

Quotation Bank of UK Government Statements on Involvement

Compiled by Peter Bates.

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Introduction

UK governments over the past 20-30 years have had a great deal to say about public involvement in general, and about involvement in health research in particular. This listing is far from not complete, but contains some quotations from government documents. The most recent statements are listed first, with others following in date order. Other bibliographies are available¹ as well as a summary of the UK law in relation to patient choice².

It is worth holding in mind that we can consider what actually happens, as well as what the Government says. Alongside many actions that support policy statements, there are other situations where alignment is harder to achieve. For example:

- **Popular demand is sometimes overridden by a minority.** For example, once an e-petition reaches 100,000 signatures, it is sent to the Office of the Leader of the House of Commons to check it is within the rules of e-petitions and the rules of the House. It is then sent to the Backbench Business Committee which has the final say on whether it will trigger a debate in the House of Commons.
- **Governments don't always achieve their own ambitions.** For example, a 2012 [report](#) from the National Audit Office found that, while Government consultations should allow twelve weeks for the public to respond, only 40% of recent consultations had met this target. This guidance changed on 17 July 2012.
- **Human beings don't always take up the opportunities that they are offered.** For example, in May 2012, the turnout for local elections averaged 33% of the electorate, with some wards seeing as few as 8% of the electorate attend the ballot box.

The following themes have been used to select items:

- Statements that place people using health and social care services in charge of their own lives and the care and support they receive – personalisation
- Statements that require public services to make decisions in partnership with the community – co-production
- Statements that focus on personalisation and coproduction with disabled people, including people who live with mental health issues
- Statements about how health research can promote personalisation and coproduction.

¹ See, for example, the free listing of additions to the Patient Experience Library at <https://www.patientlibrary.net/cgi-bin/documents.cgi?subs=364788#submehere>

² <http://www.landmarkchambers.co.uk/userfiles/documents/resources/Patient%20Choice.pdf>

- There are one or two entries that are comments rather than quotations.

Wherever possible, hyperlinks have been added, but some of these may be out of date. This list has been compiled in the course of doing other things, rather than as a project in its own right, so it may be dangerously incomplete – caveat emptor! Please send any additions or corrections to peter.bates@ndti.org.uk

The Quotations start here

“A. Consultations should be clear and concise

Use plain English and avoid acronyms. Be clear what questions you are asking and limit the number of questions to those that are necessary. Make them easy to understand and easy to answer. Avoid lengthy documents when possible and consider merging those on related topics.

B. Consultations should have a purpose

Do not consult for the sake of it. Ask departmental lawyers whether you have a legal duty to consult. Take consultation responses into account when taking policy forward. Consult about policies or implementation plans when the development of the policies or plans is at a formative stage. Do not ask questions about issues on which you already have a final view.

C. Consultations should be informative

Give enough information to ensure that those consulted understand the issues and can give informed responses. Include validated assessments of the costs and benefits of the options being considered when possible; this might be required where proposals have an impact on business or the voluntary sector.

D. Consultations are only part of a process of engagement

Consider whether informal iterative consultation is appropriate, using new digital tools and open, collaborative approaches. Consultation is not just about formal documents and responses. It is an on-going process.

E. Consultations should last for a proportionate amount of time

Judge the length of the consultation on the basis of legal advice and taking into account the nature and impact of the proposal. Consulting for too long will unnecessarily delay policy development. Consulting too quickly will not give enough time for consideration and will reduce the quality of responses.

F. Consultations should be targeted

Consider the full range of people, business and voluntary bodies affected by the policy, and whether representative groups exist. Consider targeting specific groups if appropriate. Ensure they are aware of the consultation and can access it. Consider how to tailor

consultation to the needs and preferences of particular groups, such as older people, younger people or people with disabilities that may not respond to traditional consultation methods.

G. Consultations should take account of the groups being consulted

Consult stakeholders in a way that suits them. Charities may need more time to respond than businesses, for example. When the consultation spans all or part of a holiday period, consider how this may affect consultation and take appropriate mitigating action.

H. Consultations should be agreed before publication

Seek collective agreement before publishing a written consultation, particularly when consulting on new policy proposals. Consultations should be published on gov.uk.

I. Consultation should facilitate scrutiny

Publish any response on the same page on gov.uk as the original consultation, and ensure it is clear when the government has responded to the consultation. Explain the responses that have been received from consultees and how these have informed the policy. State how many responses have been received.

J. Government responses to consultations should be published in a timely fashion

Publish responses within 12 weeks of the consultation or provide an explanation why this is not possible. Where consultation concerns a statutory instrument publish responses before or at the same time as the instrument is laid, except in exceptional circumstances. Allow appropriate time between closing the consultation and implementing policy or legislation.

K. Consultation exercises should not generally be launched during local or national election periods.

If exceptional circumstances make a consultation absolutely essential (for example, for safeguarding public health), departments should seek advice from the Propriety and Ethics team in the Cabinet Office. This document does not have legal force and is subject to statutory and other legal requirements.”

UK Government Consultation principles 2016. Available [here](#).

“Research develops the skills of staff in our universities, businesses and health and social care. It also involves patients, service users and the public in the pursuit of knowledge that may benefit them and others, not only by their participation in research but also by their involvement in its design and conduct, in public engagement about research, as members of research approval bodies such as research ethics committees or in funding research through taxes and charitable donations.’

Health Research Authority (2015) *UK policy framework for health and social care research - Issued for public consultation*. Para 1.2. Available [here](#).

‘The public includes carers, relatives of patients and service users and healthy volunteers.’

Health Research Authority (2015) *UK policy framework for health and social care research - Issued for public consultation*. Footnote 3, page 2. Available [here](#).

‘The involvement of patients, service users or the public in the design, management or conduct of research may be subject to local controls but is not subject to approval (e.g. from a research ethics committee) or management in accordance with this policy framework, even if the research itself is.’

Health Research Authority (2015) *UK policy framework for health and social care research - Issued for public consultation*. Para 3.3. Available [here](#).

‘Principles that apply to all health and social care research... The safety and well-being of the research participant prevail over the interests of science and society... Patients, service users and the public are involved, where appropriate, in the design, management and conduct of research.’

Health Research Authority (2015) *UK policy framework for health and social care research - Issued for public consultation*. Para 8. Available [here](#).

‘The research team is the group of people involved in the conduct of a research project. It may include care professionals, academics, patients and service users, members of the public, research professionals, students and/or scientists. Research team members’ accountability should be clearly agreed between them and their employer(s), especially where multiple disciplines, collaborating organisations or patients, service users and the public are involved in a single research team.’

Health Research Authority (2015) *UK policy framework for health and social care research - Issued for public consultation*. Para 9.6. Available [here](#).

‘The funder is responsible for... assessing (or arranging for assessment of) the scientific quality and, where appropriate, value for money of the research as proposed, involving patients, service users and the public effectively in funding decisions.’

Health Research Authority (2015) *UK policy framework for health and social care research - Issued for public consultation*. Para 9.9.
Available [here](#).

“Sustainable change is more likely to result from improvement approaches that involve patients and staff in their design and implementation than from a ‘command and control’ / top down model.”

NHS England (2015) *Review of centrally funded improvement and leadership development functions* (The Smith Review), para 92.
Available [here](#).

“Other possible gaps were highlighted, which a number of participants felt needed to be addressed to deliver the 5YFV. These include developing leadership and improvement skills and capability for: Patient leaders (including Healthwatch members, Foundation Trust patient governors, lay-members, expert patients etc.). Many organisations and programmes already look to patient representatives to add value, ensure a patient voice, and apply the appropriate level of scrutiny and challenge. Achieving the 5YFV will clearly require a strengthening of these arrangements. It is suggested that to maximise impact and play more of a role in identifying, delivering and supporting quality improvements, patient representatives will require the right leadership skills and capabilities.”

NHS England (2015) *Review of centrally funded improvement and leadership development functions* (The Smith Review), Annex F, page 13. Available [here](#).

“There was a strong consensus for developing leadership programmes to include, as core: Engagement skills e.g. with staff, patients and whole communities.”

NHS England (2015) *Review of centrally funded improvement and leadership development functions* (The Smith Review). Annex F, page 23. Available [here](#).

“Even people with long term conditions, who tend to be heavy users of the health service, are likely to spend less than 1% of their time in contact with health professionals. The rest of the time they, their carers and their families manage on their own. As the patients’ organisation National Voices puts it: personalised care will only happen when statutory services recognise that patients’ own life goals are what count; that services need to

support families, carers and communities; that promoting wellbeing and independence need to be the key outcomes of care; and that patients, their families and carers are often 'experts by experience'.

As a first step towards this ambition we will improve the information to which people have access—not only clinical advice, but also information about their condition and history. The digital and technology strategies we set out in chapter four will help, and within five years, all citizens will be able to access their medical and care records (including in social care contexts) and share them with carers or others they choose.

Second, we will do more to support people to manage their own health – staying healthy, making informed choices of treatment, managing conditions and avoiding complications. With the help of voluntary sector partners, we will invest significantly in evidence-based approaches such as group-based education for people with specific conditions and self management educational courses, as well as encouraging peer-to-peer communities to emerge.

A third step is to increase the direct control patients have over the care that is provided to them. We will make good on the NHS' longstanding promise to give patients choice over where and how they receive care.

Only half of patients say they were offered a choice of hospitals for their care, and only half of patients say they are as involved as they wish to be in decisions about their care and treatment. We will also introduce integrated personal commissioning (IPC), a new voluntary approach to blending health and social care funding for individuals with complex needs. As well as care plans and voluntary sector advocacy and support, IPC will provide an integrated, "year of care" budget that will be managed by people themselves or on their behalf by councils, the NHS or a voluntary organisation."

[NHS \(October 2014\) Five Year Forward View page 12-13. Available here.](#)

"More broadly, we need to engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services. Programmes like NHS Citizen point the way, but we also commit to four further actions to build on the energy and compassion that exists in communities across England. These are better support for carers; creating new options for health-related volunteering; designing easier ways for voluntary organisations to work alongside the NHS; and using the role of the NHS as an employer to achieve wider health goals.

Supporting carers. Two thirds of patients admitted to hospital are over 65, and more than a quarter of hospital inpatients have dementia. The five and a half million carers in England make a critical and underappreciated contribution not only to loved ones, neighbours and friends, but to the very sustainability of the NHS itself. We will find new ways to support carers, building on the new rights created by the Care Act, and especially helping the most vulnerable amongst them – the approximately 225,000 young carers and the 110,000 carers who are themselves aged over 85. This will include working with voluntary organisations and GP practices to identify them and provide better support. For NHS staff, we will look to introduce flexible working arrangements for those with major unpaid caring responsibilities.

Encouraging community volunteering. Volunteers are crucial in both health and social care. Three million volunteers already make a critical contribution to the provision of health and social care in England; for example, the Health Champions programme of trained volunteers that work across the NHS to improve its reach and effectiveness. The Local Government Association has made proposals that volunteers, including those who help care for the elderly, should receive a 10% reduction in their council tax bill, worth up to £200 a year. We support testing approaches like that, which could be extended to those who volunteer in hospitals and other parts of the NHS. The NHS can go further, accrediting volunteers and devising ways to help them become part of the extended NHS family – not as substitutes for but as partners with our skilled employed staff. For example, more than 1,000 “community first responders” have been recruited by Yorkshire Ambulance in more rural areas and trained in basic life support. New roles which have been proposed could include family and carer liaison, educating people in the management of long-term conditions and helping with vaccination programmes. We also intend to work with carers organisations to support new volunteer programmes that could provide emergency help when carers themselves face a crisis of some kind, as well as better matching volunteers to the roles where they can add most value.

Stronger partnerships with charitable and voluntary sector organisations. When funding is tight, NHS, local authority and central government support for charities and voluntary organisations is put under pressure. However these voluntary organisations often have an impact well beyond what statutory services alone can achieve. Too often the NHS conflates the voluntary sector with the idea of volunteering, whereas these organisations provide a rich range of activities, including information, advice, advocacy and they deliver vital services with paid expert staff. Often they are better able to reach underserved groups, and are a source of advice for commissioners on particular needs. So in addition to other steps the NHS will take, we will seek to reduce the time and complexity associated with securing local NHS funding by developing a short national alternative to the standard NHS contract where grant funding may be more appropriate than burdensome contracts, and by encouraging funders to commit to multiyear funding wherever possible.

The NHS as a local employer. The NHS is committed to making substantial progress in ensuring that the boards and leadership of NHS organisations better reflect the diversity of the local communities they serve, and that the NHS provides supportive and non-discriminatory ladders of opportunity for all its staff, including those from black and minority ethnic backgrounds. NHS employers will be expected to lead the way as progressive employers, including for example by signing up to efforts such as Time to Change which challenge mental health stigma and discrimination. NHS employers also have the opportunity to be more creative in offering supported job opportunities to ‘experts by experience’ such as people with learning disabilities who can help drive the kind of change in culture and services that the Winterbourne View scandal so graphically demonstrated is needed.”

[NHS \(October 2014\) Five year forward view page 13-14. Available here.](#)

“NHS England guidance to support citizen empowerment and participation. One of the six characteristics of high quality and sustainable care described in the planning guidance is Citizen Empowerment and Participation. One of the core aims of CCG strategic plans is to

ensure that citizens will be fully included in all aspects of service redesign and also that patients and carers are empowered to become co-producers and participants in their own care. To support this planning process, NHS England has published an interactive guide for CCGs [Transforming Participation in Health and Care](#) which provides advice, good practice, evidence and case studies on approaches to support citizen empowerment and participation. The guide may be of interest to those of you focusing on patient/citizen involvement in your AHSNs.

NHS England email 27 March 2014.

“...the following priority areas where the Government is expecting particular progress to be made [include]: ... furthering economic growth, including supporting people with health conditions to remain in or find work.”

Department of Health (November 2013) *The Mandate: A mandate from the Government to NHS England April 2014 to March 2015*. Page 6. Available [here](#).

“Where local clinicians are proposing significant change to services, we want to see better informed local decision-making about services, in which the public are fully consulted and involved. NHS England’s objective is to ensure that proposed changes meet four tests: (i) strong public and patient engagement; ii) consistency with current and prospective need for patient choice; iii) a clear clinical evidence base; and iv) support for proposals from clinical commissioners.”

Department of Health (November 2013) *The Mandate: A mandate from the Government to NHS England April 2014 to March 2015*. Para 3.2. Available [here](#).

“We want to boost professional and public pride in all the caring professions, and to empower patients to demand improvements where care is not as good as it could be.

Department of Health (November 2013) *The Mandate: A mandate from the Government to NHS England April 2014 to March 2015*. Para 4.10. Available [here](#).

“NHS England’s objective is to ensure that the new commissioning system promotes and supports participation by NHS organisations and NHS patients in research funded by both commercial and non-commercial organisations, most importantly to improve patient outcomes, but also to contribute to economic growth. This includes ensuring payment of treatment costs for NHS patients taking part in research funded by Government and Research Charity partner organisations.”

Department of Health (November 2013) *The Mandate: A mandate from the Government to NHS England April 2014 to March 2015*. Para 7.2. Available [here](#).

“I am an equal partner in determining my own health and wellbeing. I have the right to be involved in decisions that affect my life and those affecting services in my local community.”

Healthwatch England *Consumer Rights 7: The Right to be Involved*. Details [here](#).

“The Care Quality Commission and NHS England will work with Monitor, Trust Development Authority, the Information Centre and others to make patient safety data more accessible to all and provide clear guidance on what it means – and does not mean. This includes issuing a joint statement from the Care Quality Commission and NHS England on their commitment to complete alignment of patient safety measurement and developing a dedicated hospital safety website for the public which will draw together up to date information on patient safety factors, for which robust data is available. This will include information on staffing, pressure ulcers, healthcare associated infections and other key indicators, where appropriate at ward level. The website will aim to begin publication from June 2014. It will, over time, become a key source of public information, putting the truth about care at the fingertips of patients and updated monthly.”

Department of Health (Nov 2013) *Hard Truths: The journey to putting patients first*. CM8754-1. Page 12. Available [here](#).

“NHS England will begin to publish ‘never events’ data quarterly before the end of 2013, and then monthly from April 2014 to help Trusts, patients and the public drive improvement of services.

Department of Health (Nov 2013) *Hard Truths: The journey to putting patients first*. CM8754-1. Page 12. Available [here](#).

“NHS England will publish the most useful data and insight through the Patient Insight Dashboard in a format that can be understood by patients, the public and local Healthwatch, in Autumn 2013.

Department of Health (Nov 2013) *Hard Truths: The journey to putting patients first*. CM8754-1. Para 1.24. Available [here](#).

“Monitor’s assessment process also now includes review of patient surveys, meetings with patients groups, and Healthwatch and asks about how boards engage with patients.”

Department of Health (Nov 2013) *Hard Truths: The journey to putting patients first*. CM8754-1. Para 1.14. Available [here](#).

“We acknowledge that entitlement to an IMHA (Independent Mental Health Advocate) has been extended to informal patients³ patients in Wales but feel that for England, it should remain possible for advocates who are not formally accredited IMHAs to continue to provide their advocacy services.”

Department of Health (Oct 2013) *Post-legislative Scrutiny of the Mental Health Act 2007: Response to the Report of the Health Committee of the House of Commons Cm 8735*. Available [here](#).

“NHS Commissioners should:

- Make arrangements for and promote individual participation in care and treatment through commissioning activity.
- Make arrangements for the public to be engaged in governance arrangements by ensuring that the CCG governing body includes at least two lay people.
- Listen and act upon patient and carer feedback at all stages of the commissioning cycle – from needs assessment to contract management.
- Publish evidence of what ‘patient and public voice’ activity has been conducted, its impact and the difference it has made.
- Engage with patients, carers and the public when redesigning or reconfiguring healthcare services, demonstrating how this has informed decisions.

NHS England (25 Sept 2013) *Transforming participation in health and care*. Page 4. Available [here](#).

“NHS England will:

- Launch ‘Patients in control’, a comprehensive programme including practical training, support and tools to support local communities to deliver Shared Decision Making, Personalised Care Planning and better self management of their health.
- Ensure that every person with a long-term condition or disability has a personalised care plan supporting them to develop the knowledge, skills and confidence to manage their own health. NHS England will develop and implement a best practice

³ Informal patients in this context means those psychiatric hospital inpatients who are not detained under the Mental Health Act 1983.

standard that defines what good, personalised, digital care plans and planning processes look like, in order to support GPs and health professionals during 2014.

- Launch a new certification process for entrepreneurs to easily offer on-line tools and services that support personalisation, to help commissioners to identify high quality suppliers.
- Establish a national Citizens Assembly that will put a citizen voice at the heart of decision-making and hold the board of NHS England to account. We will also work with the British Youth Council and other children and young people's groups to establish a Children and Young People's Forum for NHS England.
- Launch a national 'Excellence in Participation Awards' scheme that gives status and profile to patient and public participation, promoting best practice. NHS England is working with patients and carers to develop this.
- Set up a Participation Academy, a programme of learning and development for people who want to explore roles as patient and community leaders in health and care. Working with partners, including local Healthwatch and health and wellbeing boards, we will work with local communities to identify routes to reach a diverse range of people who can champion the health needs and interests of local communities and citizens.
- Create a 'People Bank' where citizens and organisations can register their interest in participation opportunities across NHS England's activities and/or commissioners can identify interested people to engage with.

NHS England (25 Sept 2013) *Transforming participation in health and care*. Page 5. Available [here](#).

"We need to know more about what our patients think of the services we commission and act on that information in designing and delivering services. We recognise a particular responsibility to ensure that the voice and views of currently disadvantaged groups are sought out and listened to.

NHS Commissioning Board (2012) *Everyone counts: Planning for patients 2013-14*. Para 1.19 Available [here](#).

"Ambition 2: The boards and leadership of provider and commissioning organisations will be confidently and competently using data and other intelligence for the forensic pursuit of quality improvement. They, along with patients and the public, will have rapid access to accurate, insightful and easy to use data about quality at service line level."

Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report by Sir Bruce Keogh for the NHS, published 16 July 2013. Available [here](#).

“Ambition 3: Patients, carers and members of the public will increasingly feel like they are being treated as vital and equal partners in the design and assessment of their local NHS. They should also be confident that their feedback is being listened to and see how this is impacting on their own care and the care of others.

Involving patients and staff was the single most powerful aspect of the review process. Patients were key and equal members of review teams. Well-attended listening events at each trust provided us with a rich understanding about their experiences at the hospitals. Accessing patient insight in this way need not be complex, yet many of the trusts we reviewed did not have systematic processes for doing so, and all have actions in their action plan to improve in this area.”

Monitor and the NHS Trust Development Authority should consider the support, development and training needed for Non-Executive Directors and Community, Patient and Lay Governors to help them in their role bringing a powerful patient voice to Boards.

All NHS organisations should seek to harness the leadership potential of patients and members of the public as they fulfil their respective responsibilities whether as providers, commissioners or as part of future inspections by the regulators. Patient and public engagement must be central to those who plan, run and regulate hospitals and each has improvements to make in this respect.”

Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report by Sir Bruce Keogh for the NHS, published 16 July 2013, pp9-10. Available [here](#).

“The multidisciplinary nature of the review teams - involving patient and lay representatives, junior doctors, student nurses, senior clinicians and managers - was key to getting under the skin of these organisations. The review teams were not constrained by the limitations of a rigid set of tick box criteria. This allowed both cultural and technical assessments to be made, informed by listening to the views and experiences of staff, and particularly patients and members of the public. The new Chief Inspector of Hospitals has agreed to adopt and build on this review methodology as he takes forward the Care Quality Commission’s new inspection regime for hospitals.”

Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report by Sir Bruce Keogh for the NHS, published 16 July 2013. Available [here](#).

[The Government is] “making sure that disabled people can play a full role in society through the development of inclusive and accessible communities, by removing barriers to participation in public life and by ensuring an effective framework of rights and duties”

Office of Disability Issues (July 2013) Fulfilling Potential Making It Happen London: DWP. Available [here](#).

“Public Health England published *Our priorities for 2013/14* in April 2013, but it does not appear to make any reference to PPI activities or obligations, nor of co-producing their work with the public, with service users or with communities.

Available [here](#).

“The Government wants the new law to focus on the person and their needs, their choices and what they want to achieve. It should put them in control of their lives and the care and support they receive. The care and support planning process is the way of making this happen. It will provide people who use services, and carers, with clear legal rights to a care and support plan.”

Department of Health (2013) *The Care Bill – Personalising care and support planning Factsheet 4*. Available [here](#).

“In its plan for Civil Service reform, published in June 2012, the Government sets out to improve the ways in which the public could be involved in the process of policy-making. This is both to improve government policy and to provide the public with the opportunity to participate and to influence policy. It wants the Civil Service to be more open to external influence and advice, stating, “open policy-making will become the default. Whitehall does not have a monopoly on policy-making expertise”.”

House of Commons Public Administration Select Committee (3 June 2013) *Public engagement in policy-making Second Report of Session 2013–14*. London: HMSO. Paragraph 1. Available [here](#).

“A “clear model of open policy-making” is explained in the Civil Service Reform Plan as one that exploits technology and social media to engage the public in debates about policy and in the policy-making process itself. In an open policy-making model, it is understood that involvement of the public is sought before proposals have been formulated.”

House of Commons Public Administration Select Committee (3 June 2013) *Public engagement in policy-making Second Report of Session 2013–14*. London: HMSO. Paragraph 13. Available [here](#).

“The second proposed action, “contestable policy-making”, is one in which external sources are given the opportunity, through competition, to develop policy. The Civil Service Reform Plan states that this approach has “the additional benefit of bringing in expertise on specific subject matter when it does not exist in the Civil Service”. This approach has been described as “outsourcing” of policy-making. To achieve this, the Government has established a central match-fund, known as the Contestable Policy Fund, which is worth up to £1 million per year, allowing departments “to bid for an allocation of £500k funding (and

provide £500k match funding themselves) to open up specific pieces of policy development to competition”.

House of Commons Public Administration Select Committee (3 June 2013) *Public engagement in policy-making* Second Report of Session 2013–14. London: HMSO. Paragraph 14. Available [here](#).

“...the Review Panel has heard that more could be done to increase awareness of the benefits of research, what it entails, and how health and social care information may be used to support it. It is therefore vital that in order to improve and maintain public trust, researchers and the health and social care system more generally, must inform patients and the public of the benefits that the use of their information can bring to them, their families and the nation’s health.”

[Caldicott2](#), chapter 6

“The NHS commits:

- to anonymise the information collected during the course of your treatment and use it to support research and improve care for others
- where identifiable information has to be used, to give you the chance to object wherever possible
- to inform you of research studies in which you may be eligible to participate

NHS (26 March 2013) *The NHS Constitution – the NHS belongs to us all*. Page 8. Available [here](#).

“On 28 February 2013, the Mental Health (Discrimination) Act 2013 became law and so removed three legal barriers to equality by acting to:

- repeal section 141 of the Mental Health Act 1983, under which a Member of the House of Commons, Scottish Parliament, Welsh Assembly or Northern Ireland Assembly automatically loses their seat if they are sectioned under the Mental Health Act for more than six months
- amend the Juries Act 1974 to remove the blanket ban on “mentally disordered persons” undertaking jury service
- amend the Companies (Model Articles) Regulations 2008 which states that a person might cease to be a director of a public or private company “by reason of their mental health”

[Mental Health \(Discrimination\) Act 2013](#).

“The guiding principle must be to engage patients and the public in all the Clinical Senate’s work. The NHS Commissioning Board is developing a universal approach to ensure that public and patient involvement is meaningful and effective.”

“Developing Clinical Senates: The Way Forward published by the NHS Commissioning Board on 25 January 2013, available at www.commissioningboard.nhs.uk/wp-content/uploads/2013/01/way-forward-cs.pdf. Page 7.

“The policy aim underlying neighbourhood planning is that by enabling communities to have a greater say over the planning of their communities they are more likely to become supporters of sustainable growth. The Localism Act 2011 inserts new provisions into the 1990 Act and 2004 Act for communities to come together to produce a neighbourhood development plan or neighbourhood development order or a community right to build order. Take up of the new right will be voluntary and at the discretion of neighbourhoods and communities.”

Explanatory memorandum to The neighbourhood planning (referendums) regulations 2012, paras 7.1 and 7.2. Available [here](#).

“Recommendation 58: Patients, through their user group representatives, should be integrated into the structure of the Care Quality Commission. It should consider whether there is a place for a patients’ consultative council with which issues could be discussed to obtain a patient perspective directly.”

HMSO (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive summary. Report of the Public Inquiry chaired by Robert Francis QC. Available [here](#).

“Recommendation 135: Commissioners should be accountable to their public for the scope and quality of services they commission. Acting on behalf of the public requires their full involvement and engagement:

- There should be a membership system whereby eligible members of the public can be involved in and contribute to the work of the commissioners.
- There should be lay members of the commissioner’s board.
- Commissioners should create and consult with patient forums and local representative groups. Individual members of the public (whether or not members) must have access to a consultative process so their views can be taken into account.
- There should be regular surveys of patients and the public more generally.
- Decision-making processes should be transparent: decision-making bodies should hold public meetings.

Commissioners need to create and maintain a recognisable identity which becomes a familiar point of reference for the community.”

HMSO (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive summary. Report of the Public Inquiry chaired by Robert Francis QC. Available [here](#).

“The Health and Social Care Act 2012 makes clear the duties on the NHS Commissioning Board and the clinical commissioning groups to promote the involvement of patients and carers in decisions about their care and treatment, and to enable patient choice. The Care and Support Bill, expected to be introduced to Parliament next year, focuses on the personalisation of care, with people, not institutions, in control. The draft Bill also creates a right to a care and support plan, which should be prepared in consultation with the person and carer.”

Department of Health (13 Dec 2012) *Liberating the NHS: No decision about me, without me – Government response to the consultation*. Paragraph 8. Available [here](#).

“We heard clearly that a key element of patients being truly involved in decisions about their care and treatment is the ability of a patient to have a care plan. A written record of the care-planning discussion between a patient and clinician is a vital part of empowering patients to manage their condition. This is why we are introducing a pledge into the NHS Constitution to involve patients in care planning discussions and to offer them a written record of what is agreed, if they want one. The Government’s mandate will hold the NHS Commissioning Board to account for delivering this.”

Department of Health (13 Dec 2012) *Liberating the NHS: No decision about me, without me – Government response to the consultation*. Paragraph 9. Available [here](#).

“Guidance was published in 2011 to support implementation of the proposals to give patients greater choice of any qualified provider in community services and to give patients an opportunity to choose a named consultant-led team, where clinically appropriate.”

Department of Health (13 Dec 2012) *Liberating the NHS: No decision about me, without me – Government response to the consultation*. Paragraph 1.4. Available [here](#).

“The Mental Capacity Act 2005 is a vital piece of legislation underpinning the NHS that requires all health professionals to take 'all practicable steps' to help people make their own decisions, even where they have a mental impairment. Just because a patient has a mental

impairment does not mean that those patients and their carers should not be involved in decisions about their care. Options may need to be communicated in different, or more appropriate ways and patients need to be supported in understanding the options and their implications, as well as being assisted in making and communicating their choices. The principles of the Mental Capacity Act must be adhered to in any decision making where a patient lacks capacity or their capacity is predicted to deteriorate over time.”

Department of Health (13 Dec 2012) *Liberating the NHS: No decision about me, without me – Government response to the consultation*. Paragraph 3.12. Available [here](#).

“For too long people who are referred to mental health services have not been given the same choices as those referred to other elective services. Currently, mental health services are an exception to the 'free choice' offer that states that a patient has the right to choose any provider in England for a first outpatient appointment with a consultant or a member of the consultant's team for most elective care. This must change. As we set out earlier, the Government is committed to ensuring mental health has equal priority with physical health, and the Health and Social Care Act 2012 is clear that equal priority must be given to the prevention, diagnosis and treatment of both physical and mental illness.”

Department of Health (13 Dec 2012) *Liberating the NHS: No decision about me, without me – Government response to the consultation*. Paragraph 4.10. Available [here](#).

“We will use more professional experts in our inspection teams and we will involve more members of the public with direct experience of care - ‘experts by experience’ – in our inspections...We will listen much harder to what people who use services tell us about the reality of the care they receive.”

Letter to staff from David Prior and David Behan, Care Quality Commission, 30 January 2013.

“Stop translating documents into foreign languages: only publish documents in English. Translation undermines community cohesion by encouraging segregation.”

Department for Communities and Local Government (19 Dec 2012), page 11 [50 ways to save: examples of sensible savings in local government](#).

The Public Services (Social Value) Act was passed in March 2012 and came into force on 31st January 2013. The Act introduces a statutory requirement for public bodies to consider Social Value at the pre-procurement stage of commissioning services. The Act applies to all

public services contracts. Social Value means the economic, social and environmental well-being of the relevant area.

“Consultation will be particularly relevant when considering [the Social Value of] procurements for services which are delivered directly to citizens. The voluntary and community sector, along with other providers and interested groups, should be engaged from the earliest stage to help shape policies, programmes and services.”

Cabinet Office (2012) Procurement policy note - The public services (Social Value) Act 2012: Advice for commissioners and procurers. Available [here](#).

“...rushed consultation processes make it too difficult for external interests to provide expert critique at the right time...The July 2012 Principles are failing to provide the consistency and transparency that others look for in consultation exercises...There should be “... An independent, external review of their new approach to consultation without delay...”

House of Lords Secondary Legislation Scrutiny Committee, 22nd Report of Session 2012-13, The Government’s new approach to consultation – [Work in Progress](#). Paragraphs 5-7.

“Changing the approach to Government consultations without first sounding out interested parties has been interpreted as a signal of an underlying intention to reduce consultation, even though the Minister assured us that this is not the case.”

House of Lords Secondary Legislation Scrutiny Committee, 22nd Report of Session 2012-13, The Government’s new approach to consultation – [Work in Progress](#). Paragraph 65.

“29 working days (12 December 2012 until 25 January 2013), including the Christmas period, were allowed for a consultation on the development of 120 service specifications and 43 clinical commissioning policies for specialist health services across the whole country. The commissioning specifications are key to defining for providers, genuinely user-led, evidence-based, safe and effective services.

Comment from NALM [here](#)

“The UK Clinical Trials Gateway provides the public with authoritative and accessible information about clinical trials in the UK. In April 2012 the NIHR launched an update which builds on the original version but increases the amount of easily accessible summary information describing what each trial is doing. Versions of the Gateway are also now

available for the iPhone, iPad and Android devices. Since the Gateway was initially launched in March 2011 there have been over 211,000 page views by more than 91,800 unique visitors.”

HM Government (Dec 2012) *Strategy for UK life sciences: one year on*. Page 26. Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/36684/12-1346-strategy-for-uk-life-sciences-one-year-on.pdf

“Patients are unhappier with their overall general practice experience and access than this time last year, a DH-led survey shows. The 2012-13 GP Patient Survey conducted by Ipsos-MORI found 87.6% of patients rate their overall experience of their GP as 'good' – down 0.7% on 2011-12 findings.

Taken from [here](#) dated 13 Dec 2012.

“Take the Equality Act. It’s not a bad piece of legislation. But in government we have taken the letter of this law and gone way beyond it, with Equality Impact Assessments for every decision we make. Let me be very clear. I care about making sure that government policy never marginalises or discriminates. I care about making sure we treat people equally. But let’s have the courage to say it, caring about these things does not have to mean churning out reams of bureaucratic nonsense. We have smart people in Whitehall who consider equalities issues while they’re making the policy. We don’t need all this extra tick-box stuff. So I can tell you today we are calling time on Equality Impact Assessments. You no longer have to do them if these issues have been properly considered.”

David Cameron addressing the CBI conference 19 Nov 2012. Available [here](#).

“A new placeholder indicator 4c has been included, which will be based on the Friends and Family test. The inclusion of this indicator will enable more ‘real-time’ feedback to be reflected in the framework. The Friends and Family test will ask patients whether they would recommend the hospital where they received their treatment and care, to a family member or friend. It will be rolled out nationally starting with adult acute inpatient and A&E services in April 2013. The precise details of this indicator will need to be developed as national roll out takes place.”

Department of Health (13 Nov 2012) [The NHS Outcomes Framework 2013-14](#) para 1.43-44.

“Where local clinicians are proposing significant change to services, we want to see better informed local decision-making about services, in which the public are fully consulted and

involved. The NHS Commissioning Board's objective is to ensure that proposed changes meet four tests: (i) strong public and patient engagement; ii) consistency with current and prospective need for patient choice; iii) a clear clinical evidence base; and iv) support for proposals from clinical commissioners."

Department of Health (November 2012) *The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015* para 3.4.

"The NHS staff survey provides important information about organisations' health, and it already asks whether staff would recommend their place of work to a family member or friend as a high-quality place to receive treatment and care (the 'friends and family test'). However, staff are only asked this question annually, and the [NHS Commissioning] Board should ensure that much more regular feedback on the 'friends and family test' becomes the norm. Part of this objective is for the NHS Commissioning Board to introduce the 'friends and family' test for patients across the country: for all acute hospital inpatients and Accident and Emergency patients from April 2013; for women who have used maternity services from October 2013; and as rapidly as possible thereafter for all those using NHS services. Hospitals with good scores on the 'friends and family' test will be financially rewarded."

Department of Health (November 2012) *The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015* para 4.8-9.

"The NHS Commissioning Board's objective is to ensure that the new commissioning system promotes and supports participation by NHS organisations and NHS patients in research funded by both commercial and non-commercial organisations, most importantly to improve patient outcomes, but also to contribute to economic growth. This includes ensuring payment of treatment costs for NHS patients taking part in research funded by Government and Research Charity partner organisations."

Department of Health (November 2012) *The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015* para 7.2.

"The NHS and its public sector partners need to work together to help one another to achieve their objectives. This is a core part of what the NHS does and not an optional extra, whether it is working with local councils, schools, job centres, housing associations, universities, prisons, the police or criminal justice agencies such as Police and Crime Commissioners and Community Safety Partnerships. The NHS Commissioning Board's objective is to make partnership a success. This includes, in particular, demonstrating progress against the Government's priorities of:

- continuing to improve services for both disabled children and adults;
- continuing to improve safeguarding practice in the NHS;
- contributing to multi-agency family support services for vulnerable and troubled families;
- upholding the Government's obligations under the Armed Forces Covenant;
- contributing to reducing violence, in particular by improving the way the NHS shares information about violent assaults with partners, and supports victims of crime
- improving services through the translation of scientific developments into benefits for patients;
- helping people experiencing ill health, whether mental or physical, to remain in or return to work, and avoid homelessness;
- developing better healthcare services for offenders and people in the criminal justice system which are integrated between custody and the community, including through development of liaison and diversion services;
- championing the Time to Change campaign to raise awareness of mental health issues and reduce stigma, including in the NHS workforce.

Department of Health (November 2012) [The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015](#) para 7.3.

“This guidance replaces the Code of Practice on Consultation issued in July 2008 [and asserts that...].

- The governing principle is proportionality of the type and scale of consultation to the potential impacts of the proposal or decision being taken...
- thought should be given to achieving real engagement rather than following bureaucratic process...
- The objectives of any consultation should be clear...
- There may be circumstances where consultation is not appropriate, for example, for minor or technical amendments to regulation or existing policy frameworks, where the measure is necessary to deal with a court judgment or where adequate consultation has taken place at an earlier stage...
- Longer and more detailed consultation will be needed in situations where smaller, more vulnerable organisations such as small charities could be affected...
- Engagement should begin early in policy development when the policy is still under consideration and views can genuinely be taken into account...
- There are several stages of policy development, and it may be appropriate to engage in different ways at different stages...
- Timeframes for consultation should be proportionate and realistic to allow stakeholders sufficient time to provide a considered response. The amount of time

required...might typically vary between two and 12 weeks. For a new and contentious policy, such as a new policy on nuclear energy, the full 12 weeks may still be appropriate. The capacity of the groups being consulted to respond should be taken into consideration...

- Information should be disseminated and presented in a way likely to be accessible and useful to the stakeholders with a substantial interest in the subject matter...Information provided to stakeholders should be easy to comprehend – it should be in an easily understandable format, use plain language and clarify the key issues...
- Any aspects of the proposal that have already been finalised and will not be subject to change should be clearly stated.

Cabinet Office (17 July 2012) Consultation Principles Available [here](#).

“Consultation should be ‘digital by default’, but other forms should be used where these are needed to reach the groups affected by a policy.”

Cabinet Office (17 July 2012) summary of its Consultation Principles [here](#)

“What community groups can do:

- Inform JSNAs and JHWSs. proactively provide input to local needs assessments and commissioning processes.
- Raise awareness of services and support. They are ideally placed to raise awareness locally of the services and support available, as well as of people’s rights and entitlements. This includes both voluntary sector support and Government programmes such as Work Choice and Access to Work. They can also ensure local commissioners and providers are aware of the contribution of voluntary, community and user- and carer-led support available to people with mental health problems in their area.
- Support communities in holding public bodies to account. This could include:
 - Joining local Healthwatch organisations, and encouraging other individuals and groups to join.
 - Supporting people affected by mental health problems to engage with MPs, Councillors and OSCs.
 - Supporting community members to take up places for lay members on Boards or governing bodies of relevant organisations, including Foundation Trusts and clinical commissioning groups.
 - Offering mental health awareness support, including user-led training, for local public services which have a role in improving mental health outcomes.

- Raise awareness of mental health amongst relevant organisations. This could include public services, businesses and other private sector organisations. It could also include other community groups, including those with a focus on physical health, particularly long term conditions. In rural areas, this could also include Parish Councils, who work with many local voluntary organisations and are close to their communities.”

Centre for Mental Health, Department of Health, Mind, NHS Confederation Mental Health Network, Rethink Mental Illness & Turning Point. (24 July 2012) *No Health Without Mental Health: Implementation Framework*. London: Department of Health. Page 30. Available [here](#).

“We will ensure that all consultations are properly carried out.”

David Cameron, Prime Minister’s Questions, 11 July 2012.

“At the heart of making transparency a powerful agent of change in the UK is the right that citizens have to access and use public data. It is our belief that an effective right to data is neither a single nor static piece of legislation but a mix of existing laws that complement measures, such as those outlined in this White Paper, to embed a culture of openness in government.”

HM Government (June 2012) *Open Data White Paper: Unleashing the Potential* Cm 8353 para 1.10. Available [here](#).

“Greater access to public data through data.gov.uk is an essential part of our strategy for making the most effective use of data. However, we must also consider how we open up publicly funded research data in a way that maximises public benefit. The Government, in its [Innovation and Research Strategy for Growth](#), has committed to the principle that publicly funded academic research is a public good produced in the public interest and that, while intellectual property must be protected and commercial interests considered, it should be made openly available with as few restrictions as possible. In this way, we will more effectively realise the social and economic benefits of spreading knowledge, raising the prestige of UK research and encouraging technology transfer.

HM Government (June 2012) *Open Data White Paper: Unleashing the Potential* Cm 8353 para 2.61,62. Available [here](#).

“For small businesses in particular, relevant research is often difficult to find and expensive to access, limiting the spread of knowledge and innovation. To address this, Research Councils will invest £2 million in the Gateway to Research project which will launch in December 2013. This will provide a single point of access to all aspects of UK publicly

funded research. It will serve as a networking tool for use by SMEs, entrepreneurs, intermediaries and other advisors in the field. Research Councils are currently on track to develop a prototype demonstrator portal by November 2012.

HM Government (June 2012) *Open Data White Paper: Unleashing the Potential* Cm 8353 para 2.64. Available [here](#).

“Academic Health Science Networks may wish to consider how they engage with representatives of patients, carers and the public and how they link with the new clinical senates.”

Department of Health (20 June 2012) *Academic Health Science Networks: Expressions of Interest*.

“The new NHS Summary Care Record Content and Advisory Board will include people on patient representative groups and clinical professional bodies.

Taken from [here](#).

“Clinical Senates will be made up of a range of clinicians and professionals from health, including public health and social care alongside patients, public and others, as appropriate.”

NHS (20 June 2012) *NHS Commissioning Board Local Area Teams: Staff briefing pack*.

“We want the principle to be that there are choices for service users unless there are good grounds not to have them.”

NHS (23 May 2012) *Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared decision-making*. Para 5.14.

“We propose challenging commissioners to pilot and test new ways of extending shared decision-making, including through greater use of the any qualified provider model from 2013/14.”

NHS (23 May 2012) *Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared decision-making*. Para 5.21.

“Over time, data drawn directly from care records will become a core source for much of the information that is used to improve our care services: the patient activity data (rather than parallel data collections) which, when combined with data from other management systems, such as finance, estates, supplies and HR, will provide more timely and accurate information to improve planning and delivery of our care services; for research, as well as providing a rich source of information for local organisations and regulators to identify issues and intervene before they become serious problems.”

Department of Health (21 May 2012) *The power of information: Putting all of us in control of the health and care information we need*. Para 3.26.

“Independent research published in February 2012 found that hospitals recommended by patients on the NHS Choices website tend to have lower death rates and lower readmission rates. Hospitals rated as cleaner by patients have lower MRSA rates.”

Department of Health (21 May 2012) *The power of information: Putting all of us in control of the health and care information we need*. Para 4.19.

“Health and Social Care Information Centre to set up a secure data linkage service as part of its core delivery service to health and social care, and by September 2012 will:

- deliver data extracts using linked data from primary and secondary care and other sources on a routine basis at an unidentifiable, individual level
- be used and commissioned by the specialist research service (CPRD – see below) for their specific research purposes.

Complementary to HSCIC data linkage service a new secure data service, the Clinical Practice Research Datalink (CPRD), will be established within MHRA to service the specialised needs of the research and life sciences communities.”

Department of Health (21 May 2012) *The power of information: Putting all of us in control of the health and care information we need*. Table 1.

“This Government has a strong commitment to equality of opportunity. But we also have a strong desire to reduce unnecessary bureaucracy where it exists and consider alternatives to legislation. We committed last year to assess the effectiveness of the Public Sector Equality Duty. We have decided to bring forward that review and extend it to include both the general and specific duties to establish whether the duty is operating as intended.”

The review, which is part of the Government's "Red Tape Challenge" to reduce unnecessary bureaucracy, is scheduled to conclude before April 2013.

Theresa May, Home Secretary, in a written ministerial statement 15 May 2012.

"CCG Authorisation Domain 2: Meaningful engagement with patients, carers and their communities. CCGs need to be able to show they will ensure inclusion of patients, carers, public, communities of interest and geography, health and wellbeing boards and local authorities. They should include mechanisms for gaining a broad range of views then analysing and acting on these. It should be evident how the views of individual patients are translated into commissioning decisions and how the voice of each practice population will be sought and acted on. CCGs need to promote shared decision-making with patients, about their care."

CCG Authorisation: Draft Applicants" Guide (13 April 2012) Paragraph 3.13. Available [here](#).

"CCGs will be transparent and open about the decisions they make, and therefore will include a wide range of individuals, groups and communities in their work so that the population feel involved in decision-making. They will adhere to the highest possible standards of probity and transparency to account regularly to the communities they serve about their allocation of public resources. As intelligence-led organisations, CCGs will have a clear understanding of who the communities of geography and interest are in their area, and CCG leaders will invest time in building strong relationships with diverse groups and communities to understand their needs, priorities and experiences.

CCG Authorisation: Draft Applicants" Guide (13 April 2012) Page 15. Available [here](#).

"CCGs will work with LINKs/ local HealthWatch and other partners to understand the experience of people using their services, to help local people to shape and understand the need for different services, and to encourage local people to use those services."

CCG Authorisation: Draft Applicants" Guide (13 April 2012) Page 15. Available [here](#).

"Threshold for CCG authorisation 2.1.1. Constituent communities and groups within the population served by the CCG identified.

- A. CCG has mapped and analysed constituent communities and groups.

- B. Analysis of the health needs of constituent communities and groups is reflected in CCG integrated plan.
- C. CCG has outline plans in place to communicate and engage with strategic partners and diverse groups and communities.”

CCG Authorisation: Draft Applicants” Guide (13 April 2012) Page 16.
Available [here](#).

“Threshold for CCG authorisation 2.2. Plans, processes and resources are in place to measure and use insight from patients, carers, partners and stakeholders to improve services.

- A. Arrangements in place to ensure appropriate on-going patient and public involvement in CCG decision-making.
- B. Systems and processes for monitoring and acting on patient feedback, and particularly in identifying quality including safety issues.”

CCG Authorisation: Draft Applicants” Guide (13 April 2012) Page 16.
Available [here](#).

“The Secretary of State for Health must promote (a) research on matters relevant to the health service, and (b) the use in the health service of evidence obtained from research.”

[Health and Social Care Act 2012](#) (c. 7) Part 1 - The health service in England, page 3, para 6.

“Clinical commissioning group(s) must make arrangements to secure that individuals to whom the services are being or may be provided are involved (whether by being consulted or provided with information or in other ways) —

- (a) in the planning of the commissioning arrangements by the group,
- (b) in the development and consideration of proposals by the group for changes in the commissioning arrangements where the implementation of the proposals would have an impact on the manner in which the services are delivered to the individuals or the range of health services available to them, and
- (c) in decisions of the group affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact.”

[Health and Social Care Act 2012](#) (c. 7) Part 1 — The health service in England, page 41, para 14Z2(2).

“The Government intends to put patients and the public first, and give citizens more say.”

Department of Health (2 March 2012) *Local Healthwatch: A strong voice for people – the policy explained*

[No reference to patient and public involvement in the following document]

Department of Health (8 March 2012) *Developing the Role of the Clinical Academic Researcher in the Nursing, Midwifery and Allied Health Professions*

“Integration is made stronger by people taking part in local and national life, and exercising control and influence in their daily lives and in their communities. Taking action on a local issue brings people together and helps to encourage stronger pride in local identity.”

Department of Communities and Local Government (Feb 2012) *Creating the conditions for integration page 22.*

“Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.”

National Institute of Clinical Excellence (February 2012) *CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS services*

“Commissioners should engage local groups of people who use services and carers and the voluntary organisations that represent them. They should also endeavour to involve people who are hard to reach by providing advocacy and support.”

SCIE (2012) *Safeguarding and quality in commissioning care homes* [here](#)

“Government standards... You should expect to be respected, involved in your care and support, and told what’s happening at every stage.

- In hospital, you will always be involved in discussions about your care and treatment, and staff will respect your privacy, dignity and independence. Before you receive any examination, care, treatment or support, you will be asked if you agree to it.

- In your care home, You will be involved in discussions about your care, treatment and support. You will get support to help you make decisions and staff will respect your privacy and dignity. You will be given opportunities, encouragement and support to help you live as independently as possible. Before you receive any examination, care, treatment or support you will be asked whether or not you agree to it.
- In your care at home, you will be involved in discussions about your care, treatment and support. You will get support to help you make decisions and staff will respect your privacy and dignity. Before you receive any care, treatment or support you will be asked whether or not you agree to it.
- At your dentist, You will be involved in discussions about your dental care and treatment. You will get support to help you make decisions and staff will respect your privacy and dignity. Before you receive any treatment you will be asked whether or not you agree to it.”

Care Quality Commission Government Standards [here](#).

“The overall patient experience score in 2011 for Outpatient Services is 79.2 out of 100 (where 80 would suggest that patients, on average, found the service ‘very good’).”

Department of Health data [here](#)

“The NHS Commissioning Board Authority has confirmed the appointment of the following five National Directors. ... The three remaining posts of Chief Nursing Officer, National Director of Finance and National Director of Patient and Public Engagement, Insight and Informatics are expected to be appointed in the coming months.”

<http://www.commissioningboard.nhs.uk/2012/02/03/appointment-of-five-national-directors/> 3 February 2012.

“Public Health England will publish tools that support benchmarking of outcomes between and within local areas to provide insights into performance. We expect this information will assist local leaders in developing and implementing their strategies to improve health and wellbeing, and the wider public as they seek to understand how well their local services are supporting them.”

Department of Health (January 2012) *Improving outcomes and supporting transparency: Part 1: A public health outcomes framework for England, 2013-2016* Para 4:15.

“Building on the extensive engagement we have already enjoyed, we wish to see any future development of the Public Health Outcomes Framework as a joint effort – as a result of strong partnerships between national and local government, between the NHS and local government, and most importantly with the citizens and communities whose health we need to improve and protect.”

Department of Health (January 2012) Improving outcomes and supporting transparency: Part 1: A public health outcomes framework for England, 2013-2016 Para 5:6.

“We selected indicators using a set of criteria we consulted on in 2011, which were subsequently improved and refined with expert input to ensure they provided a comprehensive means of assessing the suitability of each candidate indicator. The final sift criteria are set out below....

- Meaningful to, and likely to be perceived as important to, members of the public.”

Department of Health (January 2012) Improving outcomes and supporting transparency: Part 1: A public health outcomes framework for England, 2013-2016 Pages 28, 30.

“The NHS Commissioning Board will have a statutory duty to involve the public and will engage with patients, carers and the public to ensure it focuses first and foremost on what matters to patients. It will bring the patients’ voice directly into its work from an early stage. This approach would be reflected in the Board’s leadership, governance, operating model and culture.”

NHS (January 2012) Developing the NHS Commissioning Board Available [here](#).

“Local authorities and Clinical Commissioning Groups have a duty to involve the local community – good practice would be to involve people who access or potentially could access services with the area – in undertaking Joint Strategic Needs Assessments and joint health and wellbeing strategies, through health and wellbeing boards. The involvement should be continuous throughout the process; not just at the end. The local community will include people from all walks of life, such as local residents, excluded groups such as the homeless or refugees, people who use services and their carers; and people who are working in the area.”

Department of Health (19 Jan 2012) JSNAs and joint health and wellbeing strategies – draft guidance Page 18. Available [here](#).

“An open dialogue with the community should reveal local assets and innovative ideas that commissioners can utilise; and tap into the community’s ability to provide its own services and support. It will also produce a more informed community with insight into what services are available, how their services are designed, and what they can do to improve and maintain their own health and wellbeing.”

Department of Health (19 Jan 2012) JSNAs and joint health and wellbeing strategies – draft guidance Page 19. Available [here](#).

“Ensuring the involvement of people in the most vulnerable circumstances and excluded groups, and those with complex multiple health and social care needs, will be a challenge. Although these groups may be small in volume, they are more likely to suffer from poor health and wellbeing, and have the worst life chances. Therefore, their involvement is important to shape services to best meet their needs and improve in their health and wellbeing. Local Healthwatch and other public bodies such as criminal justice agencies, the voluntary and community sector; and local user and carer-led organisations, especially those representing people in vulnerable circumstances and excluded groups often have detailed knowledge of community needs and assets, are aware of gaps in service and information provision and the support and advocacy needed by local populations. Such organisations have considerable experience in identifying need within these groups and can advise on ways to involve them.”

Department of Health (19 Jan 2012) JSNAs and joint health and wellbeing strategies – draft guidance Page 19. Available [here](#).

“All community involvement should consider accessibility, especially for people in vulnerable circumstances or chronically excluded groups. Good public engagement strategies are those with a variety of ways to engage the public, so individuals can choose the most appropriate or convenient method for themselves.

Department of Health (19 Jan 2012) JSNAs and joint health and wellbeing strategies – draft guidance Page 20. Available [here](#).

“Many local authorities already have engagement strategies in place (under their Duty to Consult and Best Value Duty), and can build on these to avoid duplication and prevent the local community experiencing involvement fatigue.”

Department of Health (19 Jan 2012) JSNAs and joint health and wellbeing strategies – draft guidance Page 20. Available [here](#).

“Equally, commissioners, patients and service users must all have an effective voice in the development of professional education and training and workforce planning.”

DH (10 January 2012) *Liberating the NHS: Developing the Healthcare Workforce From Design to Delivery* Para 48. Available [here](#).

“Alongside the professional advisory structure, it is therefore proposed that a lay/patients forum is created to advise Health Education England, whose members will provide input to the range of its new advisory structures.

DH (10 January 2012) *Liberating the NHS: Developing the Healthcare Workforce From Design to Delivery* Para 52. Available [here](#).

“In order to be fully established, LETBs will need to provide evidence to demonstrate the following:…Mechanisms for working with clinical networks, clinical senates and Academic Health Science Networks, local Health and Wellbeing Boards and to involve patients and local communities.”

(DH (10 January 2012) *Liberating the NHS: Developing the Healthcare Workforce From Design to Delivery* Para 68. Available [here](#).

“LETBs will be expected to consult on their skills and development strategies so that patients, local communities, staff and service commissioners and education providers will be able to input their views about how LETBs plan to develop the local healthcare and public health workforce.”

(DH (10 January 2012) *Liberating the NHS: Developing the Healthcare Workforce From Design to Delivery* Para 85. Available [here](#).

“The general equality duty requires public authorities, in the exercise of their functions, to have due regard to the need to:

- Eliminate discrimination, harassment and victimisation and any other conduct that is prohibited by or under the Act.
- Advance equality of opportunity between people who share a relevant protected characteristic and people who do not share it.
- Foster good relations between people who share a relevant protected characteristic and those who do not share it.”

Equality and Human Rights Commission (Dec 2011)
Engagement and the equality duty: A guide for public authorities.
 Available [here](#).

“Engagement is a broad term, intended to cover the whole range of ways in which public authorities interact with their service users and their employees, over and above what they do in providing services, or within a formal employment relationship. Engagement may be one-off or repeated over a longer period of time. It may be formal or informal. It may be focused on a specific issue, or on service delivery, or workforce issues more broadly.”

Equality and Human Rights Commission (Dec 2011)
Engagement and the equality duty: A guide for public authorities.
 Available [here](#).

“The Care Quality Commission registration requirements as set out in regulation and detailed in Guidance about compliance: Essential standards of quality and safety place a number of requirements on providers to be open with service users about the care they receive;

- they require providers to analyse incidents that could have caused harm;
- require providers to involve service users in making decisions about their care;
- require providers to have an effective complaints procedure;
- require providers to notify CQC of a range of incidents resulting in harm to service users or with the potential to harm service users;
- and crucially, require providers to reflect, where appropriate, published research evidence and guidance issued by the appropriate professional and expert bodies as to good practice in relation to such care and treatment.”

Department of Health (2011) *Implementing a 'Duty of Candour'; a new contractual requirement on providers. Proposals for consultation.* Paragraph 3.5. Available [here](#).

“Patient data can provide great insight for health research, which in turn improves the quality of diagnosis, treatments and other interventions. It is a key goal of the NHS for every willing patient to be a research patient, enabling them to access novel treatments earlier. The greater the number of patients involved in research, the wider the public benefit. The NHS could and should do more to explain to patients the benefits both to them and to society at large of their agreement to participate in clinical trials and approved research.”

Department of Health (5 Dec 2011) *Innovation, Health and Wealth: Accelerating adoption and diffusion in the NHS.* Page 17. Available [here](#). (Interesting that there appears to be no reference to co-producing research and innovation with the public in this document.)

“We want to facilitate the participation of disabled people in community and public life by, for example, supporting disabled people to become MPs or councillors. In line with the principle

underpinning the UN Convention to involve disabled people in decisions that affect them, we want to ensure that disabled people are involved in decision-making processes.

Office of Disability Issues (Dec 2011) *Fulfilling Potential: Working together to enable disabled people to fulfil their potential and have opportunities to play a full role in society – A discussion document*. Page 16. Available [here](#).

“Public Data Corporation – we have announced plans to create a Public Data Corporation to bring together government bodies to provide an unprecedented level of easily accessible public information. It will open up opportunities for innovative developers, businesses and members of the public to generate social and economic growth through the use of data. It will be a centre of excellence that will drive further efficiencies in public sector research”

Cabinet Office (2011), *Open Public Services*. Available [here](#)

“The Health and Wellbeing Board will have a duty to involve users and the public in the development of both the Joint Strategic Needs Assessment and the Joint Health and Wellbeing Strategy.”

Department of Health (Dec 2011) *Joint Strategic Needs Assessments and joint health and wellbeing strategies explained* page 23.

“The Government aims for there to be “no decision about me, without me” for patients and their own care. The same goes for the design of health and social care services at both a local and a national level.”

Department of Health (2011) Factsheet B3 *Greater voice for patients – The Health and Social Care Bill* Factsheet B3. Available [here](#).

“This NHS Operating Framework for 2011/12 needs to be viewed in the context of three inter-related themes:

- (1) transition and reform...
- (2) transparency and local accountability – what we need to involve public and patients in and give them a better understanding of how and where their money is being spent to improve services and strengthen local accountability; and in doing so make a significant contribution to the Big Society;
- (3) service accountability...”

Department of Health (2011) *The Operating Framework for the NHS in England 2011/12*. Para 1.5. Available [here](#).

“The NHS Commissioning Board (NHSCB) will be established in shadow form as a Special Health Authority in 2011/12 and will become fully operational from 1 April 2012. When fully established, the NHSCB will be responsible for... promoting and extending public and patient involvement and choice...”

Department of Health (2011) *The Operating Framework for the NHS in England 2011/12*. Para 2.7. Available [here](#).

“PCTs must continue to ensure their statutory obligations under the Duty to Involve is effectively and efficiently discharged during transition to commissioning by GP consortia.”

Department of Health (2011) *The Operating Framework for the NHS in England 2011/12*. Para 3.14. Available [here](#).

“Our vision is of a society in which social action and reciprocity are the norm and where volunteering is encouraged, promoted and supported because it has the power to enhance quality, reduce inequality or improve outcomes in health, public health and social care.”

Department of Health (2011) *Social action for health and well-being: building co-operative communities: Department of Health strategic vision for volunteering* Available [here](#).

“For clinical trials, the NIHR will from 2012 publish outcomes against public NIHR benchmarks, including an initial benchmark of 70 days or less from the time a Provider receives a valid research protocol to the time when that Provider recruits the first patient for that study.” In future NIHR funding to providers of NHS services will become conditional on meeting benchmarks, including a 70 day benchmark to recruit first patients for trials. The NIHR will make this a condition of new contracts from autumn 2011 and performance will affect funding from 2013.”

HM Treasury (2011) *The Plan for Growth* paras 2.192, 2.193

“The Government is committed to opening up information about clinical trials so that patients can find out about trials that may be relevant to their condition. The NIHR is developing a web-based UK Clinical Trials Gateway. It will present, in accessible form, information about trials conducted in the UK. By 2012, the Gateway will make it easy for patients, their doctors and carers, friends and families to see what a trial is about, where it is taking place, and who is running it. It will help patients to join in clinical trials if they are suitable and choose to do so with full information and advice.”

HM Treasury (2011) *The Plan for Growth* para 2.197

“Clinical Commissioning Groups need to be able to show how they will ensure inclusion of patients, carers, public, communities of interest and geography, health and wellbeing boards and local authorities. They should include mechanisms for gaining a broad range of views then analysing and acting on these. It should be evident how the views of individual patients are translated into commissioning decisions and how the voice of each practice population will be sought and acted on. CCGs need to promote shared decision-making with patients, about their care.”

Department of Health (2011) *Developing clinical commissioning groups: Towards authorisation* page 13.

“To achieve the best outcome for patients, Clinical Commissioning Groups will need to recognise the vital roles innovation and the promotion and support of research have to play.”

Department of Health (2011) *Developing clinical commissioning groups: Towards authorisation* page 7 – foreword by David Nicholson.

“Clinical Commissioning Groups will need to demonstrate how they will exercise important functions such as the need to promote research.”

Department of Health (2011) *Developing clinical commissioning groups: Towards authorisation* page 13

“Meaningful engagement with patients, carers and their communities – systems and processes need to be in place to promote patients’ recruitment to and participation in research.”

Department of Health (2011) *Developing clinical commissioning groups: Towards authorisation* Technical Annex 3, page 5

“Where it is appropriate, and enables meaningful engagement, conduct 12-week formal written consultations, with clear explanations and rationale for shorter time-frames or a more informal approach.”

Cabinet Office (2010) *The Compact* para. 2.4.

“In a healthcare system in which patients and the public come first, the Government is committed to supporting the emphasis that the NIHR puts on patient and public involvement in research.”

Earl Howe, 30 July 2010

“Changes to services will sometimes be required but must be consistent with the four key tests for service reconfigurations set out by the Secretary of State in May 2010:

- support from GP commissioners;
- strengthened public and patient engagement;
- clarity on the clinical evidence base; and
- consistency with current and prospective patient choice.”

Department of Health letter available [here](#).

“The Department for Business, Innovation and Skills is committed to fostering public engagement, recognising its value for research and society. From art and science festivals to school workshops and research projects involving local communities, our universities and scientific and cultural institutions have a rich history of engaging the public with research, across all disciplines. There does however remain a challenge to embed our public engagement activities, to continue to improve their scope and quality, to bring initiatives together better for greater effect, and to assess their impact.”

Research Councils UK (2010) *Concordat for Engaging the Public with Research*

“The Government’s ambition is to achieve healthcare outcomes that are among the best in the world. This can only be realised by involving patients fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone.”

DH (2010) *Equity and Excellence: Liberating the NHS*. Track progress with the Health and Social Care bill [here](#)

“International evidence shows that involving patients in their care and treatment improves their health outcomes, boosts their satisfaction with services received, and increases not just their knowledge and understanding of their health status but also their adherence to a chosen treatment. It can also bring significant reductions in cost, as highlighted in the Wanless Report, and in evidence from various programmes to improve the management of long-term conditions. This is equally true of the partnership between patients and clinicians

in research, where those institutions with strong participation in clinical trials tend to have better outcomes.”

DH (2010) *Equity and Excellence: Liberating the NHS*, para 2.3.

“The [Government] will put duties on the NHS Commissioning Board to ... promote involvement in research and the use of research evidence.”

DH (2010) *Liberating the NHS: Legislative Framework and next steps* para 4.58

“The vision is for:

- A ‘patient-led NHS’ – ‘No decision about me without me.’
- A focus on outcomes - must involve patient experience as part of ‘quality’
- Empowering professionals – Clinical commissioners must involve lay reps.

DH (2010) *Liberating the NHS: Legislative Framework and next steps*.

“First that patients must be at the heart of everything we do, not just as beneficiaries of care but as participants in shared decision making. As patients, there should be no decision about us without us.”

Andrew Lansley, CBE, MP – Secretary of State for Health, 8 June 2010. Available [here](#)

“Patient and Public Engagement PPE: is an approach to involving and empowering people using services, and taking their experiences into account. It has evolved with the NHS, generally resulting from statutory organisations and the third sector challenging services to be patient-centred. It is reinforced by the emphasis... on three strands of quality, with patient experience sitting alongside patient safety and clinical effectiveness as an equal partner.”

Department of Health (September 2009) *Putting people at the heart of care*

“The duty to involve is extended to include a broad range of public bodies including Homes and Communities Agency, English Police Authorities, Probation, and youth offending services as well as local authorities and health services.

The Local Democracy, Economic Development and Construction Act 2009

“Research is a core part of the NHS. Research enables the NHS to improve the current and future health of the people it serves. The NHS will do all it can to ensure that patients, from every part of England, are made aware of research that is of particular relevance to them. The NHS is therefore putting in place procedures to ensure that patients are notified of opportunities to join in relevant ethically approved research and will be free to choose whether they wish to do so.”

Department of Health (2009) *NHS Constitution Handbook*, p51.

“NHS services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment.”

Department of Health (2009) *NHS Constitution* paragraph 4

“The NHS is accountable to the public, communities and patients that it serves. The NHS is a national service funded through national taxation, and it is the Government which sets the framework for the NHS and which is accountable to Parliament for its operation. However, most decisions in the NHS, especially those about the treatment of individuals and the detailed organisation of services, are rightly taken by the local NHS and by patients with their clinicians. The system of responsibility and accountability for taking decisions in the NHS should be transparent and clear to the public, patients and staff. The Government will ensure that there is always a clear and up-to-date statement of NHS accountability for this purpose.”

Department of Health (2009) *NHS Constitution* paragraph 7

“The duty to involve the public under section 242 of the NHS Act 2006, and the associated policy and practice guidance *Real involvement*, raised the bar for the way NHS organisations are expected to involve and consult people and respond to the feedback received. As a result, more and more people across the country should feel better informed and supported to have a say about what really matters to them. Most NHS organisations are making great strides in involving people, and many are using the feedback and insight into patients’ needs and wants in order to inform improvements in health services.”

Department of Health (2009) *Real accountability: Demonstrating responsiveness and accountability* page 2

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- Criterion 1. When to consult - Formal consultation should take place at a stage when there is scope to influence the policy outcome.
- Criterion 2: Duration of consultation exercises - Consultations should normally last for at least 12 weeks with consideration given to longer timescales where feasible and sensible.
- Criterion 3: Clarity of scope and impact - Consultation documents should be clear about the consultation process, what is being proposed, the scope to influence and the expected costs and benefits of the proposals.
- Criterion 4: Accessibility of consultation exercises - Consultation exercises should be designed to be accessible to, and clearly targeted at, those people the exercise is intended to reach.
- Criterion 5: The burden of consultation - Keeping the burden of consultation to a minimum is essential if consultations are to be effective and if consultees' buy-in to the process is to be obtained.
- Criterion 6: Responsiveness of consultation exercises - Consultation responses should be analysed carefully and clear feedback should be provided to participants following the consultation.
- Criterion 7: Capacity to consult - Officials running consultations should seek guidance in how to run an effective consultation exercise and share what they have learned from the experience.

HM Government (2008) *Code of Practice on Consultation* London: Better Regulation Executive Department for Business, Enterprise and Regulatory Reform

“Guidance is provided here for NHS organisations on section 242(1B) of the NHS Act 2006, the duty to involve and good involvement practice as well as guidance on sections 17A, 24A and 242B of the NHS Act 2006 and information about section 242A of the Act.

Department of Health (2008) [*Real involvement: working with people to improve services*](#)

“The commissioning role could be taken to include... Ensuring meaningful participation and active involvement in commissioning processes for the citizens using services.”

Department of Health (2007) *Commissioning for Personalisation: A framework for local authority commissioners*

“Suitably trained and CRB checked LINKs volunteers may enter and view premises providing health and social care services.

Public Involvement in Health Act 2007.

“Local authorities and best value authorities have a ‘duty to involve’ under the Local Government and Public Involvement in Health Act 2007, section 138. This requires them to involve local representatives when carrying out "any of its functions" by providing information, consulting or "involving in another way".

Local Government and Public Involvement in Health Act 2007.
Available [here](#).

“Proactively seek and build continuous and meaningful engagement with the public and patients, to shape services and improve health.”

Department of Health (3 Dec 2007) *World class commissioning: competencies*. Available [here](#).

“By 2010 we will....work in partnership with all our stakeholders including patients and the public, and develop effective patient and public engagement initiatives in partnership with our partners.... patients and the public must be involved in all stages of the research process: priority setting, defining research outcomes, selecting research methodology, patient recruitment, interpretation of findings, and dissemination of results.”

DH (2006) *Best Research for Best Health: A new national health research strategy page 32 and para 5.3*. Available [here](#)

“The potential impact of choices in research design (such as sample design, data collection method and so on) on participation should be considered. In particular, the effect of research design on such groups as ethnic minorities, those with caring responsibilities, and those with physical or mental impairment should be considered. Consideration should be given to issues likely to act as a barrier to participation, and reasonable steps taken to address these. Possible measures include:

- Assistance with costs incurred in research participation: - e.g. help with childcare, or transport costs etc.
- Provision of services: e.g. transport to and from the venue for those with accessibility/mobility problems; provision of interpretation facilities/foreign language interviews; induction loops for those with hearing impairment etc.

- Methods of data collection: e.g. offering a choice between self completion and interviewer assisted interviewing in projects where respondents have difficulty reading or comprehending written material.
- Sample design: e.g. considering the implications of excluding sparsely populated areas in highly clustered sample designs; and considering the case for over-sampling under-represented or hard-to-reach groups.
- User-involvement: e.g. consulting hard-to-reach groups and/or their representatives on research design to ensure that possible barriers to participation are identified and minimised.”

GSRU, HM Treasury (2006) *Ethical assurance for social research in government* para 2.12

“NHS organisations are required to make arrangements to involve and consult patients and the public in:

- planning of the provision of services;
- the development and consideration of proposals for changes in the way those services are provided, and
- decisions to be made by the NHS organisation affecting the operation of services.”

Section 242 of the National Health Service Act 2006, section 242. Briefing [here](#).

“Disabled people have the right to take part in political and public life.”

United Nations (2006) *United Nations Convention on the Rights of Persons with Disabilities* Article 29.

“Research, and those pursuing it, should respect the diversity of human society and conditions and the multicultural nature of society. Whenever relevant, it should take account of age, disability, gender, sexual orientation, race, culture and religion in its design, undertaking, and reporting. The body of research evidence available to policy makers should reflect the diversity of the population.”

DH (2005) *Research Governance Framework for Health and Social Care Second Edition*. Paragraph 2.2.7, page 8. Available [here](#)

“Research [should be] pursued with the active involvement of service users and carers including where appropriate, those from hard to reach groups such as the homeless.”

DH (2005) *Research Governance Framework for Health and Social Care Second Edition*. Box B: Standards in quality organisations undertaking research: Ethics, page 15. Available [here](#)

“A TO Z OF THE MAIN PEOPLE AND ORGANISATIONS INVOLVED IN A HEALTH OR SOCIAL CARE RESEARCH STUDY. PARTICIPANT - Patient, service user, carer, relative of the deceased, professional carer, other employee, or member of the public, who consents to take part in a study. (In law, participants in clinical trials involving medicines are known as subjects.)”

DH (2005) *Research Governance Framework for Health and Social Care Second Edition* Available [here](#)

“Section 11 confers on each Health Authority, Primary Care Trust and NHS trust a new statutory duty to make arrangements with the aim of involving patients and the public in the planning and decision making processes of that body, in so far as they affect the operation of the health services for which the body is responsible. In relation to Health Authorities, this would cover both the hospital and community health services for which they are responsible and the family health services provided by practitioners in their area.”

Section 11 of the Health and Social Care Act 2001. Available [here](#)

“At the conclusion of the study, patients entered into the study are entitled to be informed about the outcome of the study and to share any benefits that result from it, for example, access to interventions identified as beneficial in the study, or to other appropriate care of benefits.”

Declaration of Helsinki 1975.