NHS

Liberating the NHS:

An Information Revolution

Your response to the consultation questions

DH Department of Health

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CHAPTER 1: An Information Revolution	
1. What currently works well in terms of information for health and adult social care and what needs to change?	What currently works well in terms of information for health and adult social care? There is a growing body of evidence and information which is accessible to a variety of audiences. Patients and carers even now have greater access to information to inform themselves e.g. NHS Choices and other support groups and networks. Health care professionals also now have access to more data and evidence allowing them to make informed decisions about patient care. What needs to change in terms of information for health and adult social care? For all individuals (patients/ carers, clinicians, other health professionals, library/knowledge professionals) who need to provide information and get access to it, there needs to be a more seamless interaction, there needs to be fewer places to look for information and individuals should not have to provide the same information multiple times. There are also challenges with the robustness of data as well as the ability of those using it, to make accurate interpretations of what it means. Technology also remains a challenge if the intention is for information to be widely available electronically, network bandwidth and internet speed still prove problematic for staff working within the NHS. Furthermore not all patients and carers have access to high speed broadband or even access to the internet at all. Evidence and data need to be examined together as a matter of course to ensure robust decisions are made and influence health outcomes. This will result in high quality

	care and a better patient experience. Knowledge Management (for definition please see CH4 Q24) behaviours, tools and processes need to be adopted right across the system. Comment: Social care of the entire population including children should be part of this consultation and feedback.
2. *What do you think are the most important uses of information, and who are the most important users of it?*	What do you think are the most important uses of information? There are at least six distinct types of information, which are all key: 1. Evidence 2. Research 3. Experience 4. Data 5. Drug Information 6. Medical Device Information The most important use of information is the provision of high quality patient care. Information enables appropriate decision making, diagnosis and treatment. It also enables patients and carers allowing them to make informed descisions about their care and better manage their conditions. All of the six types of information have a critical role to play in the provision of high quality patient care. Other important uses of information are commissioning decisions and management information. Who are the most important users of it? * Patients/ Carers * Clinicians * Other Health Care Professionals * Library/knowledge services professionals (to support Patients/Carers and the work of Clinicians and Other Health Care Professionals) * Monitor * Care Quality Commission All of the above are important users of information, however depending on the symptom, condition, treatment or situation, the most important users may vary. The ability of individuals to find, understand and interpret information will influence how important it is to them.
3. *Does the description*	The Information Revolution diagram currently considers only

of the information revolution capture all the important elements of the information system?	care records as the primary source of data. To provide users with high quality information in its broadest sense, other sources of information need to be included in the Information Revolution cycle. In order to ensure that patient care decisions are made with the best evidence available, information needs to be drawn from research, third party evidence, robust data, drug information and medical device information both within the UK and throughout the world.
	Library/knowledge services professionals in both the public and NHS sectors have a key role in the provision of sound evidence to enhance the data and information that is available and should be an integral part of the Information Revolution cycle. By ensuring they are actively engaged will result in higher quality information resulting in improved patient care. They also have a vital role in being a communications conduit, as they are often have the best network linkages to all users of healthcare information. Library/knowledge services professionals are navigators of quality assured information resources.
	High quality research is essential for extending the evidence base and achieving the improvements in healthcare that an ageing population will both need and expect, which may also result in greater cost efficiencies and value for money.
	Consideration needs to be given to how the information is presented depending on the category of user to enable them to make informed decisions. The tools that are available to make these decisions will also need to vary depending on the knowledge and understanding of the user. Different user groups will need to be able to access different types and levels of information such as a clinician accessing detailed drug information. In some circumstances it will be appropriate for an expert patient to have comprehensive access to information particularly for rare conditions.
	For the Information Revloution to succeed there needs to be a cultural shift towards a greater sharing of knowledge and information and a sense of responsibility to ensure that the information and data provided is accurate and robust. There will also be a significant requirement for training for all users of information to ensure that all sources of information are used appropriately and interpreted accurately.
4. *Given the current*	For this to succeed there needs to be a clear strategic

financial climate, how can the ambitions set out in this consultation - to make better use of information and technology to help drive better care and better outcomes - be delivered in the most effective and efficient way?	vision, which enables sharing of expertise, partnership working, communication within and across user groups, improved linkages between individuals and organisations, streamlined processed for capture of data and information, successful case studies to inform practice, and the effective use of knowledge management tools including those relating to knowledge transfer and communities of practice. Many library/knowledge services professionals have key knowledge management skills that will facilitate the effective and efficient delivery of the Information Revolution in a challenging financial climate.

All users of information are fundamental to the effective and efficient working in any financial climate and have a duty to be actively engaged in contributing their expertise, knowledge, information and needs.

To be sucessful in the most effective and efficient way the NHS should seek to take advantage of the knowledge and skills of the 1000 + staff currently employed in library/knowledge services roles. The national network of health library/knowledge services is well established to provide quality information and user centered services to support evidence based healthcare, and to develop the information literacy skills of the healthcare workforce, that are essential to delivering the vision of the Information Revolution.

Furthermore, consortia purchasing of information/knowledge resources at national or regional levels have achieved significant cost efficiencies and should be considered as part of the implementation of the Information Revolution. The Government should also review current approaches to purchase of public sector copyright licences and to payment of VAT on information resources and services.

Technology:
For this to succeed, technology is pivotal, but should be the driver not the enabler. How the information is structured using taxonomies, metadata and enterprise architecture is more important than the technology being used to deliver the information. If the information is not accessible in a user friendly fashion then the system will fail. |
| 5. *Where should the centre be focusing its limited financial* | The Department needs to ensure that all the drivers for change move forward together resulting in a positive outcome. |

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resources and role to achieve the greatest positive effect?	The Department has a responsbility in its capacity as executive sponsor and enabler of this work to ensure appropriate communication occurs, so that all users recognise their responsibilities in taking ownership of the changes needed for the Information Revolution to succeed.

The Department and the Government need to ensure that there is an appropriate level of infrastructure at a strategic and operational level within the NHS and Local Government and all other relevant Government Departments to deliver the outcomes of the Information Revolution.

The Department also needs to ensure that all relevant parties have the necessary skills and knowledge to deliver the Information Revolution effectively and efficiently. |

CHAPTER 2: Information for patients, service users, carers and the public

6. As a patient or service user, would you be interested in having easy access to and control over your care records? What benefits do you think this would bring?	Potentially this could improve a patient's understanding of their health condition and enhance their ability to manage their condition. Having easy access to personal medical notes would be very helpful when having to complete forms about vaccinations, medical history for insurance purposes etc. However, there are concerns about risks to privacy and confidentiality that the sharing of records could bring.
As online access to records is envisaged, what plans are in place to offer a similar service to those without internet access?
7. As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals on-line, or would you prefer face-to-face contact?	As a patient, there are many times when a quick email would have sufficed instead of spending a lot of time trying to get an appointment over the phone or in person at the surgery.
There is also potential for considerable savings if more communications with patients were undertaken electronically. Many GP surgeries and hospitals still send out letters by first class post and often these communications are duplicated. However, such methods would still be required for those without email access; but email should be the default method.
Booking GP appointments and ordering repeat prescriptions online is a huge benefit. It would be good if this could be extended to communication of the results of routine tests (e.g. blood tests and screenings where results are "normal"). However, sensitive and complex information is likely to be better handled in a face-to-face meeting, when a patient's concerns can be immediately addressed by the health professional and appropriate support can be offered. On line access probably is a bonus for those with the means to connect and the understanding of how to use/navigate the information. More consideration needs to be given to

	access for the less able in this regard.
8. *Please indicate any particular issues, including any risks and safeguards, which may need to be taken into account in sharing records in the ways identified in this consultation document.*	Access to records raises the following concerns: • Are IT systems sufficiently robust and secure to ensure sensitive information is protected? • Staff responsible for handling records need to be fully trained in using systems and understand legal issues • NHS need to ensure records cannot be accessed by unauthorised parties (e.g. employers, insurance companies) • Literacy of patients reading their own notes – many will need support to help them use the notes and understand the content • Issue of the "digital divide" – how will NHS ensure that those without internet access have equal access to their notes in whatever format they require? • How well skilled is the general public in IT security issues? People would need to understand the importance of not sharing passwords or PIN numbers to access their records. • Where patients lack capacity and a family member is acting on their behalf, procedures would need to be in place to ensure family member is using information in the patient's best interest
9. *What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?*	Information needs to be written in a succinct manner and in a plain English style. • Information which gives key contacts for further information, including details of appropriate support groups and networks • Appropriate use of "intermediaries", e.g. PALS, health trainers, librarians trained in dealing with patient information, health promotion staff, " peer" support (e.g. meeting someone who has recovered from the condition or learnt how to manage it) • Patient information centre in a hospital or health centre in which information can be obtained in a supportive and welcoming atmosphere, with a zoned area for private conversations. Library/knowledge services staff have a role to play in either managing such centres or supporting those who are responsible for them • Encouraging patients to ask the right questions during consultations, promoting the DH leaflet "Questions to Ask" For all information users, basic principles of data security and confidentiality.

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	• For specified groups, information on financial and other support, available through benefits system and elsewhere. • For carers, information on benefits, claiming back charges (hospital car parking etc) and adapted living.
10. As a patient or service user, what types of information do you consider important to help you make informed choices? Is it easy to find? Where do you look?	Types of information include: • Factual information available from NHS Choices and major health charities to give an overview of conditions and treatments available • Patient feedback available from NHS Choices • Data on mortality rates, infection rates etc. • Discussion with GP, supported by information obtained by the patient • Discussion with friends, neighbours etc. to discover "real-life" experiences of services • NICE guidance on best practice Much of this information is freely available on the internet, but those without internet access are disadvantaged. They need to be pointed towards services such a public libraries with free internet access. In addition, health centres and hospitals should have free internet access available for this purpose, with access to recommended sites such as NHS Choices, NHS Direct and NHS Evidence. Many people will require support in finding , reading and evaluating such information and this is another area where trained knowledge/library services professionals can be invaluable. Health library/knowledge services, as well established providers of quality information for health care workforce, can and should play a role in meeting the wider health information agenda for patients. Examples of these roles include: * closer working between NHS health libraries/knowledge services and local authorities/public libraries, * developing the information literacy skills of health care staff, * information support for prescription services

11. What additional information would be helpful for specific groups – eg *- users of maternity and children's health services;* *- disabled people;* *- people using mental health or learning disabilities services;* *- the elderly;* *- others?*	Disabled people and the elderly would need information about access to health facilities and transport arrangements. Information will also be needed in different formats, e.g. easy-to-read versions. All these groups may particularly benefit from advice and support from staff in patient information centres and public libraries.
12. What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?	Carers need information about support groups and networks available locally, as well as financial (e.g. benefits) and legal information (e.g. Mental Health Act). Carers may require a separate conversation with health professionals to cover such matters, as well as detailed information on how they can best support the practical care of their family member.
13. What are the information needs of people seeking to self-care or live successfully with long-term physical and mental health conditions and what support do they need to use that information?	In addition to information on conditions and treatments, they need: • Information on practical and financial support • Information on local support services (e.g. Centres for Independent Living) • Peer support via online fora or local support groups • Online / email access to GPs and clinicians, to eliminate unnecessary consultations and travel time • Information on how to use assistive technology for remote monitoring of their condition • Access to a patient information and advice centre at a hospital or health centre • Access to health literacy training, to ensure that patients can search for and evaluate quality information to support their self-care. Library/knowledge services staff (especially health librarians) are well placed to provide such training

CHAPTER 3: Information for improved outcomes	
14. What information about the outcomes from care services do you (as patient, carer, service user or care professional) already use?	- guidance and signposting to information and experts in these services, - successful outcomes and risks associated with services - specialist services and who to contact to obtain information.
15. What additional information about outcomes would be helpful for you?	More information about "quality assessment" of information, particularly relating to shared websites for patients to exchange information. An example of this would be the database of uncertainties of treatment. http://www.library.nhs.uk/duets/
16. How can the benefits of seamless and joined up information be realised across the many different organisations (NHS and non-NHS) a service user may encounter?	Here there is a role for the Chief Knowledge Officer (CKO) (see http://www.libraryservices.nhs.uk/ckosupport/), particularly with the appointments of CKOs who are Directors that span both NHS and local authorities. Senior leaders from NHS and non-NHS organisation should be attending joint strategy and planning meetings to share information and ensure key cross-sectoral issues are discussed.
17. For which particular groups of service users or care organisations is the use of information across organisational boundaries particularly important?	Patient information for clinical care pathways for children's services, mental health, maternity and the new born, elective care, long term conditions for coronary care, cancer treatments, diabetes, obesity, end of life care, as well as staying healthy. Each of these clinical care pathways requires joined-up and seamless access to patient information, particularly for discharge planning. For those with long term and/or multiple conditions and whose needs cross the health/social care/education boundaries.
18. What are your views on the approach being taken, and the criteria to be used to review central data collections?	Central data collection has significant benefits for supporting service provision across NHS and non-NHS organisations However, the criteria for reviewing data must include a robust security and quality assurance process.

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19. How could feedback from you be used to improve services?	The feedback should be evidence based and the use of the highest quality evidence should be employed to underpin improvement in services. NHS library/knowledge services can play an important role in providing the highest quality evidence.
20. What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?	There is a need to recognize an "evidence based" core of treatments, for example, clinical knowledge summaries www.cks.nhs.uk Feedback from patients, service useres, their families and carers should be encouraged at every opportunity though a consistent and easily recognised feedback process via all communication channels. Patients and their families need to know that their feedback will impact on service provision and, ultimately on improvement of services. All available communication processes should be made available to support engagement in feedback.
21. What are the key changes in behaviour, systems and incentives required to make the NHS and adult social care services genuinely responsive to feedback and how can these be achieved?	This requires a high level strategic approach to bring all NHS and adult social care services together to manage a performance monitoring and kite marking process which recognises quality in service provision. Feedback from service users should be a a key component of this monitoring.
22. Which questions, if asked consistently, would provide useful information to help you compare and choose services?	A set of key performance indicators should be created to provide transparency on the quality of service provision. Benchmarking services against each other may help to improve services but may ignore higher standards elsewhere. These would be reported in the literature and can also be found in the clinical databases eg Cochrane.
23. What will help ensure that information systems - and the data they collect - are appropriate to support good commissioning at	A high quality evidence base of impartial commissioning information is essential. This evidence should be accessible and 'owned' by all organisations involved in commissioning and regularly reviewed. There should be strong governance processes in place to underpin the NHS Commissioning Board to ensure the most effective outcomes. In addition the NHS Commissioning

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different levels, including decisions by individual patients, GP practices, GP consortia, service providers, local authorities and the NHS Commissioning Board?	Board should have the support of library/knowledge professionals.

CHAPTER 4: Information for professionals

24. How can health and care organisations develop an information culture and capabilities so that staff at all levels and of all disciplines recognise their personal responsibility for data?	While we welcome the broad thrust of this chapter, recognising the information needs of professionals, we believe there are a number of areas where the viewpoint needs to be much broader and inclusive than the focus on "data". Also, it is not just "professionals" that need information to support their day-to-day and strategic decision making; ALL NHS staff and students need a wide range of information in order to ensure safe patient care. Information is needed to support: • Clinical decision making • Effective communication • Management decisions • Life-long learning • Research and development Organisations need to develop cultures that understand that "information" is not just about data and it's analysis and utilisation; information includes knowledge and evidence that comes from both the experience of the individual and from the published and semi-published literature. There need to be robust systems in place to ensure all staff and students have the capabilities to access, retrieve and evaluate knowledge and evidence. This enables all staff to keep their skills up to date and leads to a cycle of continuous improvements in patient care. There also need to be systems to ensure the wider capture and use of the "organisational knowledge" that exists in the heads of all staff, filing systems and electronic records (such as policies, procedures, meeting notes etc) and that these systems are in place, understood and in use. Knowledge management techniques for the capture, storage and mobilisation of information should be more widespread. All NHS organisations therefore need strong, Board-level leadership around the knowledge and information agenda

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	to ensure that cultural change is delivered. The existing network of Chief Knowledge Officers could be expanded and utilised more explicitly to highlight the need for excellence in information management across all organisations. In addition, an understanding of the use of knowledge and evidence needs to be embedded in all education programmes, particularly at undergraduate level so that a life-long understanding of the value of evidence is created among all staff.
25. As a clinician or care professional, how easy is it for you to find the evidence you need to offer the best possible care and advice? What could be done better?	We are aware that many staff suffer from "information overload" and do not have the skills or the time to locate relevant information when and where they need it. As a group of health professionals working at the heart of the information revolution, library/knowledge services staff are qualified and trained to manage and deliver a wide-range of services and are ideally placed to manage the knowledge and evidence needs of all staff and students by supporting them with a range of services that provide access to the best available evidence and, at the same time, save clinical and managerial time. These services include: • Access to a wide range of quality assured information resources in a variety of formats to support all aspects of health and social care provision • Searching the evidence base to produce answers to clinical and commissioning questions • Signposting staff and patients to suitable resources which meet their specific information need at an appropriate level • Information skills training to provide NHS staff and students with the skills to access, retrieve and evaluate knowledge and evidence • Alerting services to provide individuals and teams with up to the minute information about developments in their area of expertise • Support for researchers and in particular the skills to facilitate knowledge transfer – so research does "get into practice" Library/knowledge services professionals have long-standing and highly effective networks across NHS England which support the sharing of resources and expertise and work in close partnership with higher education and public library services. These networks make the best use of scarce resources and need to be led by senior knowledge and evidence professionals and developed to extend their capacity to support the needs of NHS staff and students. In terms of what could be done better:

	• Library/knowledge services need strong professional leadership at national and local level • Library/knowledge and evidence networks should be well-resourced, strengthened and quality assured • Knowledge and evidence resources could be better procured by extending existing shared schemes both between NHS organisations and across the NHS, social care and higher education sectors.
26. Clinicians, practitioners, care professionals, managers and other service provider staff will be expected to record more data and evidence electronically. How can this be facilitated and encouraged? What will be the benefits for staff and what would encourage staff to reap these benefits?	The need for all NHS staff and students to have information literacy skills is essential if they are to use all electronic systems effectively – but they must also understand that data and data entry is only one part of the much wider information agenda which includes the knowledge and evidence resources and skills we have referred to in the two earlier questions in this chapter. All education provision should include the relevant elements of information management. The benefits of good information management should be made clear to all and risks and errors caused by poor practice should also be disseminated widely.
27. What are the key priorities for the development of professional information management capacity and capability to enable the information revolution?	The capture, organisation and mobilisation of "knowledge" is crucial in all aspects of health and social care. The key knowledge management behaviours of collaboration, knowledge harvesting and the creation of knowledge assets for multiple audiences strengthen the learning culture in all organisations and support the constant cycle of innovation and improvement. Nurturing the existing patchy areas of good practice in knowledge management and encouraging their adoption and spread would support the implementation of the Information Revolution across the system. The development needs of library/knowledge services professionals must not be overlooked; they are one of the smaller NHS professional groups within the wider health informatics workforce and there need to be mechanisms in place to meet their CPD and life-long learning needs. The role of national NHS knowledge and evidence leaders and the professional bodies - such as Chartered Institute of LIbrary and Information Professionals (CILIP) and UK Council for Health Informatics Professions (UKCHIP) are important in agreeing the way forward in developing a high quality workforce to support all aspects of the NHS.

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CHAPTER 5: Information for autonomy, accountability and democratic legitimacy

28. *The 'presumption of openness' in support of shared decision-making will bring opportunities – but may also generate challenges. What are the greatest opportunities and issues for you a) as a care professional? or b) as a services user?*	As well as issues of consistency and verification of the information provided, attitudes may need to change too. For instance, many Trusts treat documents as internal that could end up being shared through Freeddom of Information requests anyway - need to change the culture so less fear of openness. Openness should also extend to research and trials data, through open access publishing and openness in reporting of trials, information from which contributes to the treatment choices patients need to make. Copyright and publisher licences can be a barrier to sharing of information - e.g. NHS England copyright licence says that patients may be provided with only single paper copies from books and journals. Licences for electronic resources restrict access for patients and members of the public and these restrictions could increase in a market of external information providers. To address this risk, we need to extend open government licensing and creative commons licensing schemes, to actively encourage open access publishing.
29. *What benefits and issues do you think will arise as a greater range of information providers offer information? How could issues be addressed?*	In terms of information on conditions, treatments, etc. accredited national information needs to be used as much as possible to minimise time wasted on local leaflets giving the same information. Public libraries and Patient Information Centres have a role to play in getting patients and carers to the most relevant information. Issues include the risk that the NHS ends up 'buying back' its own data from external information providers and intermediaries, the risk of duplication of effort and cost in collection and presentation of information, and the risk that information is re-purposed 'out of context'. In opening up information to wider audiences and new intermediaries, which is positive and welcome, it is important not to overlook the fact that the NHS already has its own skilled information intermediaries - library/knowledge services professionals whose job is to maintain awareness of evidence and data sources, perform context-sensitive information searches, critically appraise information, and present it in ways fully consistent with data protection and copyright requirements.
30. *Would there be benefits from central accreditation or other quality assurance*	Central quality kite-marking of information is often requested and very difficult to achieve - whilst there is merit in pursuing this and building on the NHS as a trusted brand, learning perhaps from NHS Evidence's experience in this area, it should be recognised that patients and

systems for information providers and 'intermediaries'? Would factors such as cost and bureaucracy outweigh any benefits?	clinicians will continue to draw information from a wide variety of sources, and therefore that employing library/knowledge professionals with critical appraisal skills, teaching critical appraisal skills to healthcare staff, and educating patients and carers in this area, will continue to be important.
31. How can a health and social care information revolution benefit everyone, including those who need care most but may not have direct access to or know how to use information technology? This might include those who do not have access to a computer or are remote and can not access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages.	Public libraries are one way to enable access for those without the skills or access to equipment to take advantage. They could work in partnership with the NHS and health libraries/knowledge services in setting up systems to do this. Patient information centres, where they exist, are another way of doing this, and Trusts should be encouraged to provide support to their service users in finding and understanding quality-approved information.

Perhaps supermarkets could provide NHS branded information kiosks.

Core information should be made available in other media - printed or audio.

The recommendations on taking advantage of modern technology, in particular social media, to increase interaction between health services and their users are encouraging.
However there is the need to address:
• The divide between information rich and information poor among the healthcare workforce, as well as among the public.
• The recognition of the needs for modern and open technology for both internal and external communication, in Trusts' organisational policies and culture.
• The need to improve the current capacity of local IT infrastructure.
• The need to encourage innovation and creativity. |
| *32. Are there other datasets that you think could be released as an early priority, without compromising individuals' confidentiality? Would there be any risks associated with their release – if so, how could these be managed?* | |

CHAPTER 6: Setting the direction – the Information Strategy

33. The information revolution can deliver many improvements. What are particular benefits or other challenges – including sustainability, business, rural or equality issues – that need to be considered in developing the associated impact assessment?	Using a variety of regular, clear and appropriate communication processes that meet the needs of all age groups, cultural and language needs. Security of patient information. Clarity of signposting to information.
34. Are there any critical issues for the future of information in the health and adult social care sectors that this consultation has not identified?	The critical issues include: * Ensuring equality of information access * Provision of evidence-based information resources * The need for Information Revolution IT infrastructure and standards at both national and local levels to enable the realisation of the Information Revolution, including good inter-operability with other public sector networks, good practice guidelines to make sure the use of web based tools is not unnecessarily blocked and strategies to facilitate simplified sign-on across sectors. * Provision of education and training to support information retrieval, analysis, appraisal, and evaluation * Enabling infrastructure and the development of the skills required to support delivery of the vision of the Information revolution.

Please send your responses via email to:

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Comments should be received by 14 January 2011.

A summary of the response to this consultation will be made available before or alongside any further action, such as laying legislation before Parliament, and will be placed on the Department of Health consultations website at:

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

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[+] Options for Organisation type

- Patient / Service user / Carer
- Public
- Healthcare provider
- Social Care provider
- Charity or Voluntary organisation
- Advocacy or support organisation
- SHA
- PCT
- Local Authority
- Health professional
- Social care professional
- Clinician
- Commissioner
- Management and staff
- Regulatory body
- Academic / Professional Institution
- Employer representative
- Employee representative
- Trade union
- Supplier
- Information provider
- Information professional
- Informatics professional
- Other – please specify

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