

Liberating the NHS:

An Information Revolution

Your response to the consultation questions

Your details (optional)	
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CHAPTER 1: An Information Revolution	
<p>1. <i>What currently works well in terms of information for health and adult social care and what needs to change?</i></p>	<p>Examples of what works well include the use of electronic patient record systems in general practice, where information is captured at the point of consultation, which has not only supported clinical care but has also provided important information for public health and health service management purposes, and is a valuable resource for health-related research. The UK also has internationally respected examples of integrated information systems, where information management is part of a specialist function and there has been development of information standards and/or record linkage that has added significant value to outputs, such as those that provide cancer intelligence and that underpin the control and prevention of infectious disease.</p> <p>Information from or about secondary care (hospital) services works less well, with the information that is available being less timely and complete than from primary care (e.g. the lack of information on prescribing in hospitals). There is relatively little information, or mechanisms for collecting such information, on risk factors for disease (e.g. on smoking and dietary habits, or on exercise and sexual behaviour), or on the (long term) effectiveness of treatments. Such information is essential for public health policy, for clinical decision making, and if the public is to be able to make informed choices about lifestyle and about health interventions. There is also little information on the health status of adults in social care.</p>
<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>	<p>The consultation document is almost entirely focussed on the potential added value of the Information Revolution to clinical care and clinical service delivery, and fails to take into account adequately the potentially even greater value to public health e.g. benefits in population health status and health needs assessments, detection of infectious disease outbreaks and epidemics. In determining the most important uses and the the most important users, consideration must be given to health improvement and health protection uses.</p> <p>It is important to distinguish between information about a specific individual, which is important for making decisions or taking action about the clinical care of that individual or the protection of those</p>

	<p>around them, and information about groups of individuals/patients or the wider population, which is important for making policy, for guiding and auditing clinical and public health practice, and for enabling members of the public to make health-related decisions or take health-related actions. In the case of the former (information about the specific individual), the most important uses are in ensuring that clinical care and health advice are appropriate, proportionate and safe, and the most important users are the patient and their immediate health provider. Such information may also be of use for clinical audit, in which case the most important users are the clinical team and, in some circumstances, the appropriate regulator.</p> <p>The most important uses of information about groups of patients or populations, particularly information that includes data on potential risk factors or outcomes, are (a) in threat detection, needs assessment and resource planning for developing public health policy, setting priorities, and for commissioning and managing services, (b) in developing information, guidance and guidelines about determinants and the effectiveness of interventions, that health and social care professionals and members of the public can use in making decisions and choices about health and health care, and (c) in developing outcome or other performance indicators.</p> <p>Health information is also critically important for research, although "routine" information derived from patient or service user consultation will often need to be supplemented by additional information for research purposes.</p>
<p>3. <i>Does the description of the information revolution capture all the important elements of the information system?</i></p>	<p>The description should also include the sources and the uses of information about determinants of disease and wellbeing, such as smoking, dietary and sexual behaviour in the general population, not just in patients seeking care, and on levels of exercise and levels of access to recreation facilities that encourage exercise. Information that is collected and made available by the Office for National Statistics is an important example of non-NHS information that is of fundamental importance to assessing health needs and evaluating the impact of public health interventions. Decisions and actions, particularly about healthy choices and disease avoidance, should be informed by information on exposure and rates rather than just numbers.</p>
<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>	<p>There needs to be strong leadership in reducing duplication, improving quality and maximising the re-use of data ("record once, use many"). This will require developing and promoting the use of information standards and quality standards, and promoting the sharing of information (within a clear information governance framework). Greater use of the NHS number and adoption of information standards will also facilitate realisation of the potential for adding value through record linkage that new technologies will allow. Information collection should focus on measuring outcomes to ensure that resources are used to greatest effect, and on detecting</p>

<p><i>outcomes - be delivered in the most effective and efficient way?</i></p>	<p>avoidable threats or preventable risks, to reduce the costs associated with treatment. Open technologies and economies of scale should be used wherever possible.</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 its financial resources on information that it is necessary to collate and analyse rapidly at a national level to ensure national safety (e.g. adverse drug effect monitoring, infectious disease surveillance to detect emerging threats or epidemics), or to inform national policy, or to provide benchmarking for service delivery and outcomes. It should also support the setting of information and information system operating and governance standards, and provide leadership in promoting innovation.</p> <p>The centre should focus its resources on information systems and services for which expertise or capacity to conduct the function to the quality standard or to the timescales (e.g. for policy development) required is sufficiently specialised that it is not available to local service providers or in the marketplace. Greater integration of information functions within suitably specialised centres would provide opportunities for efficiencies and added value through consistent expert analytical services, such as those provided by the National Cancer Information Network, the Public Health Observatories and the Health Protection Agency. The creation of a national data repository, overseen by the NHS Information Centre, also offers opportunities for delivering benefits through record linkage and providing a common point of access for users of health data.</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>N/A</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</i></p>	<p>N/A</p>

<p><i>on-line, or would you prefer face-to-face contact?</i></p>	
<p><i>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.</i></p>	<p>While the proposals to enable patients to update their own health records offers clear benefits for clinical care and for public health (such as the recording of lifestyle information or exposures), considerable caution will be required over the validation and quality assurance of such information. There may also need to be additional safeguards regarding the disclosure of sensitive personal information about third parties (relatives, partners) by patients updating their own records.</p> <p>Safeguarding of patient confidentiality and privacy will require strict access controls and consent mechanisms, with such controls applying also to sharing of data between health and social care services. These safeguards should not, however, prevent information sharing that is necessary for health protection or in emergency response, nor should it prevent use of anonymised information for public health and research purposes.</p>
<p><i>9. What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?</i></p>	<p>This needs to be formally assessed through a systematic review of existing evidence and appropriate research</p>
<p><i>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?</i></p>	<p>N/A</p>
<p><i>11. What additional information would be helpful for specific groups – eg</i> <i>- users of maternity and children’s health</i></p>	<p>This needs to be formally assessed through a systematic review of existing evidence and appropriate research</p>

<p>services;</p> <ul style="list-style-type: none"> - disabled people; - people using mental health or learning disabilities services; - the elderly; - others? 	
<p>12. What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?</p>	<p>N/A</p>
<p>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?</p>	

CHAPTER 3: Information for improved outcomes

<p>14. What information about the outcomes from care services do you (as patient, carer, service user or care professional) already use?</p>	<p>Information on outcomes are used by public health professionals for a variety of purposes. Examples include: the use of mortality and other data by Cancer Registries calculating survival rates associated with different treatments; monitoring of surgical site infection and other healthcare associated infections to identify failures in infection control; birth rate and gestational age specific perinatal and infant mortality rates; iatrogenesis related to cesarean section.</p>
<p>15. What additional information about outcomes would be</p>	<p>There is a need for additional outcome measures in general to allow benchmarking and evaluation of service provision, and to enable patients and professionals to make informed choices about treatment options. However, outcome data need to be linked to</p>

<i>helpful for you?</i>	other information about the patient and their disease if they are to be interpreted appropriately. Priority should be given to addressing gaps in outcome data, and any additional information required for analysis of the outcome data, for diseases associated with high morbidity or mortality rates, or high treatment costs. The proposal that outcome indicators or measures derived from NICE Quality Standards are developed is welcomed.
<i>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?</i>	This will require developing and promoting the use of information standards and promoting the sharing of information (within a clear information governance framework). Greater use of the NHS number and adoption of information standards will also facilitate realisation of the potential for adding value through record linkage that new technologies will allow.
<i>17. For which particular groups of service users or care organisations is the use of information across organisational boundaries particularly important?</i>	There is likely to be particular value in sharing of data across organisational boundaries for service users with chronic disease and multiple care needs, such as patients with dementia and other forms of chronic severe mental impairment. It will also be important for particular vulnerable groups with both health and social care needs, including children in special care.
<i>18. What are your views on the approach being taken, and the criteria to be used to review central data collections?</i>	The criteria are too focussed on clinical care and clinical service delivery, and fail to take into account adequately the use of data returns for public health purposes e.g. surveillance of infectious diseases (particularly those that are not statutorily notifiable) would not necessarily meet one or more of these criteria, yet the rapid national collation of such data are essential to the detection of outbreaks and epidemics. Additional criteria, based on meeting the needs of health improvement and health protection, are needed. There is a real danger that unless considerations of public health information needs are taken into account in the current Fundamental Review of Data Returns that important sources of information for public health policy and health needs assessment will be lost.
<i>19. How could feedback from you be used to improve services?</i>	N/A
<i>20. What would be the best ways to encourage more widespread feedback from patients, service users, their</i>	This should be assessed through a systematic review of any relevant literature and appropriate research. There is evidence from other areas that feedback is improved when users can see that such feedback is resulting in service improvements. The use of technology to make it easier to give feedback should be explored. It is likely that assurances that critical feedback will not adversely

<i>families and carers?</i>	affect future treatment by the services being criticised would encourage some users.
<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>	
<i>22. Which questions, if asked consistently, would provide useful information to help you compare and choose services?</i>	N/A
<i>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?</i>	Ease of use (low burden), timeliness of outputs, high quality of data (inputs) and relevance of analysis (outputs), service level (practice, Trust) analysis and appropriate benchmarks.

CHAPTER 4: Information for professionals

<i>24. How can health and</i>	Organisations should have board-level ownership of governance standards and policies, with induction and in-job training
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<p><i>care organisations develop an information culture and capabilities so that staff at all levels and of all disciplines recognise their personal responsibility for data?</i></p>	<p>programmes for staff on the importance, and principles, of information governance, with clear sanctions for significant breaches of those standards and policies. Examples of best practise, and the value of that to service users and to staff, should be widely disseminated.</p>
<p><i>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?</i></p>	<p>There are many good sources of evidence, advice and information that are available for public health professionals e.g. NICE, Public Health Observatories, Health Protection Agency, the Office for National Statistics, NHS Evidence. Identifying and using these resources would be made easier if there was a common portal for access, and if there was greater standardisation of presentation. More consistent quality marking of the information, advice, evidence, such as through the use of established systems for scoring strength of evidence, would also be of value.</p>
<p><i>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?</i></p>	<p>Systems should be easy to use (low burden on data provider), with re-use of data to avoid unnecessary repetition of data entry. The use of technology to automate data recording would also help. Regular and timely feedback of relevant (useful) analysis e.g. service level (practice, Trust) analysis and appropriate benchmarks.</p> <p>Clinical teams would benefit if outputs and data were provided that facilitated clinical audit and research.</p>
<p><i>27. What are the key priorities for the development of professional information management capacity and capability to enable the information revolution?</i></p>	<p>The consultation paper's comments on the importance of strong leadership from CEOs and Boards, clinical leaders and leaders of the information and IT professions are welcomed. Health organisations need to support clinical and managerial leaders by ensuring that they have access to a professional information management workforce. Development of such a workforce should be underpinned by an explicit framework of information management skills and competencies, linked to job descriptions and person specifications, such as those developed as part of the Informing Healthier Choices project. The focus should be on information management and analytical skills, as well as on</p>

	informatics. On-line training materials, such as those developed as part of the Informing Healthier Choices project would also be beneficial.
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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 professional? or b) as a services user?</i></p>	<p>The 'presumption of openness' provides a real opportunity to establish the benefits of engaging people in living healthier lives that was envisaged in Wanless' Report of 2004 (Securing good health for the whole population). It also offers the opportunity of access to a wider range of information for use in priority setting, such as through the joint strategic needs assessment process. Potential issues include that publication of uninterpreted or inappropriate analysis of data by individuals or organisations that lack the experience or expertise in such analysis could generate unnecessary anxiety or damage public confidence in health programmes.</p>
<p>29. <i>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>As for Q28</p>
<p>30. <i>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>Yes, there would be significant benefits from there being clearly defined standards, relating to quality assurance and information governance arrangements, for information providers. Formal accreditation could be considered, but the international nature of information service provision may limit the utility of this.</p>
<p>31. <i>How can a health and social care information revolution benefit everyone, including those who need care</i></p>	<p>There is not likely to be any single or simple solution to achieving this aim. The consultation document notes the excellent work that has been done by voluntary organisations to improve inclusion of groups for whom electronic information may be less accessible. working with such organisations is likely to be an important part of</p>

<p><i>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.</i></p>	<p>the solution, as is identifying ways of channelling information through care providers and carers. Public libraries and social care centres may be other routes to consider.</p>
<p><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></p>	

<p>CHAPTER 6: Setting the direction – the Information Strategy</p>	
<p><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></p>	<p>The consultation document identifies the majority of the key benefits, to which the FPH would add the benefits to priority setting, policy formulation and service delivery and evaluation in the areas of health improvement and health protection. The consultation document also highlights the key challenge of ensuring equity of access to products of the information revolution. A potential challenge that has already been mentioned in this response is the possible adverse effect of uninformed or inappropriate analysis of data. Addressing current issues around the quality and completeness of data available from secondary care settings will be important. Developing and maintaining the information management and analysis workforce, and finding ways of ensuring that the burden on data providers are manageable in the face of resource constraints are likely to be challenging.</p>

<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>	As noted previously, the criteria are too focused on clinical care and clinical service delivery, and fail to take into account adequately the use of data returns for public health purposes e.g. surveillance of infectious diseases (particularly those that are not statutorily notifiable) would not necessarily meet one or more of these criteria, yet the rapid national collation of such data are essential to the detection of outbreaks and epidemics. Additional criteria, based on meeting the needs of health improvement and health protection, are needed.
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Please send your responses via email to:

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or via post to:

**Consultation Responses
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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