.* **RCGP**
- *[We suggest that] more training and examples of good practice in overcoming communication difficulties with patients with learning disabilities, or with conditions such as dementia, would help health professionals work confidently to maximise patients' capacity and empower them to make decisions about their lives and care.* **The General Medical Council**
- *The simplest and most effective change that has shifted the culture for many consultants in my Trust is to make it the norm for the letter written by the doctor following each outpatient consultation to be addressed to the patient rather than the referring GP.* **Consultant physician**
- *Require more audits and patient feedback collected at the time patients are receiving their care.* **Member of the public.**
- *[We requested] patient feedback from care at different providers, other standardised outcome data on provider quality.* **Cambridgeshire LINk**

Voluntary sector and patient-led groups:

- *Ensure that Carers Support Groups are established in every area of the country with representation on local health commissioning bodies.* **Senior Council for Devon**

- *[It was felt that all healthcare providers should establish] carers' protocols especially around matters of consent and confidentiality, that has been developed and reviewed by patients, carers and their families.* **NHS Tower Hamlets**

- *[We suggest] utilising and support PPGs as well as existing community and voluntary groups to encourage people to be more involved in decisions about their healthcare.* **The User Panel (patient steering group) for the Central London Healthcare GP consortium**

- *National and local funding for the third sector must be sustained for us to play a part in making choice a reality across the country.* **Parkinson's UK**

- *[Voluntary groups] must be fully transparent about their sources of income, such that those in receipt of their advice and support are able to make clear judgements as to its efficacy.* **The Royal College of Nursing**

Patient Decision Aids

- *Decision aids, if quality assured, evidence-based and accessible, could be very useful as part of the GP consultation and follow-up care.* **RCGP**

- *Yes, they help people think about the things they want before they make a difficult decision.* **Leeds LINk**

- *[Decision aids] ensure that carers and the families of patients have a greater say in decisions about the care of the people that they support.* **Atrial Fibrillation Society**

- *[It was felt that a] simple decision making tool to support doctors and patients with asking the right questions at the right time will be of more value. Any decision making tool will benefit from being designed with input from a wide range of patients.* **The User Panel (patient steering group) for the Central London Healthcare GP consortium**

- *The deficit presently isn't entirely around advice and information. What the system must do is to automate the systems to make the process as easy as* *possible to operate.* **University Hospitals Birmingham NHS FT - PPI Group**

Encouraging people to be involved in healthcare decisions

- *People need health education and education about personal responsibility for their health from a young age.* **South East Coast SHA People's Engagement Development Network**

- *Consideration needs to be given to diversity such as new migrant children in schools who may have language barriers.* **University Hospitals Birmingham NHS Foundation trust - PPI Group**

- The Royal Pharmaceutical Society referred to the 'First prescription service' which *"as part of the community pharmacy contractual framework provides an great opportunity for a healthcare professional to have an in depth discussion with patients about their condition and the medicines they may need to take, as well as the elements of self care, including healthy lifestyle advice" .*

Ensuring that people's choices can reflect different backgrounds

- *True engagement inevitably picks this up because it is personalised engagement with the particular person, proportionate and appropriate.* **NHS Cumbria Patients Voice Group**

- *Training of staff at all levels and the requirement that staff at all levels of seniority have regular refresher courses on ethnic, cultural and religious requirements relevant to the communities from which they are likely to receive patients would greatly improve treatment decisions. No newly-appointed member of staff - at any level and whether clinical or administrative - should be allowed to practise until they have undergone relevant religious, cultural and ethnic instruction.* **Member of the public**

- *Early discussion about specific values – ethnic, cultural, religious or whatever – so that those that impact on health choices are on records.* **Member of the public.**

- *People do not have one set of choices predicated on a particular ethnic or religious background.* **British Society for Rheumatology**

Healthcare professionals' support for the choices their patients make

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

- *Assuming a patient has mental capacity and it is within the law the practitioner should facilitate the patient's choice.* **Member of the public**

- *Generally, yes assuming the patient has capacity, and understands and accepts responsibility for the consequences of their choice. Healthcare professionals should retain their existing right to conscientious objection.* **Medical Protection Society**

- *It would be foolish for healthcare professionals to support choices made by patients that would be detrimental to their health.* **West Sussex PCT**

- *There needs to be a pro-forma signed after a conversation has been undertaken to advise why health staff think it is wrong.* **Cardiac & Stroke Shadow Board & Stroke Association**

- *Patients cannot force healthcare professionals to act against their own judgement or codes of conduct.* **Alliance Boots**

Advance care planning

Q.25 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?

Q.26 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?

- *At this point in time emotions would not be so high and it is likely patients would be thinking more clearly.* **The Royal Pharmaceutical Society**

- *The options can be more fully explored and considered if a person has time to plan and think through various scenarios.* **North Tyneside LINk**

- *Things change when situations become real rather than theoretical [so it would be necessary to have] the ability to change plans as peoples situations change.* **Bedford Borough Council**

- *There is ample evidence, for example from quality of life studies, that those with a condition view things differently from healthy people.* **The British Society for Rheumatology**

- *What you might do theoretically may be completely different to what you actually do in reality when faced with a diagnosis.* **General Practitioner**

- *It would be a waste of time speculating about potential illness.* **2020 Think Tank**

- *It could be a considerable drain on resources: this discussion might have to be repeated regularly over a long time period as treatments and situations change.* **NHS South Gloucestershire/South Gloucestershire GP Commissioning Consortium**

- *The same approach to care will not work for everyone – this is a key area for emphasising the importance of personalisation.* **Age UK**

- *Advance care planning at this moment is a very difficult concept. Many people do not even consider their own mortality let alone end of life decision making.* **NHS worker**

Making advance care planning an easier and more commonplace topic of discussion.

- *Engendering the culture of openness and having adult conversations about what will happen in the patients future is crucial to success in this area.* **Healthcare at Home**

- *Patients and carers/family members need to be informed about Advanced Care and End of Life Care planning at the earliest possible time, well before such plans may be required.* **Member of the public**

- *Healthcare providers in La Crosse, Wisconsin have implemented a successful system for talking to patients and families early on in diagnosis. This has positively impacted on end-of-life experiences.* **Compassion in Dying**

- *There also needs to be a constant promotional campaign, with TV ads, posters in GPs surgeries, articles in magazines and newspapers, etc.* **Member of Shropshire Disability Network**

Concerns

- *If this is to become the norm, there may be a need for open discussion and promotion throughout society in general.* **RCGP**

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

The availability of information on relevant research

Q 36 ‘How should people be told about relevant research and how should their preferences be recorded?’

Information and support

- *Research details should be published on a centralised website.* **Children Living with Inherited Metabolic Diseases**
- *I feel strongly about this. Evidence based medicine, well validated, up to date quality research should support practice.* **Member of the public**

Suggestions for dissemination of information

- *It is no good just telling people about research they need help to understand it and the implications.* **Community Provider**

Role of GPs

- *Research governance is a growing area whereby GPs, as the future commissioners of healthcare services, will need to ensure that they are aware of the latest treatment research, and also opportunities to participate in the relevant research. Patients should be able to find out about some of this through available information and the internet and Trust websites but should also be informed about it by their healthcare professional.* **NHS Cornwall and Isles of Scilly**

Risks

- *If the patient is offered the opportunity to be involved then the risks/lack of clinical evidence needs clarity and this relies again on accessible communication targeted to meet individual patient needs.* **Plymouth LINk**

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?’

Local implementation issues

- *Independent providers can struggle to have their services listed for technical reasons. In order to operate a Choose and Book service which is genuinely* *indicative of the choice of NHS funded services available to patients, the Department [of Health] must ensure that the Choose and Book system is technically capable of including all providers.* **British Pregnancy Advisory Service**

- *For more healthcare professionals to use Choose and Book when they make a referral more work needs to be done to make the system easy and quick to use during patient consultations. New developments of the system need to be done with the involvement of these professionals to ensure understanding of the practical considerations.* **Royal Liverpool and Broadgreen Hospitals NHS Trust**
- *It is currently difficult to set up a directory of service, hard for GPs to use it and even harder for patients to understand. The system needs redesigning.* **British Society for Rheumatology**
- *Healthcare professionals often complain that they can only "Choose and Book" some services as providers do not make available clinic slots for some specialties. This results in two systems having to be used, paper and electronic referrals, which can be onerous for healthcare professionals.* **Capita**
- *When I used it there were no appointments given so not much use to me as a patient.* **Patient**
- *Is Choose and Book consistent? Locally it is only available by telephone which is inconvenient, would need different formats for convenience and accessibiity.* **STEPS**

Mandating the use of choose and book

- *Make it obligatory, don't give them [referrers] other choices.* **Herefordshire County Council**
- *The national contracts for GPs should be amended to require the use of Choose and Book for all referrals, except where there is a substantative clinical reason to use another referral method.* **East of England SHA**
- *If everyone has to use C&B and they are not listed, no-one will go there and their income will drop.* **Member of the public**
- *…in many areas significant implementation problems have been encountered with Choose and Book and as such we would not support its mandatory use.* **British Medical Association**

Incentives and penalties.

- *A nominal penalty charge should be incurred for all paper referrals made to a service which is available in Choose and Book.* **North West London Hospital NHS Trust**
- *The financial incentives for GPs to use Choose and Book proved highly influential over their willingness to engage with the system, and we believe*

that an associated payment system may prove to be an effective method to encourage greater use of Choose and Book. **The King's Fund**

- *If further development of Choose and Book service remains an objective of our NHS then, the sure way is to reward its users with payment.* **British Geriatric Society**

Expansion of who can refer through Choose and Book

- *…enabling relevant healthcare professionals to directly refer patients to services they require, rather than having to go through their GPs could save time and money for patients and the NHS as a whole.* **Royal Pharmaceutical Society**

- *Patients should be able to self refer which would greatly reduce the need for GPs to waste resource in this area.* **Specsavers**

- *Choose and Book does not currently support referrals from secondary care into tertiary care.* **Papworth NHS Foundation Trust**

- *Choose and Book in its current format would not allow Healthcare at Home to list its services. We provide services as part of an integrated service provision, the system would need to allow the choice of treatment pathways and modalities before we could be a meaningful part of this.* **Healthcare at Home**

Information and support

- *Staff awareness and training.* **North Somerset PCT**

- *The Allied Health Professionals Choose and Book roadshows which took place in each Strategic Health Authority in 2009 were effective in terms in reaching a lot of service managers to demystify what Choose and Book is about. In April 2008 there were only six NHS physiotherapy services on Choose and Book but by September 2010 there were 47.* **The Chartered Society of Physiotherapists**

- *Until this system becomes universal, backed by a wide range of information – from reliable data on which to assess treatment outcomes, to ease of parking, local infection rates and types of accommodation available - patient choice will remain fiction rather than fact.* **The Community Voice**

- *At present many GPs do not inform patients about Choose and Book even if they use it. It should be a duty of GPs to inform patients about their choices and options through Choose and Book.* **Harrogate and District NHS Foundation Trust**

Technical Issues

- *Clearly the performance of the IT available affects who uses 'Choose and Book' within GP practices. Healthcare professionals may be willing to use it themselves, or ask their staff or simply not use it –if the IT is inadequate.* **Norfolk and Waveney Local Medical Committee**

- *In many areas Choose and Book has been a failure, due to largely inadequate IT systems and insufficient telephone lines.* **East Sussex LINk**

- *Have more interoperable electronic systems in place so all relevant providers can have access to Choose and Book when talking to patients.* **Royal Pharmaceutical Society**

Personal health budgets - conditions or services

Q 44 "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?"

Support for introduction of personal health budgets

- *All possible conditions and services [should] be included.* **Birmingham Sandwell and Solihull Cardiac and Stroke Network**
- *We think that access to personal health budgets should be extended as widely as possible, as this will allow more people to benefit from them.* **LighterLife**

Eligibility

- *The Patients Association welcomes personal health budgets but recognise these are not suitable for all***.** **Patients Association**
- *These should not be conditions specific. Personalised Health Budgets should be provided based on the person's preference and circumstances.* **East Midlands SHA**

Risks

- *Those eligible for continuing care are usually near the end of their lives and very unwell, and to introduce this system at this stage would be unnecessarily stressful.* **North Tynside LINk**
- *Personal Health Budgets – Having recently undertaken a piece of work in respect of social care personal budgets, Members feel that incorporating health into personal budgets would be positive as it allows the patient more control, but are apprehensive that some of the more vulnerable patients who would not be capable of planning and paying for the personal care and treatment, without intensive support and assistance.* **Darlington Borough Council**

5. Safe and sustainable choices

Making sure that limits on choice are fair

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?

Ensuring local tailoring:

- *Take into account existing research that exists locally into the inequalities and geographical matters that affect a local population. Make it mandatory [so] that those implementing national policy at a local level can adjust policy to reflect local variations.* **Cornwall LINk**
- *[The] mapping of available services in areas/localities and ensuring appropriate match for local health needs.* **Harrow LINk**
- *We recommend an equalities impact assessment be conducted…patient choice can only reflect ethnic and religious diversity if the menu of choices is wide enough to accommodate these criteria.* **BUPA**

National standards

- *Limits on choice would need to be nationally applied to avoid inconsistency across the country.* **UK Genetic Testing Network**
- *Who judges services to be safe and appropriate? If those things are decided by local commissioning then it could lead to postcode lotteries.* **South Coast SHA**

Equality Risks

- *[We] believe that choice in itself will have an unequal effect on those groups and communities whose personal circumstances limit the choices available to them.* **Citizens Advice Bureau**
- *There will always be patients who are able to work their way through the system better than others.* **Birmingham FT PPI group**

The Role of NICE

- *NICE is expert in this field - in bringing together patients and professionals to produce clear, well justified guidance. I would ask NICE to take on this work.* **National Institute for Health Research Collaborative for Leicestershire, Northampton and Rutland**

Information and Support

- *It is vital that the definitions of choice are made clear to the public. Managing expectations if this is not done will be problematic.* **Royal Liverpool and Broadgreen Hospitals NHS Trust.**
- *Patients need to be aware of their rights as set out in the NHS Constitution.* **The King's Fund**

Financial implications

- *There should be clear criteria by which choice (as defined by the NHS) does not exclude those whose treatment is necessarily expensive.* **The Race Equality Foundation**
- *Financial constraints on the NHS budget are likely to lead to rationing of treatment and restriction of choice.* **East of England SHA Competition Panel**

Ensuring integration of services

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?

Risk of 'Any Qualified Provider' causing service fragmentation

- *[We] believe that the any willing provider policy is a significant barrier to joined-up services. Multiple routes to obtain a single service risk fragmentation of the service.* **British Medical Association**
- *Agencies [could be] reluctant to pool their resources - unless there are incentives or sanctions.* **Cheshire West and Chester Council**
- *One of the ways to promote joined up services will be to develop health and social care records based on a common standardised structure.* **The Royal College of Physicians**
- *Overall governance will be crucial to ensure a joined-up provision***.** **Healthcare at Home**

Communication, information and financial transfer between providers.

- *The transfer of clinical information between organisations is a significant challenge, which prevents the provision of joined up care.* **North West London Hospitals NHS Trust**
- *High quality information is one key to the provision of joined up services – this requires the information systems being in place, and the training, resourcing and motivation of staff to make full use of them. Once there are shared patient records, with full and accurate information inputted at all levels of health and social care services, it will be much easier.* **Royal College of GPs**
- *All registered providers will need to be able to view the patient's health record.* **2020 think tank**
- *Reducing the divide…between Social Services and the NHS should remove some current breakdown in continuity.* **East Sussex Seniors Association**
- *The use of a multi-agency care pathway approach will help to join up the provision of services.* **Association for Children's Palliative Care**
- *Coordinator roles can be an effective means of improving collaboration.* **British Heart Foundation**

Financial Risks

- *The main challenge is an absence of joint commissioning and separate budgets funding one individual's care.* **Independent Mental Health Services Alliance**
- *Currently the health and social care budgets are separate which means that there is always a discussion to be had on who funds which services. If the budgets were joined up or pooled or related then this would not be an issue.* **Royal Pharmaceutical Society**

Equality Issues

- *Lack of representation in committees and strategic bodies and national and local level, of members of local communities and groups.* **Race Equality Foundation**
- *We believe…progress with the engagement of health bodies in the work of local partnerships and Children's Trusts has been slow. The introduction of the local-authority led Health and Well-being Boards offers an opportunity to improve joint working across different sectors.* **The Children's Society**

Legislative entitlements to choice and accountability

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

In favour of legislation

- *If choice is going to be done, it must be legislated for so that it is universal, and organisations should have to fully account for this.* **Patient**
- *As far as is ethical, moral and affordable.* **Hollybank Trust**
- *Where clinically appropriate.* **Anonymous**
- *It is absolutely right to legislate for choice and to hold organisations to account. We welcome the proposed duty on the NHS Commissioning Board to promote patient choice.* **Rethink**

Prefer use of non-legislative methods.

- *It would be wise to monitor the rollout of these untested concepts before creating too much legislation and further bureaucracy.* **Health Professional**
- *There are a number of practical difficulties with enshrining an entitlement to choice in legislation and would therefore recommend that the choice agenda is reflected in GP contract terms, appraisals and contract management.* **East of England SHA**

Uncertainty about extent of legislation

- *This may need a light-touch legislation to begin with as the complexities and implications of offering choice become more apparent through implementation - over time legislative responsibilities can be developed.* **British Association for Counselling and Psychotherapy**

- *Given the complexities of what is proposed it seems that it would be better to see how well it can be made to work before it is made law.* **Member of the public**

Total opposition to legislation

- *[We] support a flexible healthcare system, led by medical professionals in partnership with patients and the public. Establishing a legal right to choice risks creating a rigid system that does not allow for flexibility on the ground, for example, in cases where there is tension between choice and affordability or patient safety.* **British Medical Association**

Encouraging GP consortia to maintain and extend the choice offer

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

Introduce incentives or disincentives.

- *GP consortia who can demonstrate that they are actively engaging and extending the choice on offer by commissioning from a variety of sources should be recognised and rewarded, perhaps through an equivalent to the QOF system.* **Berkshire Local Pharmaceutical Committee**
- *[We] would support a scheme similar to CQUIN, whereby a proportion of a GP consortia's income is linked to it demonstrating that it has maintained and extended choice offers.* **Royal College of Midwives**

Encouraging patient participation

- *[Make available] comparative data about the extent of choice in different services by consortium.* **NHS East of England**
- *[Encourage] regular consultation and discussion between patient champions and GP consortia.* **East Sussex LINk**
- *[Give] patients an effective appeal system, so if patients aren't happy with the treatment choices they are given, there is some recourse.* **Medical Technologies Group**

Encourage flexibility for patients

- *Greater flexibility in choosing GP (and ensuring that money follows the patient's decision).* **Member of the public**

Expand membership of GP consortia

- *They [the Commissioning Board] need to encourage GP Consortia to invite other professionals to be part of the consortia including nurses, therapists, social workers, community hospitals etc. This will ensure a greater understanding of what is currently being provided in the community beyond the doors of the GP surgery.* **Anonymous**

Exceptions

- *Costs of providing various options will vary between different consortia depending on geography and other factors...penalising a consortium that is remote from large centres and unable to offer many choices would be unfortunate.* **NIHR CAHRC for LNR**[23]
- *There should be no exceptions for routine/urgent care, only emergency care.* **Member of the public**

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

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

Monitor GP consortia

- *GP Consortia need to be accountable to the National Commissioning Body and its monitoring arms and to the local community via … [HealthWatch] patient feedback and an imposed duty to carry out their own patient / community satisfaction surveys.* **Member of the public**

Incentivise the introduction of choice

- *Recognition and reward through the QOF system plus a ranking system that allows patients to identify which practices would offer choice.* **Berkshire Local Pharmaceutical Committee**

Encourage local consultation

- *[We recommend] patients and alternative providers to challenge commissioning decisions"* and giving them *"a right to appeal to the NHS Commissioning Board if the challenger is not satisfied.* **Optical Confederation**
- *[As] part of wider engagement activities.* **Age Concern**
- *[Consortia, should have] community representation … through the local Health Watch.* **Nottingham City LINk**
- *[Consortia should] work with allied health professionals in assessing the services required.* **Royal College of Speech and Language Therapists**

Information and Support

- *[GPs need] a clear picture of existing services (what is working well or not, including a picture of the area they are commissioning within/numbers, demographics, needs of local populations).* **Plymouth LINk**
- *GP consortia need to ensure patients have access to all the relevant information to enable them to make a fully informed choice.* **Royal Pharmaceutical Society**

---

[23] The National Institute for Health Research Collaboration in Applied Health Research and Care for Leicestershire, Northamptonshire and Rutland

Concern over specialist services

- *The choice to travel for such specialist services should also be extended to surrounding areas.* **The Lesbian Gay Foundation**

Legislation [DN add]

- *It all comes down to attitude and when the medical profession ceases to be dictatorial the rest will follow. Until then, legislation is the only way, but may be relaxed at a later date.* **Member of the public**
- *Legislation.* **Member of the Public**

No action needed

- *GP consortia will work to offer choices to their populations where they are shown to be beneficial to patients.* **Royal College of GPs**

Collecting patient feedback on choice

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

Using Patient Surveys

- *[Use] existing patient experience mechanisms.* **Papworth NHS Foundation trust**
- *[Surveys should] be collected in real-time – collected at or shortly after the time of consultation, rather than months afterwards, and utilising a variety of feedback tools (whether electronic or paper-based) to ensure the whole range of patients have the opportunity to express their views.* **Royal College of GPs**

Using Patient participation groups

- *The best ways to gather patient feedback about the extent to which commissioners have put choices in place include patient services, service user forums, patient groups, HealthWatch and Scrutiny.* **Durham County Council**
- *[Patients might be unable to give adequate feedback] may not know what choices should be available.* **The British Association of Dermatologists**

Other suggestions:

- *Encouraging patients to comment on their experiences of their GP practice and providers on the NHS Choices website.* **Anonymous**
- *A huge list of ideas were (sic) proposed by the public .... However, the consensus was that 'one size doesn't fit all.* **North West SHA**

Ensuring that choice is offered where appropriate, safe and affordable

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?

Government proposals sufficient

- *The responsibilities as spelt out are not sufficiently definite to ensure no-one is disadvantaged by the way choices are offered or the decisions they make.* **Member of the public**
- *Yes but everyone in the health service must be signed up to concept and time to discuss choice factored in.* **NHS Bournemouth and Poole PCT**

Ensuring Local integration

- *Local organisations (and the NHS CB) are sufficiently funded and work well together.* **RCGP**

Ensuring recourse

- *There should be a mechanism for complaints, as well as recourse to local patient groups. The key thing is that such complaints must be handled with sensitivity and realism, including an awareness of the financial circumstances which may or may not make certain kinds of choice impossible.* **RCGP**

Further detail needed

- *Clarity is needed in terms of the role of Health and Welfare Boards and in terms of the role of GPs being both commissioners and providers of services.* **South East Essex Community Healthcare**
- *Not convinced that the mechanisms for providing accountability in the new NHS settlement are adequate: the opportunities for holding professionals and institutions directly to account seem few.* **Motor Neurone Disease Association**
- *The paper states that Local Government and HealthWatch will have 'a role in joining up the NHS, social care etc' Without even an outline of this role, it is impossible to comment.* **Member of the public**

Ensuring Equalities

- *You cannot avoid the problems that poor, uneducated … people have, and consequently the choice agenda will differentiate according to ability, the more able will always make better choices.* **GP**
- *There is a real risk that the choice agenda could create inequalities.* **South East Coast SHA**

When choice is not offered

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

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

Ensuring proper recourse

- *Mediation must be swift as ill people need reassurance.* **Harrow LINk**
- *Where choice is an entitlement, representation and redress processes must be available. This could require, local determination procedures through to independent appeal mechanisms.* **Barchester Health Ltd**
- *There should be a formal mechanism in place that enables you to complain at the appropriate level i.e. locally or nationally, and this may be something that could be led by Healthwatch England.* **Royal Pharmaceutical Society**

The balance between local and national

- *Patients should have the ability to raise the matter with their local HealthWatch and/or their local elected representative on their Local Authority.* **The National Osteoporosis Society**
- *[Establish a] national forum to register complaints.* **British Nuclear Society**
- *It would be better if there were independent organisations set up to provide advocacy around choice and challenge when choice has not been granted.* **CAMHS[24] team at Yorkshire and Humber SHA**

Role of GPs

- *People should, in the first instance, have a full explanation as to why choice has not been possible.* **Age Concern**
- *In order for patients to be able to complain that they have not been offered a choice in care they must be aware of their full range of options initially.* **British Pregnancy Advisory Service**

Process of Appeal

- *Where choice is an entitlement, representation and redress processes must be available. This could require local determination procedures through to independent appeal mechanisms.* **Barchester Health Ltd**
- *[Patients should be able to] appeal easily and quickly with the minimum of work and fuss.* **West Oxfordshire District Council**
- *If patients do not get the choice they are entitled to, they should be able to change their commissioner.* **South East Coast SHA**

Financial limits to choice:

---

[24] Child and Adolescent Mental Health Services (CAMHS)

- *[We counsel against rigid entitlements to choice] which risk being raised beyond available funding for services if there is too great an emphasis on 'entitlement' over availability and affordability.* **BMA**

The main risks associated with choice, and mitigating these risks

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

Q54. What are the main risks associated with choice?

Financial and NHS resource risk

- *The need for overprovision would be particularly costly in …rural areas*. The **Royal College of General Practitioners**
- *Patients would perceive the most expensive care as best for them.* **Herefordshire Council**
- *[Patients should be] given clarity over what choice means in each situation and that their expectations are left realistic.* **NHS Dorset**
- *All excessive travel costs should be patient paid unless there is a good clinical reason for the choice.* **Member of the public**

Equality risks

- *Only people who are literate and have access to the internet will have access to the information required to base choice upon.* **Turning Point**
- *There is a risk that some people will advocate more assertively than others.* **The British Association and College of Occupational Therapists**
- *Increased choice would lead to increased inequality if resources such as finance, transport, and physical ability were not taken into consideration.* **South East Coast SHA**

Annex C. List of organisations that responded to the consultation questions

Organisation Name
2020health
AAH Pharmaceuticals Ltd.
Abbot Healthcare Ltd.
Academy of Medical Royal Colleges
Advanced Dynamics
Age Concern
Age UK
Airedale Foundation Trust
Airedale Mums
All Party Parliamentary Group on Skin
Alliance Boots
Arthritis and Musculoskeletal Alliance
Arthritis Care
Arthritis Research UK
Association for Children's Palliative Care (ACT)
Association for Clinical Biochemistry
Association for Clinical Pathologists
Association of British Healthcare Industries
Association of Directors of Adult Social Services and Local Government Group
Association of Paediatric Chartered Physiotherapists
Association of the British Pharmaceutical Industry
Assura Medical
Astellas Pharma Ltd
Asthma UK
Atrial Fibrillation Association
Avon and Wiltshire Mental Health Partnership NHS Trust
Barchester Health Ltd.
Barking & Dagenham Local Authority
Bayer (Women's Health Business Unit)
Bedford Borough Council
Berkshire Local Pharmaceutical Committee
Birmingham Sandwell and Solihull Cardiac and Stroke Network
Blackpool Council
Blackpool Local Involvement Network (LINk)
Bliss
Blue Ribbon for the Awareness of ME
Bolton Local Pharmaceutical Committee
Bowel Cancer UK
Bradford LINk
Breakthrough Breast Cancer
Breakthrough UK

Breast Cancer Care
British Association and College of Occupational Therapists
British Association for Counselling and Psychotherapy
British Association of Dermatologists
British Dental Association
British Diuretic Association
British Geriatric Society
British Heart Foundation
British In Vitro Diagnostics Association
British Liver Trust
British Lung Foundation
British Medical Association
British Nuclear society
British Pregnancy Advisory Service
British Society for Rheumatology
British Society of Hearing Aid Audiologists
British Specialist Nutrition Association
BUPA
Bury Council
Cambridge Weight Plan
Cambridgeshire LINK
Cancer Research UK
Canons Park Residents Association
Capita
Cardiac and Stroke Shadow Board and Stroke Association
Care Quality Commission
Cares Sandwell
Centre for Mental Health
Chartered Society of Physiotherapists
Cheshire and Wirral Partnership NHS Foundation Trust
Cheshire West and Chester Council
Chesterfield Royal Hospital Council of Governors
Chief Scientific Officer
Children Living with Inherited Metabolic Diseases
Citizens Advice Bureau
City University
College of Optometrists
Community Action on Health
Compassion in Dying
Confederation of British Industry
Cornwall LINK
Council for Disabled Children
Coventry LINK
Crossroads/Princess Royal Trust
Darlington Borough Council
Department of Health Long Term Neurological Conditions Delivery Support Team
Derby City PCT
Diabetes UK
Dispensing Doctors Association

Dorset Cancer Network Patient Partnership Panel
Dudley and Walsall Mental Health Partnership NHS Trust
Durham County Council
East Midlands SHA
East of England Heads of Midwifery
East of England SHA
East Sussex LINK
East Sussex Seniors Association
Ehlers-Danlos support group / Hollybank Trust
Elders Voice
English Community Care Association
Epilepsy Action
Epilepsy HERE
Essex County Council
European Medicines Group
Faculty of Pharmaceutical Medicine
Faculty of Public Health
Faculty of Sexual and Reproductive Healthcare (RCOG)
Family Planning Association
Federation of Irish Societies
Fitness Industry Association
Foundation Trust Network
Gateshead Advocacy and Information Network
General Medical Council
Genetic Alliance UK
Greater Manchester Neurological Alliance
GlaxoSmithKline (GSK)
Gloucestershire LINK
Great Yarmouth PCT (Southwold Surgery)
H3Plus Commissioning Consortium
Haemolytic Uraemic Syndrome Help (HUSH)
Hampshire Partnership NHS Foundation Trust
Harbury Trust
Harrogate and District NHS Foundation Trust
Harrow LINK
Hastings PCT
Health Foundation
Health Scrutiny Committee for Lincolnshire
Health Service Ombudsman
Healthcare at Home
Heart of Mersey
Help the Hospices
Herefordshire Council (staff)
Hertfordshire LINK
Hertfordshire Partnership NHS Foundation Trust
Homeless Link
Inclusion North
Independent Healthcare Advisory Services
Independent Mental Health Services Alliance
Information Commissioners Office

Institute of Biomedical Science
Institute of Physics and Engineering in Medicine
Isle of Wight Service User Group
Joint Department of Health National Clinical Directors
Joseph Rowntree Foundation
Kent Good Health Group
Kidney Research UK
Knowsley Council
Lambeth Council
Learning Disability Parliament Project - Dawlish
Learning Disability Parliament Project - Kingsbridge
Learning Disability Parliamentary Project - Devon
Leeds LINK
Leeds, Bradford and Airedale, Calderdale and Kirklees Local Pharmaceutical Committees
Leicestershire LINK
Lifeblood
Lift Council
LighterLife
Lincolnshire PCT
Liverpool Joint Health Unit
Liverpool Mental Health Consortium
London SHA (Pathology clinic - expert panel)
Lundbeck
Macmillan
Marie Curie Cancer Care
Markyate Parish Council
Medical Protection Society
Medical Technologies Group
Medical Women's Federation
Mencap
Mental Health Providers Forum (Engagement Event)
Middlesborough Council
Mid-Yorks NHS Trust
Milton Keynes Wheelchair User Group
MIND
Motor Neurone Disease Association
Multiple Sclerosis Society
Muscular Dystrophy Campaign
Nacro
NAPP Pharmaceuticals
National AIDS Trust
National Association for Collitis and Chrone's Disease
National Association for Patient Participation and Local Patient Participation Groups
National Centre for Independent Living
National Childbirth Trust
National Children's Board
National Clinical Homecare Association
National Infertility Awareness Campaign
National Information Governance Board for Health and Social Care
National Institute for Health Research Collaboration for Applied Health Research Care for

Leicestershire, Northampton and Rutland
National Osteoporosis Society
National Physiology Diagnostics Board
National Rheumatoid Arthritis Society
National Specialised Commissioning Team
National Voices
NAVCA
Newcastle City Council
Newcastle Upon Tyne NHS Foundation Trust
Newlife Foundation for Disabled Children
NHS Bournemouth and Poole PCT
NHS Cambridgeshire
NHS Confederation
NHS Connecting for Health
NHS Cornwall and Isles of Scilly
NHS Counter Fraud and Security Management Service
NHS Cumbria Patients Voice Group
NHS Dorset
NHS East Midlands Inclusion Directorate
NHS East of England Competition Panel
NHS Hertfordshire
NHS Hull
NHS Isle of Wight
NHS Leicester City
NHS Lewisham
NHS Lincolnshire PCT (engagement feedback)
NHS Medway
NHS North of Tyne
NHS Nottingham City
NHS Partner Network
NHS Salford
NHS South Gloucestershire and South Gloucestershire GP Commissioning Consortium (pathfinder)
NHS South of Tyne and Wear PCT
NHS South West
NHS Suffolk Community Reference Group
NHS Sustainable Development Unit
NHS Tower Hamlets
NICE
Nightingale
Norfolk & Waveney Local Medical Committee
Norfolk LINK
North Somerset PCT
North Tees and Hartlepool NHS Foundation Trust
North Tyneside Council
North Tyneside LINK
North West London Hospitals NHS Trust
North West SHA
Northamptonshire LINK Members
Northumberland LINK

Notes from meeting with healthcare scientists chaired by Sue Hill
Nottingham City LINK
Novartis
Ophthalmology Sector Group
Optical Confederation
Outreach Worker North Staffordshire Users Group
Oxfordshire PCT
Pan-Birmingham Cancer Network
Papworth NHS Foundation Trust
Parkinsons UK
Patient Information Forum
Patient Involvement Group
Pelvic Pain Support Network
Pharma Mar
Pharmaceutical Services Negotiating Committee
Pharmacy Voice
Picker Institute Europe
Plymouth LINK
Pohwer
Poole LINK
PPS Interim Support Limited: 'www.chooseandbookit.co.uk'
Proprietary Association of Great Britain
Prostate Cancer Charity
Queen Elizabeth Hospital Birmingham
Race Equality Foundation
RAISE
Reach
Redcar and Cleveland Borough Council
Regional Action West Midlands
Regional Voices
Rethink
Revolving Doors Charity
Richmond Carers Centre
Richmond Council for Voluntary Services
Right Care Right Here Partnership
Roche Diagnostics
Roche Products Ltd.
Roy Castle Lung Foundation
Royal College of Anaesthetists
Royal College of GPs
Royal College of Midwives
Royal College of Nursing
Royal College of Obstetricians and Gynaecologists
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Physicians
Royal College of Physicians of Scotland
Royal College of Psychiatrists
Royal College of Radiologists
Royal College of Speech and Language Therapists

Royal College of Surgeons
Royal College of Surgeons Patient Liaison Group
Royal Liverpool and Broadgreen Hospitals NHS Trust
Royal National Institute of Blind People
Royal National Institute of Deaf People
Royal Pharmaceutical Society
Ryedale LINK
Sandwell Link
Sanofi - Aventis
Senior Council for Devon
SHA Leads for Long Term Conditions
SHA Scientist Network
Sheffield Centre for Independent Living
Sheffield LINK
Shropshire Disability Network
Shropshire LINK
Social Enterprise Coalition
South Central NHS
South East Coast SHA
South East Coast SHA Events
South East Coast SHA Online Survey (public)
South East Coast SHA People’s Engagement Development Network.
South East Coast SHA Technical Response
South East Coast SHA Technical Response for Mental Health
South East Coast SHA Voluntary Sector Groups
South East Coast Specialised Commissioning Group
South East Essex Community Healthcare
South Tees Hospital (Staff Responses)
Southampton City Council
Specialised Healthcare Alliance
Specialist Orthopaedic Alliance
Specsavers
St Mungos
Staffordshire, Shropshire & Black Country Newborn and Maternity Network
Standing Commission on Carers
STEPS
Stockton Helps All
Stonewall
Stroke Association
Sunderland City Council
Sunderland Local Pharmaceutical Committee
Surgeon General, Armed Forces
Target Ovarian
Teenage Cancer Trust
Terrence Higgins Trust
The Alzheimer's Society
The Children's Society
The Community Voice
The Hepatitis Trust
The Ileostomy and Internal Pouch Support Group

The Information Standard
The Kidney Alliance
The King's Fund
The Lesbian and Gay Foundation
The National Council for Palliative Care
The National LGBT Partnership
The Patients Association
The Society and College of Radiographers
The Stroke Association
Thyroid Patient Advocacy
Thyroid UK
Tomorrow's People Charity
Tunstall Healthcare
Turning Point
UK Genetic Testing Network
UK Homecare Association
UK National Screening Committee
UK Public Health Association
Unison
University Hospitals Birmingham NHS FT - PPI Group
University Hospitals of Leicester
University of Cambridge Radiology Department
University of Newcastle Upon Tyne
Urology Trade Association
Urology User Group Coalition
User Panel (patient steering group) for the Central London Healthcare GP consortium
Venous Thrombo-Embolism Group
Vision2see
Voluntary Sector North West
Walsall Centre for Independent Living
Waterside Medical Centre
West Midlands Programme for IT
West Oxfordshire District Council
West Sussex PCT
WHICH
Wiltshire User Group
Wolverhampton City PCT
Women’s Health and Equality Consortium
Women's Resource Centre
York People First
Yorkshire and Humber Child and Adolescent Mental Health Services Team
Young Minds

Annex D. Events and activities

The following is a list of events during the consultation period at which the *Liberating the NHS: Greater choice and control* consultation was discussed or referred to. These range from dedicated events to brief references to raise awareness of consultation:

19 Oct 2010	Transforming the NHS Summit 2010: Building a 21st Century Health Service. Westminster Briefing
20 Oct 2010	Joint Medical Consultative Committee Council Meeting
20 Oct 2010	Strategic Partner Programme Meeting
20 Oct 2010	Meeting with Macmillan
20-22 Oct 2010	Unite CPHVA Conference
21 Oct 2010	National Clinical Directors Meeting
25 Oct 2010	NHS Employers Weekly Bulletin
26 Oct 2010	Adjournment debate on maternity provision
28 Oct 2010	Nursing in the Big Society
28 Oct 2010	National CAMHS Support Service participation conference
28 Oct 2010	NHS Comms Link Weekly bulletin
Nov 2010	NHS Choices stakeholder meetings
1 Nov 2010	PiF session
2 Nov 2010	South Central Physiotherapist Forum
2 Nov 2010	NHS Confederation – Mental Health beyond the White Paper conference
3 Nov 2010	South Central SHA Choose and Book Forum
4 Nov 2010	Yorkshire and Humber Choice and Choose and Book Network
4 Nov 2010	RiO User Group
5 Nov 2010	PIMS event (NHS Choices) – Leicester
8 Nov 2010	PIMS event (NHS Choices) – Leeds
9 Nov 2010	PIMS event (NHS Choices) – London
9 Nov 2010	DH webchat on choice and information consultations
11 Nov 2010	NHS Choices Operations Board
11 Nov 2010	Quality Observatories
11-12 Nov 2010	Royal College of Obstetricians and Gynaecologists
15-17 Nov 2010	Self Care Week
16 Nov 2010	National Voices Event – Expert policy group
16 Nov 2010	Chief Scientific Officer's White Paper consultation meeting for Healthcare Scientists
16-17 Nov 2010	Royal College of Midwives annual conference
16-18 Nov 2010	NHS Employers Conference
17 Nov 2010	Shared Decision Making event
17-18 Nov 2010	CNO Annual Summit
18-19 Nov 2010	NHS Alliance 13th Annual Conference

22 Nov 2010	Capita Patient Choice Conference
22 Nov 2010	National Centre for Independent Living Regional Event
23 Nov 2010	Choice/information consultation learning event for voluntary sector organisations
23 Nov 2010	Kings Fund Annual Conference
25 Nov 2010	ACEVO HSC Conference – Manchester
25-26 Nov 2010	NHS Medical Directors Conference – London
26 Nov 2010	Primary Care Live – London
29 Nov 2010	Northwest Regional Engagement Event
30 Nov 2010	Race Equality Foundation Event – Liverpool
30 Nov 2010	National Stakeholder Forum
1 Dec 2010	National Council of Palliative Care Forum
1 Dec 2010	Mental Health Strategy Board
1 Dec 2010	Race Equality Foundation event – Exeter
3 Dec 2010	Regional Voices Event – London
6 Dec 2010	Race Equality Foundation Event – Leeds
8 Dec 2010	Macmillan Stakeholder event
8 Dec 2010	Choose and Book User Group meeting
8 Dec 2010	Learning Disability Today
8 Dec 2010	National Council of Palliative Care Conference
8 Dec 2010	PiF Partners Consultation
8 Dec 2010	Race Equality Foundation Event – Sunderland
9 Dec 2010	Yorkshire and Humber Regional Voices Network
9 Dec 2010	Race Equality Foundation Event – Leicester
10 Dec 2010	South Central SHA Event
10 Dec 2010	North East SHA event
10 Dec 2010	NICE event: implications of the White Papers, and its relation to NICE & NHS Evidence
13 Dec 2010	Meeting of top 10 patient organisations
13 Dec 2010	DH Equalities event
14 Dec 2010	Social Care Stakeholder Forum
15 Dec 2010	NHS Chief Executive’s Conference
21 Dec 2010	ACEVO Roundtable
Dec 2010	Are you working QIPPly? - Article for Feb 2011 Occupational Therapy News (submitted Dec 2010)
13 Jan 2011	South Central NHS Workshop
13 Jan 2011	Equalities even