Liberating the NHS:

An Information Revolution
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The White Paper *Equity and Excellence: Liberating the NHS*, published on 12 July 2010, sets out proposals for the NHS to become a truly world-class service that:

- is *easy to access*,
- treats people as *individuals* and
- offers care that is safe and of the *highest quality*
The White Paper set out a vision for an NHS that:

• Puts patients at the heart of everything that we do

• Achieves outcomes that are among the best in the world

• Empowers our clinicians to deliver the best results based on the needs of patients
A key part of the White Paper is about “putting patients first”, creating a revolution for patients, giving people more information and control and greater choice about their care.

In order to make the vision a reality, the White Paper set out a commitment to seeking further views on proposals to give people more information and greater choice about their care.

Two further public consultations have been launched setting out our proposals for what is needed to achieve this vision:

- Liberating the NHS: An Information Revolution
- Liberating the NHS: Greater choice and control
What would success look like?

- For patients and service users, there should be “No decision about me, without me”
- People should be involved as much as they want to be in every decision about their care: what care they want and how and where they want it delivered
- In order for this to happen, people need to be given a greater range of choices, and high quality information to help them take greater control of their care
- Information is used to support the delivery of safe, high quality, people-centred care
An Information Revolution

• Information and information technology support the delivery of high quality care.

• Information on treatments, conditions and lifestyle choices should reach everyone.

• People’s care records should become routinely available to them.

• Intermediaries should be free to innovate and present data.

• There should be greater openness, transparency and comparability.

• The most important source of data is the patient or service user’s care record, with data recorded once at the point of care. This can then be used to generate a wealth of high quality information that, in turn gives people real knowledge and choice.
What does ‘An Information Revolution’ propose?

Liberating the NHS: An Information Revolution proposes moving:

• away from information belonging to the system to information enabling patients to be in control of their care
• away from patients and service users merely receiving care to being active participants in their care
• away from information for administrative and technical needs to information based good clinical and professional practice
• away from top-down information collection to a focus on meeting the needs of individuals and local communities
What does ‘An Information Revolution’ propose?

*Liberating the NHS: An Information Revolution* proposes moving:

• away from information held close and recorded in forms that are difficult to compare to openness, transparency and comparability

• away from the Government as provider of information about the quality of services to a range of organisations offering service information

• away from replacing information systems centrally to connecting and joining up systems
Liberating the NHS: An Information Revolution

Chapter 1: An information revolution
Overview of the information revolution in health and social care

- Consistent high quality care and shared decision-making
- Information captured as part of the care giving process
- Information available similar to that in other services
- Openness to enable choice
- Improvements fund themselves by improving efficiency
The information revolution

- Care records
  - Your records form the primary source of data
  - The main source for aggregate data sets for secondary uses, such as research

- Creating intelligence
  - As data is analysed and interpreted to create meaningful information

- Encouraging clinicians and care professionals
  - To respond to your needs and capture data at the point of care
  - Leading to more person-centred care

- Improving service quality and outcomes for you

- Promoting benchmarking of outcomes by clinicians and care professionals

- Allowing you to share information from your record with others

- Enabling direct communication between you and your professionals

- Enabling more direct transparency through publication of core data

- Improving data quality as data is exposed to professional scrutiny

- The quality of data recording improves

- Leading to greater transparency

- Enabling you to make properly informed choices

- Leading to easily understandable information published by a range of organisations to meet your needs
Chapter 1 key issues for discussion*

- In terms of information, what works well in health and adult social care? What needs to change?
- Does the description of an information revolution capture the important elements?
- How can the ambitions of an information revolution be delivered effectively and efficiently in the current financial climate?

Comments particularly welcome on where the government should be focusing limited financial resources to achieve the most positive effect.

*Please note that this slide pack’s engagement questions address the essence of consultation document questions, to inform discussions, rather than reflecting them all exactly
Chapter 2: Information for patients, service users, carers and the public
Greater patient and service user control of health and care records

- Promotes informed discussions between patients and their health and care professionals
- Increases people’s ability to manage their health and care
- Improves safety
- Starts with access to GP records
- Enables people to share their own record
- Confidentiality and security remain critical
Proposals to increase choice and control

- Own health status or condition
- Suitable treatments, risks, benefits and side effects
- More information needed about conditions
- Information and assistive technologies will support self care
- Good information and technology will help people live healthier lives
Proposals to increase choice and control

• “No decision about me without me”
• Information underpins shared decision-making,
• More information about conditions
• Information and assistive technologies will support self care
• Good information and technology will help people live healthier lives
### Information that patients and service users might want*

<table>
<thead>
<tr>
<th>Own health status or condition</th>
<th>Track record, expertise and experience of clinicians or other professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suitable treatments, risks, benefits and side effects</td>
<td>About co-ordination of care package (for those with multiple care needs)</td>
</tr>
<tr>
<td>Clinical outcomes and success rates, such as readmission or mortality rates</td>
<td>Experiences of other patients, friends and relatives;</td>
</tr>
<tr>
<td>Other indicators of quality and performance, such as infection rates</td>
<td>Experiences of staff in the organisation providing their care</td>
</tr>
<tr>
<td>Availability of appropriate treatment or care in different locations</td>
<td>Views and advice of GP or other care professionals</td>
</tr>
<tr>
<td>Expected waiting times (average and maximum)</td>
<td>Care environment (facilities, food and catering, and cleanliness)</td>
</tr>
<tr>
<td>Convenience of services (location, accessibility by public transport or car parking)</td>
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*Work carried out with users by NHS Choices*
Chapter 2 key issues for discussion

• As a patient or service user, how interested would you be in having easy access to and control over your records? What benefits do you see? What are the issues - particularly in sharing records?

• What types of information are helpful to make informed choices about health and care?

• 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 always prefer face-to-face contact?

Comments particularly welcome on what additional information would be helpful for specific groups (e.g. carers, young and elderly people, disabled people, those with learning disabilities, etc)
Chapter 3: Information for improved outcomes
Moving away from targets to outcomes

- New frameworks for measuring NHS, social care and public health outcomes
- How outcomes information may be mandated in Quality Accounts
- A new focus on patient and service-user generated information
  - Patient reported outcomes measures (PROMs)
  - Real-time patient feedback
  - Patient experience surveys
- Information which supports GPs to take commissioning decisions
Review of Data Collections

• Fundamental review of data collections in health and social care.

• Public consultation in 2011 will lead to a set of data returns that meets one or more of the following criteria:
  – is essential to and necessarily generated as part of the care giving process;
  – helps achieve a key priority, focusing on outcomes/NICE Quality Standards;
  – provides comparable information about the quality of services;
  – supports and empowers patients and service users to make informed choices;
  – is required to fulfil a statutory obligation; and
  – supports more efficient stewardship of public money.
Chapter 3 key issues for discussion

• What information about outcomes from health and social care services do you use or would you like to see?

• What are your views on the criteria and approach for the review of data collections?

• How could patient and service-user feedback be used? How can we encourage wider feedback? How do we ensure services are genuinely responsive to feedback?

• What data will be needed to support decision-making in commissioning?
Liberating the NHS: An Information Revolution:

Chapter 4: Information for professionals
Health and care professionals

• Access to the best evidence of outcomes, interventions and risk
• Critical role in capturing quality data at point of care
• Close involvement in developing excellent information systems
• High quality evidence is crucial for shared decision-making
• Openness in communication

The information revolution depends on all staff developing their information management capability, not just informatics professionals
Chapter 4 key issues for discussion

• 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?

• Clinicians, practitioners, care professionals, managers and other service provider staff will be expected to record more data and evidence electronically, at point of care. What are the benefits to these groups, and what would encourage them to reap these benefits?

• What are the key priorities for developing professional information management capacity and capability to enable the information revolution?
Chapter 5: Information for autonomy, accountability and democratic legitimacy
Information for autonomy, accountability and democratic legitimacy

• ‘Presumption of openness’ is crucial for accountability
  – encourage more accurate data recording
  – enable easier benchmarking
  – facilitate organisations in accessing and analysing data
  – stimulate a market for information providers

• We are identifying national data sets for early release and we attach great importance to ensuring trust in published data
Information to drive efficiency and digital services

• Using information to drive efficiency of services
• Digital technology will provide innovative, convenient and efficient services
• 5 areas where digital technology could lead to major improvements:
  – delivery of services, not just information;
  – removal of time as a barrier,
  – removal of geography as a barrier,
  – tailoring information and services,
  – efficiency across supply chains.
Chapter 5 key issues for discussion

• What are the greatest opportunities and issues for you in openness of information:
  – as a patient or service user?
  – as a health or care professional?

• What are the benefits and issues in a greater range of information providers offering information? How could issues be addressed?

• How can the information revolution benefit everyone, including those who need care most but who may:
  – not have direct access to information technology (IT)
  – need support using IT
  – not know how to use IT?
Chapter 6: Setting the direction - information strategy
Information strategy

• How the information revolution will be achieved

• Include an emerging information architecture based on:
  - consistent national standards,
  - interoperability
  - marketplace innovation

• Accompanied by an impact assessment and an equality impact assessment
Chapter 6 key issues for discussion

• The information revolution can deliver many potential benefits. What are the particular benefits or other issues - including sustainability, business, rural impact or equality issues - that need to be considered in the associated impact assessment?

• What are critical issues for the future of information in the health and adult social care sectors that the consultation document has not identified?
Liberating the NHS: An Information Revolution:

The Consultation
Next steps

• The full information revolution will not become a reality without your ideas and practical proposals. Please give us your views on the document and the consultation questions

• The full *Information Revolution* consultation document and support materials are available at [www.dh.gov.uk/informationrevolution](http://www.dh.gov.uk/informationrevolution)

• Responses to the consultation are sought by 14 January 2011:
  – Online via [www.dh.gov.uk/informationrevolution](http://www.dh.gov.uk/informationrevolution)
  – By email to InformationRevolution@dh.gsi.gov.uk
  – By post to:
    • Information Strategy Team
    • Department of Health
    • 7th Floor, New Kings Beam House
    • London, SE1 9BW
Next steps

• In addition, from www.dh.gov.uk/informationrevolution you can access the online consultation space to share views, add comments and:
  – Read an introduction to the consultation document
  – Participate in the webchat with the Secretary of State
  – See video and images of events and visits
  – Find links to related information and consultation activities on stakeholder websites
  – Read features and updates on the consultation

• The White Paper *Equity and Excellence: Liberating the NHS*, the closely linked consultation on *Liberating the NHS: Greater Choice and Control* and other related consultations are available at www.dh.gov.uk/LiberatingtheNHS
Sources of information and contacts

• A summary of the response to this consultation will be made available in the Spring at:

• For any concerns or comments about this consultation process please contact:
  Consultations Co-ordinator
  Department of Health
  3E48 Quarry House
  Leeds, LS2 7UE
  consultations.coordinator@dh.gsi.gov.uk