

Liberating the NHS:

An Information Revolution

Your response to the consultation questions

Your details (optional)	
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CHAPTER 1: An Information Revolution	
1. <i>What currently works well in terms of information for health and adult social care and what needs to change?</i>	<p>Services which produce succinct documentation in plain English on what they do, how to access the service and what is achieved, works well.</p> <p>Information which is produced that describes systems, rather than services, and uses terminology, phrases and language that are not in every day use creates barriers for ordinary people.</p>
2. <i>What do you think are the most important uses of information, and who are the most important users of it?</i>	<p>The most important use of information is to provide facts so we can learn something about a service which will help us to make decisions and be more involved.</p> <p>All users are important. It is important to understand what each user or user group needs and what format works for them.</p>
3. <i>Does the description of the information revolution capture all the important elements of the information system?</i>	<p>Yes, but there is a need to consider the importance of keeping information current and how this will be achieved.</p>
4. <i>Given the current 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</i>	<p>Greater emphasis should be placed on providing routes to education through information rather than spending time and resources on producing information processes and monitoring tools, when those involved know what works well and can provide the evidence to prove it.</p>

<p><i>outcomes - be delivered in the most effective and efficient way?</i></p>	
<p>5. <i>Where should the centre be focusing its limited financial resources and role to achieve the greatest positive effect?</i></p>	<p>The centre should focus on co-ordinating local information, producing guidance and sharing best practise.</p>

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

<p>6. <i>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?</i></p>	<p>Yes. If you are better informed then you are in a position to make decisions and ask questions about your services which enables you to be more involved.</p>
<p>7. <i>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?</i></p>	<p>On-line access to communication is increasingly convenient and efficient, but options for face to face communication are still vitally important for some people, or in some circumstances, and can not be substituted.</p>
<p>8. <i>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.</i></p>	<p>There will be concerns about confidentiality of data and privacy issues - some individuals may choose not to share.</p>

<p>9. <i>What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?</i></p>	<p>Succinct information, repeated in a variety of formats and corroborated by feedback can work well when communication is challenging.</p> <p>Support from someone with a personal connection or part of a supportive relationship can also help when giving information under stressful circumstances.</p>
<p>10. <i>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?</i></p>	<p>Information on services, specific conditions, treatment and associated risks or consequences help us make informed choices.</p> <p>This information can sometimes be difficult to find because the first step is to know what you are looking for. Even then if things do not have an obvious title they can be hard to locate. The internet is a growing resource for this kind of information, but often local, personal knowledge is held by key people with local experience.</p>
<p>11. <i>What additional information would be helpful for specific groups – eg</i></p> <ul style="list-style-type: none"> - <i>users of maternity and children’s health services;</i> - <i>disabled people;</i> - <i>people using mental health or learning disabilities services;</i> - <i>the elderly;</i> - <i>others?</i> 	<p>Patient experience and satisfaction, as well as measures of success, are helpful for everyone.</p> <p>The circumstances of each individual may make their needs in certain areas greater than others. For example the environment of where a service is delivered; the transport considerations needed to locate a service; waiting areas; toilet facilities etc. If this information has been considered and is well communicated it can make people feel safer and better cared for.</p> <p>Specific user groups may need information to be provided in their preferred formats.</p>
<p>12. <i>What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?</i></p>	<p>Condition specific information should always be written from the perspective of the person experiencing the condition.</p> <p>However, carers also need to understand the condition of the person they are caring for, in order to maintain their own health and well being. They will need information on how to care for themselves, their physical and mental health needs, their finances, employment and practical support needs.</p>

<p>13. <i>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?</i></p>	<p>They may require information on the risks and possible consequences of their choices. They may also require information on the safeguarding considerations they could expect from any support services.</p> <p>Support to use the information should be provided by a service/person who understands the circumstances of the individual and their communication needs.</p>
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CHAPTER 3: Information for improved outcomes

<p>14. <i>What information about the outcomes from care services do you (as patient, carer, service user or care professional) already use?</i></p>	<p>Outcomes are still hard to find. Activity data is more readily available. NHS information on measures of success such as mortality rates and infection control are useful, but do not always provide all groups with what they need to know.</p>
<p>15. <i>What additional information about outcomes would be helpful for you?</i></p>	<p>How successful other patients have rated the results of their treatment.</p>
<p>16. <i>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?</i></p>	<p>Information on care pathways that cross health, social care and the community can be helpful if presented in a way that is easy to follow and understand.</p> <p>A way of presenting care information that spans and informs all sectors could be agreed and cut down on the plethora of information available.</p>
<p>17. <i>For which particular groups of service users or care organisations is the use of information across organisational boundaries particularly important?</i></p>	<p>Anyone who doesn't work in the system. But particularly people with learning disabilities, people with dementia, people with mental health difficulties and those with any other communication challenges, including those whose first language is not English.</p>

<p><i>18. What are your views on the approach being taken, and the criteria to be used to review central data collections?</i></p>	<p>It is essential that an immediate review of the information already circulating within the care system is carried out to determine whether it is the right information to be recording.</p> <p>The information should only be collected if it is to be used. It should focus on what is achieved for patients/service users, be comparable, support us to make choices, ensure efficient use of resources and ensure legal compliance.</p> <p>The review should result in the removal of unnecessary information collection and reduce costs.</p>
<p><i>19. How could feedback from you be used to improve services?</i></p>	<p>Feedback from patients, service users and cares can be used to improve services by making the adjustments necessary to a service based on the patient/service users experiences.</p> <p>This may seem obvious but collecting feedback does not always result in a change and often no explanation is given as to what has happened to the feedback and what use it has been.</p>
<p><i>20. What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?</i></p>	<p>Ensure people know that their feedback has resulted in change for the better for others. Use examples to illustrate this and ensure those who have given feedback are thanked and kept informed.</p> <p>Making it quick and easy to give feedback is also essential, it should be part of the everyday task of those delivering a service.</p>
<p><i>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?</i></p>	<p>Those responsible for running the services must be open to feedback. Often, because they are delivering a service in difficult circumstances and in a culture of blame, these workers can become understandably defensive, because individually they are doing their best. They should not be blamed for the failings of a system, we should all bear this responsibility collectively and work together to improve things.</p> <p>It is often easy to see mistakes once they have happened, but pointing them out doesn't always change things for the better. It is more important to learn for situations in a supportive way and put things in place to support people to improve services as a team. The people involved in delivering and receiving the service must all feel part of it and feel they have the opportunity to influence and change things.</p>

<p>22. Which questions, if asked consistently, would provide useful information to help you compare and choose services?</p>	<p>What did the service say it would do? Did it do this? How do you know? Can you give me some examples?</p>
<p>23. What will help ensure that information systems - and the data they collect - are appropriate to support good commissioning at different levels, including decisions by individual patients, GP practices, GP consortia, service providers, local authorities and the NHS Commissioning Board?</p>	<p>Clear information about need and comparable results and efficiency will be useful at all levels.</p> <p>A stronger role for local authorities in promoting greater integration of care, particularly for people with more complex needs that cross the boundaries of health and social care will be greatly beneficial and could result in more services being available in the community.</p> <p>Local authorities and the proposed local HealthWatch should provide accountability to local people and communities through the sharing of information to better understand local needs and preferences, which will be vital to improving results.</p> <p>The front-line perspective of GPs as commissioners will provide a much needed ground roots perspective on community health and wellbeing, which should also inform national delivery.</p>

CHAPTER 4: Information for professionals

<p>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?</p>	<p>Encouraging service user feedback is essential and it should be part of the everyday tasks for everyone involved in delivering a care service. In a lot of cases this will mean a cultural shift to enable staff to recognise the importance and validity of patient/service user opinion.</p>
<p>25. As a clinician or care professional, how easy is it for you to find the evidence you need to offer the best possible</p>	<p>Often, the availability of evidence for general advice on conditions, standard procedures or treatment is good. What is more difficult to provide is advice that is tailored to an individual's needs and circumstances - in order to provide this you must understand that individuals particular needs and circumstances, which takes time and skill. This is an area that could be much improved, especially for those who have communication difficulties.</p>

<p><i>care and advice? What could be done better?</i></p>	
<p>26. <i>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?</i></p>	<p>Staff will need the resources to achieve this. This will involve providing training and making time available as well as developing a process.</p> <p>If staff can use the information collected to help inform their practise they will recognise the benefit of sharing this information. Also, if they are able to use it to support better patient/service user choice they can better involve people in their decisions on their care and feel much greater job satisfaction.</p>
<p>27. <i>What are the key priorities for the development of professional information management capacity and capability to enable the information revolution?</i></p>	<p>It is true that it will be staff who will lead the information revolution and therefore information management and IT capability will be essential.</p> <p>National education and training in approved informatics standards will need to be available and recognised as essential professional development.</p> <p>However, although new information technology will become increasingly important, many patients, service users and carers will still either need or prefer face-to-face contact. For that reason these skills should also be an essential part of the workforce core skills.</p>

CHAPTER 5: Information for autonomy, accountability and democratic legitimacy

<p>28. <i>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</i></p>	<p>a) Sharing information openly will provide many learning opportunities to inform better practise. However, this can only be achieved in a trusting, safe environment that is free from blame and judgement of the individual. To create this culture will be a challenge.</p> <p>b) Trust in those who advise you and in the information you use to inform you is essential. Greater openness should make it easier for organisations, such as those representing patients and service users, to access and analyse data about the quality of services, which will in turn, make it possible to communicate this information to the</p>
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<p><i>professional? or b) as a services user?</i></p>	<p>public in a way that is useful to them.</p>
<p><i>29. What benefits and issues do you think will arise as a greater range of information providers offer information? How could issues be addressed?</i></p>	<p>If information was provided by independent sources it may t may drive information providers to ensure their information is useful for the public, rather than a publicity exercise.</p> <p>It could also lead to information formats being developed for specific groups of the community who have special needs.</p> <p>In order to ensure the reliability and accuracy of the information schemes would need to be audited and accredited which will of course involve a cost.</p>
<p><i>30. Would there be benefits from central accreditation or other quality assurance systems for information providers and ‘intermediaries’? Would factors such as cost and bureaucracy outweigh any benefits?</i></p>	<p>The benefits would be that pateints and service users would have some confidence in the information available, however resourcing such schemes could be an issue.</p>
<p><i>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</i></p>	<p>Specialist advocates could be used to work through these processes with individuals who may have a need to be supported to make decisions.</p>

<i>in other ways or other languages.</i>	
<i>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?</i>	The data sets seem fairly comprehensive.

CHAPTER 6: Setting the direction – the Information Strategy	
<i>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?</i>	
<i>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?</i>	

Please send your responses via email to:

InformationRevolution@dh.gsi.gov.uk

or via post to:

**Consultation Responses
Information Strategy Team
Department of Health,
7th Floor, New Kings Beam House
London
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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>

+ 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