

Liberating the NHS:

An Information Revolution

A summary of consultation responses

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Contact Details	The Information Revolution Team Informatics Directorate 7th Floor New Kings Beam House 22 Upper Ground London SE1 9BW www.dh.gov.uk/liberatingthenhs
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1. Introduction: An information revolution

- 1.1 This document provides a summary of responses to the Government's consultation *Liberating the NHS: An Information Revolution*¹. It explains the engagement process that took place during the consultation period between 18 October 2010 and 14 January 2011, and provides a summary of consultation responses.
- 1.2 The Information Strategy for health and adult social care in England that will follow this document will set the high-level agenda resulting from analysis and consideration of views expressed through this consultation process, and from the 2011 listening exercise relating to the Health and Social Care Bill.

The consultation proposals

- 1.3 *Equity and excellence: Liberating the NHS*² and the subsequent response *Liberating the NHS: Legislative framework and next steps*³ set out the critical role of information in modernising the NHS.
- 1.4 Within that broader context, *Liberating the NHS: An Information Revolution* set a clear vision for health and adult social care in England where:
 - people have the information they need to stay healthy, to take decisions about and exercise more control of their care, and to make the right choices for themselves and their families;
 - people are able to see an accurate record of their care, which is available to them electronically, and use it as a basis for interacting with their care providers;
 - health and adult social care information is liberated from a closed, bureaucratic system in order to serve patients and the public, and to help drive better care, improving outcomes, fostering innovation and facilitating the better use of resources.

¹ 'the consultation document' - see http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_120080

² See www.dh.gov.uk/liberatingtheNHS

³ See www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122661

1.5 The consultation document also stressed the Government's commitment to moving:

- to **patients and service users being active participants in their care;**
- to information which is **based on the patient or service user consultation and on good clinical and professional practice;**
- to a focus on **meeting the needs of individuals and local communities;**
- to a culture characterised by **openness, transparency and comparability;**
- to **a range of organisations being able to offer service information to a variety of audiences;** and
- to an approach in relation to digital technologies, where we **connect and join up systems.**

Your responses to the consultation proposals

1.6 The scope, principles and structure proposed in the consultation document were broadly supported by respondents, as Chapters 3 and 4 of this document explain in detail. Responses to this consultation will be used as the basis for developing the Information Strategy, to be published following this document.

1.7 This document draws on a number of direct quotes from responses to the consultation, to illustrate the issues discussed. The views expressed below highlight support for the broad thrust of the proposals set out in the consultation document, but also highlight some of the challenges in making this vision a reality.

- *“The scale and pace of the productivity challenge faced by the NHS over the next five years cannot be met without much greater and more effective use of information and IT.”* **BCS, The Chartered Institute for IT**
- *“The NHS Confederation supports the thrust of the proposed information revolution and recognises the benefits that more intelligent collection and use of information and new technologies may bring. In particular, the ‘presumption of openness’ is likely to provide opportunities to make better use of the data and improve information provision.”* **The NHS Confederation**
- *“Let me applaud a number of the important statements and aspirations set out in the consultation paper”* **service user**
- *“We welcome the forthcoming information strategy for the NHS. We recognise that, for patients at home, better information, wider use of assistive technologies⁴, remote monitoring, easy access to their own records and efficient processes for accessing hospital appointments are all vital components of a better service. With the increase in the number of older people, and people with long-term conditions, living at home, we believe these smarter ways of working are essential to give them the care they need.”* **The Queen's Nursing Institute**

⁴ An umbrella term that includes assistive, adaptive, and rehabilitative devices for people with disabilities and also includes the process used in selecting, locating, and using them

- “We welcome the proposals set out for requirements of the new ‘information architecture’, including interoperability; accuracy and quality of data; and mandating a unique NHS identifier, since these practical measures will support high standards in patient records that are essential to underpin excellent care in the NHS” **Wellcome Trust**
- “Healthcare and the NHS in particular are quite different in the ways in which information and knowledge are handled, and parallels often quoted such as banking risk trivialising the challenges we face. Therefore we need to develop approaches suitable for the NHS and healthcare”
University College London Computational Life and Medical Sciences (CLMS) Network and the UCL Division of Population Health

1.8 Responses also made the case for how the information revolution can demonstrate both greater efficiency and improved quality of care.

- “Good quality info will soon pay for itself in terms of impact on health needs and outcomes. If you spend more time to ensure that info provided is *ONLY* that which is highly valued and has a high impact on choices, autonomy and independence ... then the investment will be well made.” **service user**
- “Benefits include better patient engagement, greater understanding, improved performance, reduced costs, quicker responses, faster dissemination, less stress and evidenced compliance.” **service user**
- “This is a journey of no small distance, but as you begin to make connections (I suggest between GP and acute, followed by social care, as the most beneficial) the ability to coordinate care (eliminate duplicate diagnostics, avoid conflicting drugs and/or treatments, etc.) goes up rapidly. This yields significant improvements in care and reductions in cost from the avoidance of the duplicate activities.” **MedeAnalytics**

1.9 However, responses also raised the challenge of implementation costs.

- “The cost and extra workload for health care professionals to collect and store data needs to be considered and costed, as would any increase in regulatory burdens. It would be detrimental to patient care if we cannot do the job as efficiently because of the extra workload entailed.” **service provider**

2. The consultation process

- 2.1 The full public consultation on *Liberating the NHS: An information revolution* ran for over twelve weeks, between 18 October 2010 and 14 January 2011.
- 2.2 The consultation document set out the vision and broad principles for how an information revolution for care can be developed and asked 34 questions (attached as an Annex to this document) which spanned the following areas:
- An information revolution: the challenge and the opportunity
 - Information for patients, service users, carers and the public
 - Information for improved outcomes
 - Information for professionals
 - Information for autonomy, accountability and democratic legitimacy
 - Setting the direction – the Information Strategy
- 2.3 The consultation document and feedback form were both made available on the Department of Health's website⁵. Responses could be returned by post, by email or entered directly into an online response form. Recognising that the information revolution needs to be for the benefit of everyone, a summary of the consultation document was made available to download - including the consultation questions - available in Easy Read⁶, in three common languages (Urdu, Punjabi and Polish), in large print, and in a Word version that could be loaded for audio playback.

Engagement activity throughout the consultation period

- 2.4 The consultation process included an extensive programme of engagement activity, tailored to facilitate meaningful discussion and dialogue with identified stakeholder groups and to encourage patients, staff and all interested groups to put forward their views when responding to the consultation.
- 2.5 The consultation, communication and engagement activities and supporting briefing materials were developed jointly with those for the parallel White Paper consultation *Liberating the NHS: Greater choice and control*⁷, both of which complement the joint narrative *A revolution for patients*⁸. Engagement activity paid particular attention to using relevant existing events, networks and meetings, often focussing on joint information and choice opportunities.

⁵ See <http://www.dh.gov.uk>

⁶ See http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_121927.pdf

⁷ See http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_119651

⁸ See http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_120607.pdf

2.6 This activity enabled contact with 479 distinct stakeholder organisations, of which 134 were patient or voluntary sector groups. In addition, during the consultation, 130 clinical professional and regulatory organisations were contacted and encouraged to participate in the consultation.

2.7 Key engagement events among some 150 sessions throughout the consultation period included:

- Joint Medical Consultative Council - 20 October 2010
- Intellect Roundtable event - 2 November 2010
- BCS Hosted Health Open Debate - 4 November 2010
- EHI-Live - 8-9 November 2010
- Royal College of Surgeons - 3 November 2010
- NHS Alliance - 18 November 2010
- Voluntary Sector Learning Event - 23 November 2010
- Patient and public consultation event - 10 January 2011

Full details of the range of engagement events are provided in the Annex at the end of this document.

2.8 The approach to the formal consultation followed the traditional Department of Health consultation mechanisms, enhanced by online and digital methods to reflect the nature of the strategy:

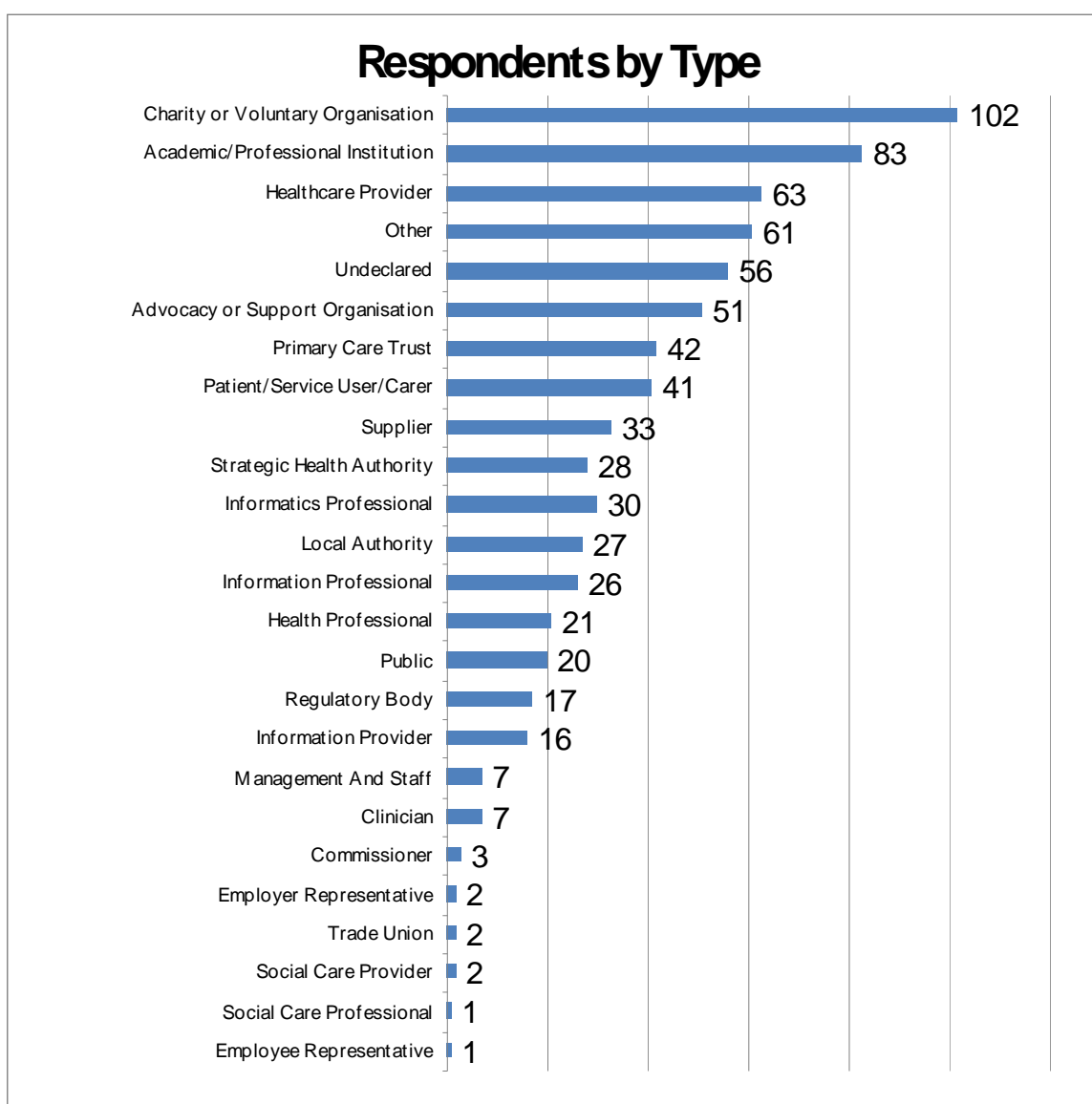
- Secretary of State for Health, Andrew Lansley, hosted an online webchat on 9 November 2010 - with over 230 online participants and with discussion of 19 questions 'live' during the webchat itself, with many more of the questions being answered subsequently.
- Twitter was used to promote updates of content to the main Department of Health website, and to support messages from stakeholders by re-Tweeting.
- We also worked with other key stakeholder representative bodies, to extend further the use of digital and non-digital channels to generate engagement with and interest in the consultation.

2.9 In addition to this centrally-coordinated approach, all 10 Strategic Health Authorities in England co-ordinated regional activity - working extensively with their local NHS organisations to seek the views of a wide range of audiences using a variety of mechanisms, including face to face meetings, web briefings, e-bulletins, newsletters, social media, radio, mail-shots, posters, magazine articles and webchats. Presentations and other materials to support this regional and local activity were also provided on the consultation website.

Details of consultation responses received

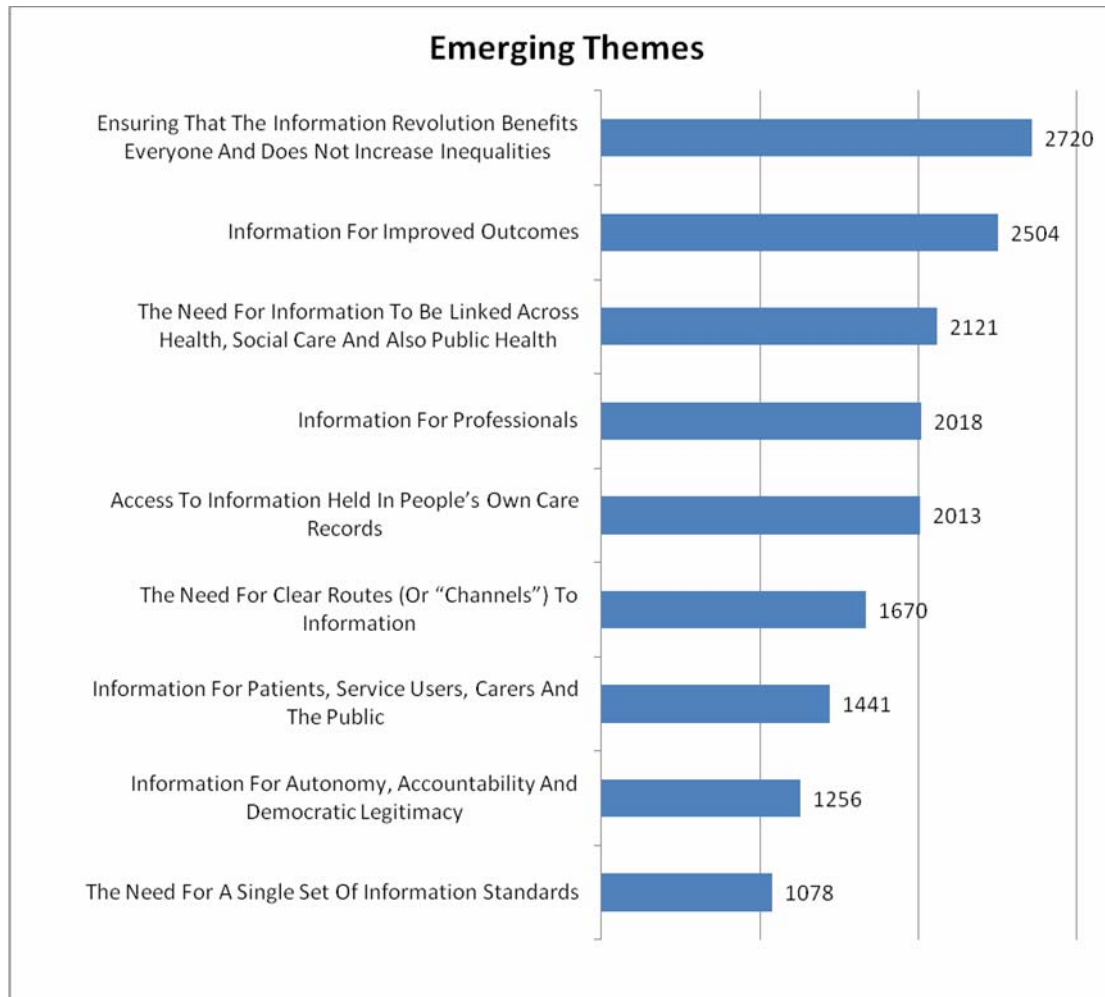
2.10 In total, 742 formal consultation responses were received from our stakeholders. The consultation was published on the Government’s shared consultation platform, allowing responses to be completed online – of the 742 formal responses 117 were received through this online mechanism.

2.11 Numbers of responses are broken down by type of organisation in the figure below:



2.12 We were pleased to receive responses that covered a wide range of views, with some providing depth of thought to specific areas, while others provided more strategic views on the overarching themes.

2.13 The figure below shows the breakdown of particular points made or issues raised within responses, grouped into a number of broad emerging themes:



2.14 Further analysis of the themes identified within consultation responses is shown in Annex C.

3. Key themes arising from the consultation responses

3.1 As well as demonstrating broad-based support for the ambitions set out in the consultation document, responses highlighted the following strong themes, which are discussed in more detail in this chapter:

- **ensuring that the information revolution benefits everyone and does not increase inequalities** - recognising that some people will require support in accessing and using information;
- **information for improved outcomes** - including patient and service user generated information;
- **the need for information to be linked across health, social care and also public health** - with the NHS Number used to link a person's care record information wherever they receive care;
- **information for professionals** - information to help professionals deliver higher quality care, including the key role of informatics as a profession;
- **people's control of and access to information held in their own care records** - with clear governance and consent models to ensure the balance between accessibility and data security for this very personal information;
- **the need for clear routes (or "channels") to information** - including clear online signposting to information and online services, connecting to and signposting other services;
- **information for patients, service users, carers and the public** - including information to support choice, to help people live healthier lives and to help patients to care for themselves;
- **information for autonomy, accountability and democratic legitimacy** - covering a range of issues around transparency, including proposals for information 'intermediaries' and how information drives research; and
- **the need for clear information standards across health, public health and social care** - adhered to across the health and adult social care system, allowing information to move freely and meaningfully through the system whilst maintaining essential information governance and security standards, and also helping to inspire trust in the quality of information.

Ensuring that the information revolution benefits everyone

3.2 Consultation proposals set the ambition that the information revolution should benefit all those who use care.

3.3 **What we heard:** Many responses supported ensuring that information benefits everyone and does not increase inequalities. Some included ideas for support in accessing and using information for those who need it which will be considered further.

- *“It is important that the increasing use of online services does not disenfranchise those people who do not have internet access. It is often the case that those with the greatest health needs are those with the least access to up-to-date technology and so increased IT use can deepen inequalities between those who have internet access and those who do not. People who do not wish or who are unable to use the internet must not inadvertently miss out on care.”* **BMA**
- *“A key challenge will be to ensure that people - particularly the most vulnerable and least health literate - have access to the interpretation, navigation and support they need to make sense of information and gain the motivation to act on it”* **National Voices⁹**
- *“Professional information staff can play a key part in ensuring people have access to good quality information.”* **informational professional**
- *“A clearly named ‘care navigator’, based at a GP surgery, who could help patients negotiate their care pathway would be greatly welcomed by the PA. Patients often contact us stating that they are confused about their care pathway and have not been provided with enough information about what to expect next.”* **Patients Association**
- *“There are library and information services in a wide variety of other organisations as well. These include schools, colleges, universities, government and statutory agencies, the third sector and many workplaces. This constitutes a wide national network offering excellent opportunities to provide both targeted and general health information.”* **Chartered Institute of Library and Information Professionals**

3.4 Responses also recognised that for many people and in many situations, face-to-face contact with care professionals will remain a vital part of their care.

- *“...there are substantial numbers of older people who are unable to access new methods and the amount of information actually and potentially available on screen. Their need for on-going personal contact must not be forgotten.”* **Ripon Centre Women’s Institute**
- *“flexibility in service provision is important to ensure that service users can feel they are in control and can access face to face support when they need it”* **FPA**
- *“many people will want to continue to use the NHS in the ‘old-fashioned way’.*

⁹ National Voices were responding to the White Paper *Equity and excellence: Liberating the NHS* in which paragraphs 2.5 – 2.17 outline the principles of the Information Revolution

This need not be a problem. For instance, if a significant number of people choose to access their GP through an e-consultation taking half the time, this will leave more time available for those people who need face-face contact.”

BCS, The Chartered Institute for IT

- 3.5 Consultation responses also made the clear case that, to have a positive effect in reducing inequalities, datasets need to include equalities data.
- *“The intelligence that is created by the system must include data that identifies health inequalities within the system. This information could then be used to ensure that health and social care is delivered more efficiently and better meets need”* **St Mungo Community Housing Association**

Information for improved outcomes

3.6 The consultation sought views on how a focus on outcomes will align efforts across the NHS and adult social care on what really matters: improving the lives of patients and service users. A culture of safety and accountability against outcome measures will need to draw upon open, accessible information from a range of sources. Issues covered included:

- the central role of information in improving outcomes for patients and service users and in narrowing inequalities;
- our commitment to review central data collections in health and adult social care and to remove any that do not contribute to the aim of improving care and outcomes;
- how we can make better use of patient and service user generated information, such as real-time feedback and ratings of services, patient reported outcome measures (PROMs) and patient experience surveys; and
- how improving the quality of information that is available to GP and local authority commissioners can help secure the best possible services and outcomes for their local populations, relative to need.

3.7 **What we heard:** Responses supported the approach of providing and using greater information on outcomes for all aspects of care services, with an increasing desire to see outcomes at the level of professional teams. They also highlighted some issues for consideration on its implementation.

- *“If I required surgery, I’d want to know my surgeons success rate.”*
NHS manager
- *“important to avoid danger of outcomes being published like school league tables - difficult to interpret and not taking into account different individual circumstances, could give unhelpful impression”* **Kidney Research UK**
- *“The main issue is not necessarily the amount available but the quality of the information fed into the systems and how accurately it measures the quality of care provided.”* **Foundation Trust governor**

3.8 Responses also supported the greater use of information, feedback and user-experience information and highlight matters to consider in improving feedback.

- *“The importance of patient or service user feedback is of particular value in how we respond to our delivery and shape models for the future.”*
Turning Point
- *“Giving feedback should be simple and straightforward. People need to know where to go in order to complain about or offer comment on the service they have received; they need to know that negative feedback will not count against them or their family in any way, and it must be clear to them that their views matter and are taken account of.”* **Suffolk County Council**
- *“We should always be looking and listening to better our services.”*
Birmingham Sandwell and Solihull Cardiac and Stroke Network

The need for information to be linked across health, social care and also public health

3.9 **What we heard:** Many responses discussed the need for information to be linked across health, social care & public health (with data linked by the NHS Number). Views and insights made in consultation responses also stressed the need for information to flow between NHS providers, as well as between health and social care service providers more generally.

- *“In future, there must be safe and secure ways to integrate clinical information from different electronic records across all providers and pathways so that a patient’s healthcare is managed safely and effectively, especially between health and social care.”* **Royal College of Nursing**

- *“The benefits of joined up information are:*

Sharing the record between care professionals to avoid errors in transmission or data, lost or delayed notes, patients have to repeat information. Enabling the patient to have access to a complete record of their care; and

Enabling commissioners and providers of care understand the performance of health care systems rather than individual units within the system.”

Dr Foster Intelligence

- *“As a service user you would not have to keep repeating your story to different clinicians. You would tell someone once what the problem was, your symptoms etc and then would not have to explain again. As a service user it is very frustrating and time consuming to have to keep repeating yourself, there is also the risk that you miss things out a second or third time that perhaps were important.”* **patient / service user**
- *“Information across organisational boundaries is crucial for caring for people at the end of life. This is partly because of the wide range of people who may be involved in one individual’s care but also because of the imperative of rapid access to information when circumstances may change suddenly. The Information Revolution must not just consider information across health boundaries but also the links with social care, voluntary sector providers (both those commissioned at a statutory level and those not) and other independent providers such as care homes.”*

National Council for Palliative Care

- *“Individual provider organisation systems by and large work well as independent systems. Communication between these systems, that would give clinicians all the relevant information about the patient in front of them, are in many cases very poor.”* **NHS London**
- *“As health and social care provision is increasingly aligned there are real opportunities to introduce more efficient working practices by combining visits and reducing the amount of intrusion to patients receiving homecare. To achieve this, social and healthcare professionals need common platforms and interoperable systems”* **Research in Motion**

- “[Para 2.34 of the consultation] recognises the need to strengthen the links between the information generated by the NHS and by the public health professionals and organisations. This is crucial and as stated is needed to monitor outcomes and reduce health inequalities.” **Health Intelligence Team, Staffordshire Public Health**
- “By the creation of shared care record that consolidates information about the care provided to an individual patient, which is in an easily accessible place. Local experience of this has seen better information sharing, better medicines compliance, improved choices and a reduction in repeat tests. All reduce the risk to patients and improve service delivery.” **NHS Salford**
- “We agree that adoption of the NHS number is important for joined up provision.” **Surrey County Council**

3.10 In line with the Government's response to Sir Ian Kennedy's report, *Getting it right for children and young people: Achieving Equity and Excellence for Children*¹⁰, a number of responses covered specific issues around information about care of children and young people, including:

- “Better information and shared decision making will ensure that children, young people and families have real choices in the system, so that it works for them and is set up to be responsive to their views and experiences”
National Deaf Children's Society
- “Safeguarding and the health and well being of children is a partnership responsibility in which health and educational professionals play a key role; information sharing across agencies is a vital aspect of safeguarding. For children with disabilities, shared records could alleviate some of the problems with multiple appointments and lack of streamlined care.”
College of Occupational Therapists
- “The availability and use of information across organisational boundaries is of fundamental relevance to antenatal and newborn screening programmes, where:
 - antenatal screening results may be of relevance to newborn screening programmes;
 - there is a need to link parental health records with newborn records;
 - the population can be highly mobile;
 - the service depends on multiple providers (maternity, pathology, Child Health) with different organisational boundaries.”

UK National Screening Committee

¹⁰ See - http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119449

Information for professionals

3.11 Clinicians and care professionals have a critical role to play in developing information systems, capturing data accurately at the point of care, ensuring the quality of that data, and then acting upon the data to improve the quality of services. The consultation sought views on:

- the importance of professionally endorsed and universally applied standards for the recording of care;
- the need for high quality evidence - from clinical audit, staff feedback, research and other sources- to make shared decision-making a reality; and
- the key role of informatics as a profession - in ensuring that those who develop, maintain and use information systems are trained, supported, developed and valued in their organisations.

3.12 **What we heard:** many responses highlighted the importance of systems ‘working’ for the care professionals who use them - not adding to the burden of clinicians - and the linked issues around how this can improve data quality.

- *“Recording information - whether clinical or administrative should be seen as an integral part of patient care and clinicians required to undertake this activity rather than delegating these activities to administrative and support staff. Clinician training and professional bodies must support the IT revolution in this. The quid pro quo is that NHS IT systems must be modern, powerful, up-to-date, fast and have universal access. It is not reasonable to expect busy clinical staff to use technology that is slow, requires complex security access and has limited availability for access at the point of patient care.”* **Cambridge University Hospitals**
- *“data quality ownership can be fostered by talking of the benefits of clean data at performance reviews, and also by encouraging staff to see the benefits of the useful reports that can be drawn from the system to support their work as a result of careful data entry and configuration”*
Chartered Society of Physiotherapy
- *“Acute Trusts have a long way to catch up before their data quality approaches that of primary care, and that is far from perfect...If the Trusts are to make progress, they have to get the day to day users convinced of the value of accurate data recording, and understand what is in it for them.”*
BCS Primary Health Care Specialist Group
- *“Even though the data may be less than perfect initially the best way to improve data quality is to **use** the data.”* **academic**

3.13 Responses also highlighted the importance of professional and managerial staff embracing the principles of leadership, culture change and education of staff that will all be required in taking this agenda forward.

- *“There needs to be a cultural change: not only in patients, but also in those health professionals who regard patient data as ‘theirs’.”*
East of England SHA

- *“Clinicians may underestimate or undervalue the information needs of patients. They may also lack the skills to give information effectively.”*

The Stroke Association

- *“Greater clinical engagement and professional leadership will be essential if we are to create systems which gather data that is trusted by clinicians and have their ‘buy-in’.”* **Royal College of Physicians**

- *“Good data quality is achieved at source with a principle of “right first time”, underpinned by robust standards and processes, validation at input and continuous monitoring and audit. Trying to fix problems later in the information chain is costly, ineffective, weakens local ownership and undermines the confidence of users.”* **The NHS Information Centre**

- *“Feeding back to staff the implications of inaccurate and missing data will help to improve data collection”*

Faculty of Dental Surgery, Royal College of Surgeons

- *“While there are examples of good practice which illustrate clinical involvement in coding and ensuring the accuracy of data, many of our members tell us that they experience significant difficulties in accessing information within their employing Trust - often clinical coding departments are “off limits” for surgeons and this needs to change.”*

Royal College of Surgeons

3.14 Responses also recognised the need for developing and retaining adequate informatics capability and skills.

- *“In order to realise many of the objectives of the information revolution, the health and social care workforce must be equipped with the necessary skills and time to explain information and treatment options to patients and their carers to facilitate informed decisions about their care.”* **Astellas Pharma**

- *“the Information Revolution clearly reinforces that Health Informatics staff are key to ensuring that the infrastructure is in place and managed”*

informatics professional

- *“There is clearly a need to enhance training of commissioners, managers, clinicians and other care professionals in informatics skills to ensure the information revolution will succeed.”* **academic**

- *“Staff at all levels will need to embed information standards across all disciplines and staff, through job roles and key skills frameworks. Informatics skills will need to take on increasing prominence within core training programmes and job role requirements.”* **NHS worker**

- *“it is very important that the limited IT skills of many health and social care workers is recognised and addressed.”* **National End of Life Care Programme**

- *“Clinicians will also need substantial up-skilling in information utilisation to be able to maximise the benefits of greater information access.”*

NHS Commissioning Support for London

- *If clinicians and practitioners value the information that can be derived from the information they record, they are much more likely to feel ownership of this data, and take responsibility for recording it correctly.”*

Essex County Council

People's control of and access to information held in their own care records

- 3.15 **What we heard:** There is a clear desire to enable people to be more in control of their own care, supported by greater access and use of health information, including access to the information held about them in their own care records.
- 3.16 Respondents to the consultation, including those below, raised a number of questions as to how this might work in practice, as well as highlighting some potential associated risks. (*Aspects of patient control of records have also been covered previously, where they align with other themes such as 'ensuring that the information revolution benefits everyone'*).
- *"Having access to care records would be an excellent idea. This would allow the individual to share their records with other healthcare providers ... This would make the care record a more accurate reflection of the person's health and care"* **local pharmaceutical committee**
 - *"The BMA agrees that patients should have easier access to their health records. ... We agree that this should start with GP practice records. ... System suppliers are already developing systems which enable patients to access their records."* **British Medical Association**
 - *"I deal with everything else online (bank, bills etc) so access and control over my records would be a benefit. I would also like to see my records easily and think this would bring much needed efficiencies into patient records. If the data is being kept electronically then I should be able to access it electronically."* **information professional**
 - *"Hampshire CAFA Project has found that most individuals and most health and social care practitioners are able to use information about an individual, provided by others, and for this to be useful to them. The project has found the provision of extended personal information to all health and social care staff through a local information hub to be particularly useful in reducing the time taken to get the care they need. ... By sharing the specialist or particular information about an individual, it is easier to improve the care for that person. It also helps to generate a more effective relationship between the practitioner and the individual, when they work together to deliver the care that is needed."* **Hampshire Common Assessment Framework for Adults Project**
- 3.17 Responses stressed the need for information held in care records to be clear and understandable.
- *"By giving patients and their carers the ability to read their health and care records away from the health professional, they are given the time to digest the information at their own speed. However, it is important that the record [is] formatted and used in such a way that it does not detract from the information that needs to be recorded, while still allowing the patient to understand the information in their record."* **Royal College of Midwives**

- *“We are concerned that patients will not understand the details of their health records without proper support from their healthcare professional to do so.”* **Breast Cancer Care**

3.18 Responses also raised a number of concerns about how information from care records might be used, or potentially abused, by others who might be able to access their records – risks include coercion or abuse by violent partners, employers, family members or insurers.

- *“We have found mixed views on the subject of access to patient records. Some people we have spoken with feel that it would be difficult for them to understand and interpret what was written and therefore it could be potentially frightening without support to explain what things mean. Some felt they did not need detailed information. There were concerns that records might get into the wrong hands and that more electronic records would make this easier. Others thought that it would be useful to be able to access records and that this would support patient choice and control. Also carers could find it very useful to access records to help those they are caring for eg medication and side effects. However it was noted that there might be confidentiality issues related to this”* **Coventry LINK**

- *“there are potentially significant benefits from increasing patient control over their records. However there are concerns about this control being abused, not by the individuals themselves but by third parties seeking to exploit this control for their own purposes. This could range from attempting to sell unnecessary services to organisations using this information to profile individuals, for example in connection with offering employment or providing insurance services or bank loans.”* **Information Commissioners Office**

- *“As a major provider of social care services Turning Point feels that our service users would benefit from access to their patient records, which will provide more control and understanding of care and allow for more informed choices and decisions around care.”* **Turning Point**

- *“The Terrence Higgins Trust would broadly welcome a move to make care records more accessible. In a clinical setting with time restrictions, it can be challenging to service users to be fully prepared for consultations in terms of getting all the information they require to make informed decisions about their care and then accurately recalling all the relevant details afterwards.”* **Terrence Higgins Trust**

- *“The fact that some do not feel able to ask basic questions of those providing their care and treatment needs addressing but access to their records will enable them to seek answers where they can. Teenage Cancer Trust is pleased to see recognition of the value this access will add to those seeking peer or formal support. From our perspective this is invaluable.”*

Teenage Cancer Trust

3.19 Many responses included practical suggestions as to how people accessing information within their own care records could also provide specific benefits.

- *“access to care records for most patients over internet and web will encourage better self management of various allergies, long term illness and even providing small information back to clinicians such as increase in blood pressure can promote better self management for various illnesses.”*

service user

- *“It would enable me to obtain third-party advice from multiple sources, including private research, consult other clinicians and in future use on-line information and decision tools. My medical records should be made available to me in a simple standardised format, (e.g. encrypted on a USB stick¹¹) that can be understood by other tools.”* **Abies Ltd**

- *“Yes, we could spot errors, and address them. We would also have a record of conversations with GPs- which many patients find difficult to remember afterwards. Patients could co-operate with care more easily.”* **service user**

- *“Yes I would like to have access to my care record especially if it would help me to keep track of referrals, test results and screening milestones.”* **patient / service user**

3.20 **Information Governance:** Responses to the consultation discussed the need for clearly understood and universally applied rules that balance the need for access to information held in people’s care records for those who need it, with the need for data security, confidentiality and also consent. Responses highlighted the complexity and the variety of perspectives of this area, outlining the very real concerns that personal information must be held securely, whilst also recognising that barriers to sharing information can get in the way of providing high-quality, joined-up care and can create inefficiencies.

- *“Administrators are unable to pull off notes for clinicians due to confidentiality which means clinicians time is lost retrieving documents.”* **clinician**

- *“The need for privacy is acknowledged but better processes are required so that they do not stand in the way of care practitioners or other legitimate users of data.”* **IBM**

- *“There is huge potential for access to highly sensitive data by violent partners and abusive carers. ... we need clarity and reassurances over which agencies will be able to share data, and what data they will share. We suggest that patients should have the full implications explained to them before being asked to give consent to share data.”* **Regional Action West Midlands (RAWM) and the West Midlands Core Equality Partnership**

- *“There needs to be more detail around the protection of women who disclose domestic violence and access to her medical records. We would also want to see much clearer information on how those who may be suffering abuse from their carers would be protected.”* **Women’s Health and Equalities Consortium**

¹¹ Small, removable and rewriteable storage device

- *“Any arrangements for accessing patient records must have a focus on seeking explicit patient consent for sharing healthcare information for purposes which go beyond direct contributions to the care or treatment of the patient, with the doctor acting as the record guardian.”*

British Medical Association

- *“[While] we believe this is positive move overall, there are issues that should be considered in implementing the policy and some safeguards that should be put in place to ensure all patients can reap the benefits. These include policies and guidelines for professionals in implementing the policy, and adequate IT systems to ensure data safety and confidentiality as records are shared.”*

Macmillan

The need for clear routes (or “channels”) to information

3.21 **What we heard:** Responses to the consultation highlighted the need for clear signposting to the information that people, service users and, indeed, care professionals may need.

3.22 A frequently held concern (particularly from patient organisations) was that a greater range of information providers could mean more confusion and variable quality. Responses considered that the NHS brand provides the necessary assurance, as would a single access point or ‘portal’ and that a single access point would also help people to navigate through an increasingly complex health and social care system.

- *"Our leading theme throughout this response has been our strong support for a "one NHS website" where patients, GPs / HPCs and commissioners can access accurate information and intelligence." ... "Those unable or unwilling to access NHS information via the "one NHS" website would be able to access the same information by calling the 111 number." **Harmoni / Advanced Health and Care***
- *"There are ways of ‘badging’ or branding sources clearly but this needs consistency. Multiple sources can be very confusing. There should be one, branded, known and trusted central source from the NHS." **Strategic Health Authorities Analytical Network***
- *"For people with disabilities, for example, limited sight or hearing, many of whom are patients and service users with long term health conditions, having one information system will be of real value." **Institute of Strategic Leadership & Service Improvement, London Southbank University***
- *"information should include gateway info for support organisations" **NHS Commissioning Support for London***
- *"Much greater use should be made of universal media - TV, radio, twitter et al in getting public health messages across to vulnerable individuals and groups." **patient / service user***
- *"Participants in our focus groups and hall tests were worried about multiple online providers and emphasised the importance of a single trusted provider they could trust to be objective. For many the spontaneous and natural provider was the NHS, while for others an independent provider was preferred due to concerns about objectivity." **Which?***

3.23 Responses also considered how people could know which information sources can be trusted and what further steps, if any, would be needed to increase trust and confidence in information and in its providers - including the potential for accrediting or kite-marking information sources. One view expressed was that attempts to regulate the market through accreditation could preserve the status quo and stifle innovation. A number of responses supported existing schemes - such as The Information Standard, Information Prescriptions, NHS Evidence and NHS Choices - arguing that building on these existing schemes could

reduce bureaucracy and cost. Many responses believed that the costs of wrong information would be greater.

3.24 One specific concern was about the possibility of the NHS making information available to the market free of charge, then having to buy it back.

3.25 Particular points raised in responses to the consultation included:

- *“People need to easily know if information is objective”... “there is too much subjective information in the form of blogs or commercial sites”*
service user
- *“Central quality kite-marking of information is often requested and very difficult to achieve...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.”*
SHA Library Leads in NHS East of England
- *“The [NHS] brand is well recognised and respected and could be licensed to information providers in parallel to developing an accreditation system. This would allow individuals to immediately identify providers of high-quality and trustworthy information. As part of the accreditation or licensing process, those operating in the market for profit could also be asked to pay a levy which would go towards supporting digital access programmes in disadvantaged areas.”* **Northgate Public Services**
- *“Rather than seeking to control the output of information, a better approach may be to support and encourage the health literacy of the population whilst at the same time supporting the role and expertise of information and healthcare professionals”* **NHS Croydon**
- *“The CSP believes these issues can be addressed by building on the two information standards that have been launched in last few years. Firstly, the ‘Information Standard for patient based information’ and secondly, ‘NHS Evidence accreditation scheme¹² for evidence based health information’. Both these standards give patients and health care professionals kitemarked resources showing they have been developed via a robust, evidence based process.”* **The Chartered Society of Physiotherapy**
- *“THT is very much in favour of the Information Standard for health care information. It would give patients and service users a clear indication of where they should go for reliable information.”* **Terence Higgins Trust**

¹² See - www.evidence.nhs.uk/Accreditation

Information for patients, service users, carers and the public

3.26 The principle of ‘no decision about me without me’ relies on good information and a culture that enables people to make use of it. This, in turn, relies upon accurate and up-to-date health and care records, which then form the basis of information systems for patients and service users. The consultation sought views on:

- patients and service users being able to keep a copy of their care record themselves, and share that copy as they see fit with others;
- GPs and other care professionals being encouraged to enable patients and service users to communicate with them and to access services online;
- how to ensure that confidentiality and privacy in relation to personal information remain critical priorities for those who hold patient and service user records;
- the Government’s commitment to promoting shared decision-making and information to support informed choices by patients, service users and carers;
- the types of information that need to be available to enable patients, service users and their carers to make fully informed choices;
- the critical role that technology and information will play in supporting self-care, at or close to home; and
- information that can help people to make healthy choices, and act as the basis for taking more responsibility for their own health and well-being.

3.27 **What we heard:** Many responses supported the need for greater use of information to support choice, shared decision making and greater partnership between service users and those providing their care.

[people need:] “As much information as possible about the situations in which they may find themselves and a clear strategy for dealing with those situations. A clear idea of the circumstances in which they must seek professional help. A clear list of contact points and access to appropriate support groups. A comprehensive set of written advice and instructions in a form appropriate to the person's ability and needs.” **patient / service user**

- *“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.”* **North Tyneside LINK**
- *“Sharing information (ie. patient notes; communication with carers) can present challenges but transparency and openness encourage mutual respect and better outcomes. Failure to share information can result in concerns about ‘conspiracies of silence’ and in some cases misunderstandings about a condition or its treatment.”* **Standing Commission on Carers**

- *The reliance of the NHS and adult social care services on information which is not comparable or easily accessed by patients leaves many older people as passive recipients of care, instead of being active and willing advocates for their own needs.*” **Counsel and Care**

3.28 A number of respondents explained the types of information that were helpful in making choices. These included:

- *“You need information about your condition, how it progresses, what treatments are available and their side effects, likelihood of success and timing.”* **service user**
- *“Simple and helpful advice about managing my condition. A brief explanation of the issues and options and suggestions of where to go for further help and at which point in the disease process.”* **health professional**
- *“To make an informed choice if being referred the information I need is: Who has best results/outcomes Where and when can I be seen by them? Where and when can I be seen by an alternative provider? Information is not always easy to find, certainly not for the average patient, but also it is not always easily comparable.”* **informatics professional**
- *“Carers need access to information from support services and organisations and the various programmes that exist to support them but may not be aware of. They also need emergency contact numbers for assistance and support for unplanned incidents which may affect their ability to act as a carer.”* **information professional**

3.29 Responses also raised specific support for information prescriptions¹³.

- *“Information Prescriptions (IPs) offer a structure by which high-quality, personalised information can be provided to patients and carers by NHS professionals throughout their cancer journey, alongside appropriate support. Commissioners and providers should be incentivised to offer them”* **Macmillan Cancer Support**
“There needs to be clarity of the self care offer to patients (and their carers) which should be considered using the self care continuum and the five pillars framework for self care - Education / Information / Tools and Technology / Networks / Prevention. Clearly, care planning and information prescriptions are critical here.” **patient / service user**
- *“Information Prescriptions (IPs) are important to providing information and choice for patients and should continue to be implemented within the NHS.”* **British Lung Foundation**
- *“Information Prescriptions [Service] is a great tool and could be even better with more information uploaded”* **North West London Cancer Network**
- *“For those just getting on with life with their condition contact with a specialist or GP may be infrequent. Therefore we can't rely on Health and Social Care specialists being the only avenue to promote Information Prescriptions”* **Sheffield Teaching Hospitals**

¹³ See - www.nhs.uk/ipg/Pages/AboutThisService.aspx for patients and www.informationprescription.info for service professionals

3.30 As well as the need for information to help people live healthier lives, a particular set of issues related to information helping patients to care for themselves, with a strong emphasis on long term conditions.

- *“Access to accurate, high quality information is vital to empower the public to take control of their own health and wellbeing to enable them to live healthy and active lives”* **The Chartered Society of Physiotherapy**
- *“80% of spending is for patients with Long Term Conditions. Just 2% of patients with chronic conditions account for 30% of unplanned hospital admissions and 80% of GP consultations. Investment should be made to ensure LTCs are managed effectively, reducing duplication of tests / unnecessary trips to hospital etc.”* **Graphnet Health Ltd**
- *“many people want to have control of their own care, even if this does require some compromise. Although most will seek reassurance from experts, having a significant degree of control over their own care helps an individual to deal with their problems more effectively.”* **Hampshire Common Assessment Framework for Adults Project**
- *“Much more important than any information provision is the training [people] are given about their condition and requirements and then how best to get those requirements met.”* **Enhancing Quality Programme, Kent Surrey and Sussex**
- *“We could envisage the emergence of patient mentors and/or Information Coaches who could provide skilled and effective support for people with long term health conditions.”* **Institute of Strategic Leadership & Service Improvement, London Southbank University**
- *“People with long-term conditions want better information about health, treatments and lifestyle issues and better support from health professionals to practice self-care. Information and support is considered to be one of the most useful things received at diagnosis and is viewed as lacking within current NHS services by a high proportion of Diabetes UK members.”* **Diabetes UK**

Information for autonomy, accountability and democratic legitimacy

3.31 Transparency and openness are key to accountability. *Equity and Excellence: Liberating the NHS* and the Health and Social Care Bill set out reforms that will free NHS organisations from direct government control. But with that freedom comes an increased responsibility to be locally accountable for the quality of services provided and the efficient use of public money. The consultation sought views on:

- how we see the publication of data, both locally and nationally, as being crucial to public accountability;
- which national datasets are most suitable for early release;
- how making data freely available will encourage innovative information providers, such as patient and service user charities, to better inform the public;
- the importance of ensuring all parts of society can access the information they need about health and care services;
- how information and technology can, when used well, radically improve efficiency, user experience and outcomes; and
- examples of imaginative uses of digital technology from the Quality, Innovation, Productivity and Prevention (QIPP) programme¹⁴, which seeks to harness and spread innovative best practice across the service.

3.32 **What we heard:** Responses welcomed the desire for transparency and the proposals for opening up a market of information ‘intermediaries’ – organisations, including voluntary sector, commercial or other bodies, that can analyse and present information to the public, helping to promote innovation and tailor information to individual needs.

- *“There are ‘service user groups’ for almost every condition who provide this information on-line and in books or pamphlets. When patients are diagnosed with particular conditions they should at the same time be given details of where to find this information, and on what local groups could help them.”*

public health professional

- *“the information required by such patients is buried in data that is already to a substantial extent routinely recorded. However, it is not repackaged in a manner that is appropriate to the needs of such people.”*

National Diabetes Information Service

- *“early release of current data should be carried out in forms that are meaningful to lay people and service users. Levels of interpretation may be required.”* **Royal Pharmaceutical Society**
- *“Allow a marketplace to evolve, and groups with needs you would never have thought of (and they would never have hired lobbyists for) will emerge, and entrepreneurs will serve them.”* **Patients Know Best**

¹⁴ See <http://www.evidence.nhs.uk/qipp>

3.33 Responses also discussed issues around liberating the information held in nationally collected datasets and the role of the Health and Social Care Information Centre (“the Information Centre” or “IC”) as the focal point for national datasets, as well as the need to minimise the burden of collecting data.

- *“We support the envisaged role of the Information Centre in handling and publishing all centrally collected datasets and returns and welcome the proposed fundamental review of returns and the development of outcome based indicators.”* **Milton Keynes PCT**
- *“The role of the Health and Social Care Information Centre will be important not only in collecting data but in disseminating such data in a format which is relevant to improvement and innovation at local level.”*

Standard Commission on Carers

- *“There is a tendency for information gathering creep to occur, with information collectors tending to devise new and somewhat unnecessary information gathering”* **Independent Mental Health Services Alliance**
- *“Quickly gathered and accurate data collections that provide practical approximate information are often better than slowly gathered, onerous or inaccurate data collections that are theoretically perfect. The Information Centre should be given a clear goal of developing processes that facilitate both quick-and-dirty and slow-but-clean access to the same datasets.”*

PA Consulting

- *“We suggest that there should be rules for determining which datasets could be released as an early priority. Datasets from vulnerable patients and children should certainly not be released until the system is proved to be secure.”* **Medical Protection Society**
- *“rather than having the NHS Information Centre commission multiple datasets that services then have to report on by adapting their clinical information management systems, the NHS should focus on standardising the makeup of the care record with accompanying standardised data fields and associated data field definitions that can be universally reported on from clinical information systems. These requirements could be put together centrally by a group of health care professionals, and rolled out to save future duplication of effort in localities. A myriad of different datasets could then be drawn from the care record depending on need.”*

Arthritis and Musculoskeletal Alliance

3.34 Linked to the points listed above, consultation responses drew attention to the beneficial role that centrally-held and connected-up information can play in improving care through clinical trials and research.

- *“The information revolution should be the main source of data sets for secondary uses such as research.”* **Association of the British Pharmaceutical Industry (ABPI)**
- *“Research & clinical trials are key to improving clinical care within a population - anonymised data, retaining meaningful demographic information, on clinical conditions which can be used for research and training of clinicians, to improve patient care and patient outcomes.”*

RCR Imaging Informatics Group

- *“Provided they understand the purpose of research, the majority of people are happy that anonymised medical data is used for research, and some happy to take part in trials or other research with consent”* **Sanofi-Aventis**
- *“Researchers would benefit from linkage of primary and secondary care data and resources should be made available to facilitate this.”* **AstraZeneca PLC**
- *“Presenting aggregate data is helpful, but much service planning and monitoring, epidemiological monitoring, health and health care research that requires access to linkable individual records. For example, to establish where people with diabetes live, and engage others in identifying undetected cases, we need access to significant patient level data.”*
information professional
- *“many of the routine needs assessments do not include information about the health needs of excluded groups, or more hidden populations who are not registered with mainstream services. To ensure services can be responsive to the needs of all patients in a community, new commissioning structures must identify, include and act upon information about needs of homeless people who can be less visible but often have the most severe and costly health needs in our communities.”* **Homeless Link**

The need for clear information standards across health, public health and social care

- 3.35 Using consistent agreed technical and data standards allows information to move freely and meaningfully through the system. This section discusses types of standards. Standards are likely to be needed to cover the structure of recorded information, use of consistent terminologies and the use of a unique identifier (ie. the NHS Number), as well as record keeping and sharing, safety, security, reliability and resilience.
- 3.36 The consultation document proposed coherent national informatics standards with which creators and users of care data will have to comply; with standards for the NHS to be set by the NHS Commissioning Board, and with standards for public health and social care set by the Department of Health.
- 3.37 **What we heard:** Responses to the consultation expressed strong support for consistent information standards applied across users of care information.
- *“Clear standards for communication between systems are needed along with appropriate data sets for sharing.”* **NHS London**
 - *“We support the creation of standards”* **Nuffield Health**
 - *“Setting the information need as a standard requirement within health and social care should be mandated by the Government for all service providers and suppliers of information technology.”* **Clinical Solutions Ltd**
 - *“Clarity around the nature, application and ways in which use of such standards are to be encouraged or enforced is essential to avoid confusion”* **General Medical Council**
 - *“Contracts with any willing provider have to support the same interoperability and standards expected of NHS, this must be a barrier any willing providers have to overcome before they are allowed to contract.”* **informatics professional**
 - *“standards need to be set at a national level around the IT infrastructure and dataset definitions that should be collected in respect of particular healthcare pathways and treatments. The adoption of the standards will need to be an agreed approach between health and local authority and voluntary organisations but one organisation needs the responsibility for leading this process.”* **Royal Orthopaedic Hospital NHS Foundation Trust**
 - *“A significant factor currently delaying even self-funded integration is the lack of direction regarding which among these standards options to use. This makes organisations reluctant to commit effort to interoperability initiatives for fear they will choose a standard that becomes obsolete.”* **HL7 UK, IHE UK & British Computer Society Joint Response**
 - *“Standards for interoperability are key to allowing System providers to invest for the whole community, rather than for each individual area and we welcome the focus on this.”* **Surrey County Council**

4. Summary of other responses

- 4.1 In addition to the main themes listed in Chapter 3, consultation responses also drew out a number of more generic issues. This chapter summarises those further issues, grouped in the following areas:
- an information revolution: the challenge and the opportunity; and
 - setting the direction - the Information Strategy.

An information revolution: the challenge and the opportunity

- 4.2 The consultation document set the vision for the information revolution, starting from the premise that the primary use of information is to support the provision of high quality care; that the most important source of data is the patient or service user's care record, generated at the point of care; and that care records also provide much of the data needed for other, secondary purposes.

- 4.3 The consultation sought views on:
- the different types of information that modern health and care systems need to function effectively and efficiently;
 - the vital importance of capturing data accurately - and once - at the point of care in the patient or service user's care record;
 - the primary use of data being to provide high quality care to the individual;
 - the wider benefits to patients, service users, clinicians, care professionals and the public of routinely releasing aggregate datasets for other purposes; and
 - how effective use of information and modern technology will create efficiencies that will free up resources to meet new challenges.

- 4.4 **What we heard:** In addition to the specific issues discussed in Chapter 3, responses emphasised the specific importance of care records as the primary source of data and of recording information **once** at the point of care, but also highlighted concerns about how this could be achieved.

- *"I fill in data online, but the GP also wants it hand written as does the midwifery PCT, so I write information out 3 times for every woman! it is MAD"* **midwife**
- *"Data recorded once, at the point of care ... can then be used to generate a wealth of high quality information that, in turn, gives people real knowledge and choice"* **patient / service user**

- *"Our members tell us that firstly, integration would ensure that all care services share core common information about an individual patient or service user. Core information could be recorded only once (saving staff time), recorded accurately (avoiding mistakes and misunderstandings), and be timely."* **College of Occupational Therapists**
- *"A necessary starting point for doctors to record data electronically is the availability and provision of suitable electronic recording systems. In many secondary care settings, systems are difficult to use and frustrate rather than facilitate the safe, user-friendly recording of relevant information in a timely and accessible manner."* **General Medical Council**
- *"One of the key priorities of the information revolution for the RCM is to ensure that every midwife has access to the hardware to capture data at the point of care and he/she has the training to use the technology to capture data."* **Royal College of Midwives**
- *"We recommend that in order to record more data and evidence electronically, there will need to be much better information technology facilities and access to them, especially on the wards and in outpatient settings. Mobile devices would seem essential but carry their own risk regarding security and loss of data."* **Medical Protection Society**

4.5 Responses also stressed the potential for digital technologies to improve the way that care is delivered, as well as the ways in which people access information. A few examples of suggestions are included below:

- *"Technology is a resource; it is a responsibility for us to design it to respond to the needs and important vision of how healthcare systems can provide the best possible quality, safe care to many people as efficiently as possible whilst gathering quality data for the future."* **Agfa Healthcare, UK**
- *"There are some aspects of contact which could be done on-line. This could include some administrative elements of treatment such as requests for repeat prescriptions and appointment bookings."* **Cancer Research UK**
- **Asthma UK** *"highlighted the importance of clinician skills and the use of evidence-based decision aids in the implementation and development of shared decision making."*
- **Durham County Council** suggested *"a 'trip advisor' type system for care" facilitating "Systematic and ongoing user feedback system about the quality of care received from providers"*
- **Royal College of Paediatrics and Child Health** suggested that *"If speech recognition systems could be put into place with secure wi-fi enablement, the clinician could dictate into a dictaphone and upload it remotely."*
- **An informatics professional** suggested technologies to interact with patients and service users, including increased use of :
 - digital TV
 - Smart phone apps
 - social media
 - kiosks for access in health care setting
 - NHS access cards with smart chips for basic health information
 - giving patients the choice to opt in or out"

Setting the direction - the Information Strategy

- 4.6 The Government consultation sought views on a number of vital issues that will need to be addressed as we take the Information Strategy forward, including:
- improving the quality of health and social care information;
 - improving the recording of key parts of the record;
 - the role and use of clinical terminologies;
 - ensuring the use of the NHS Number as the unique identifier;
 - the roles of the NHS Commissioning Board and the Department of Health in setting clear national informatics standards for the NHS, and for adult social care and public health respectively; and
 - the significant cultural changes that will be required to realise the information revolution.
- 4.7 **What we heard:** In terms of taking forward the vision set out in the consultation document, responses highlighted that this will require a shift in the role of Government and of central bodies.
- *“There needs to be a move away from centralised systems”*
informatics professional
 - *“It is important that government (DH and others) do only what Government needs to do and not what other suppliers can do much more effectively and efficiently”* **supplier**
 - Need *“government acting as a canny facilitator but not a rigid director.”*
National Diabetes Information Service
 - *“We need to change the business model to one where there is scope for small scale innovation in such areas as decision support, data capture and patient related outcomes”* **health professional**
- 4.8 Responses also covered the role that financial incentives can play in driving efficiencies and helping make the information revolution a reality.
- *“reliable information is the basis of tariff pricing. Given the centrality of PbR [Payment by Results¹⁵] / the tariff to the operation of the NHS, this appears to be a significant omission” ... “For tariffs to become more precise and more evidence-based, which in turn will enable stronger distinction between good and poor provider performance per unit cost, there needs to be continued emphasis on gathering of accurate activity data which in turn will need to be linked to outcomes data. This in turn links through to accurate information for patients.”* **Association of British Healthcare Industries (ABHI)**

¹⁵ See - www.dh.gov.uk/en/Managingyourorganisation/NHSFinancialReforms/index.htm

- *"access to local episodic/spells/admissions¹⁶ data works well and the information source is rich in depth and detail. This is because it has long been attached to financial payments systems requiring fairly rich information for charging and monitoring contracts."* **health professional**
 - *"the cost of drugs, the cost of a GP appointment, the cost of a specialist consultation" ... "will become important to patients if they are to hold their own care budgets and in the meantime can help patients understand the actual cost of all the work that is being carried out on their behalf - perhaps leading to a reduction in waste."* **Sunderland Local Pharmaceutical Committee**
- 4.9 Several responses stressed that infrastructure across care services is not yet adequate to deliver the benefits of the information revolution and that financial investment will be needed to make this happen.
- *"There is a large gap between where the Trust's system are today to where they would need to be in order to deliver the services described in the consultation document. Such changes would need significant funding for equipment and resources in both the clinical and informatics areas."* **health professional**
 - *"The solution to this challenge involves considerable investment in the necessary [Information Systems] resources and associated training."* **General Medical Council**
- 4.10 Lastly, many responses highlighted the point that the NHS and adult social care services have a solid basis on which to build to achieve the Government's ambitions - stressing that 'we are not starting from scratch'.
- *"The UK has some of the longest standing and best health data and collection systems in the world. It led the way in developing mortality data collections, has one of the most computerised primary care systems in the world, has developed sophisticated health protection and other surveillance systems based on routine data and has high quality cancer data through long standing cancer registration."* **Association of Public Health Observatories**
 - *"The UK health system is fortunate in having national information flows that do not exist in many other developed countries. For example, there is excellent data on public health (the Compendium indicators¹⁷ etc), hospital care (Hospital Episode Statistics¹⁸), and on hospital infections from one of the most internationally effective surveillance systems run by the Health Protection Agency. There is also data on the experience of patients using the NHS, and on patient-reported outcome measures (PROMs), from some of the largest and most comprehensive survey programmes internationally. The NHS is therefore data rich in very many ways."* **The King's Fund**

¹⁶ See - www.dh.gov.uk/en/Managingyourorganisation/NHSFinancialReforms/index.htm

¹⁷ See - www.nchod.nhs.uk/

¹⁸ See - www.hesonline.nhs.uk

- *“we need to keep the good things that came out of initiatives like Connecting for Health and to build on these and not simply start again from scratch”*
NHS Cambridgeshire & Cambridgeshire & Peterborough Public Health Network
- *“I think the information revolution should be about laying the foundations and when they're in place you can start to build on them. ... Don't run before you can walk”* **information professional**
- *“In our view, it is vitally important that as the health and social care system becomes increasingly pluralistic in nature, with a variety of different providers from a number of different sectors, the DH makes sure that the flow of information between providers is urgently improved.”* **Help the Hospices**
- *“It is often said that the NHS is data rich but information poor. Universal health coverage; a comprehensive delivery system; near universal Electronic Health Record (EHR) adoption in primary care; and a lifetime patient identification number put the NHS in an enviable position. However, the lack of data system interoperability between primary and secondary care; the lack of consistent coding and data collection; and the failure to fully utilise the patient identification number to track a patient's health experience across a lifetime can prevent the system from maximising the benefits of its impressive foundation.”* **United Health UK**

5. Next steps - The Information Strategy

- 5.1 The Information Strategy, to be published following on from this document, will form the Government's formal response to this consultation and will draw on views expressed through the consultation process and through the subsequent listening exercise.
- 5.2 We have asked the NHS Future Forum to support the development of the Information Strategy - looking at how information can best be used by patients and service users, by carers, by the public and by care professionals to improve health, care and well-being. The NHS Future Forum is now considering how it can best inform development of the forthcoming Information Strategy, taking the responses to the Information Revolution consultation as the starting point for this further work.

Equality and regulatory impact of the Information Strategy

- 5.3 We are fully committed to developing and publishing an impact assessment and an equality analysis to accompany the forthcoming Information Strategy.
- 5.4 The Department of Health has been carrying out an equality analysis to inform this document and the development of the subsequent Information Strategy. A high-level summary of equality issues is published alongside this document. As the Information Strategy policy is finalised, the Department of Health will ensure that potential adverse impacts on equality are addressed. Where it is proposed that an action to address a potential adverse impact is to be carried out by another organisation, the Department will put measures in place to ensure that necessary steps or actions are taken by that organisation. This will include monitoring actions so that potential adverse impacts are appropriately mitigated.
- 5.5 This document does not set any firm proposals for regulatory activity. Following on from publication of the Information Strategy, any subsequent, more detailed decisions will also be informed by appropriate consultation exercises and equality analysis. Where there is an action that would require substantial investment, there will be an economic impact assessment undertaken by the business owner to inform the decisions whether and, if agreed, how it is taken forward. These further decisions will be informed by appropriate consultation exercises and completion of business cases.

Annex A

Consultation questions

Q1: What currently works well in terms of information for health and adult social care and what needs to change?

Q2: What do you think are the most important uses of information, and who are the most important users of it?

Q3: Does the description of the information revolution capture all the important elements of the information system?

Q4: 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 outcomes - be delivered in the most effective and efficient way?

Q5: Where should the centre be focusing its limited financial resources and role to achieve the greatest positive effect?

Q6: 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?

Q7: 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?

Q8: 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.

Q9: What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?

Q10: 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?

Q11: 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?

Q12: What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?

Q13: 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?

Q14: What information about the outcomes from care services do you (as patient, carer, service user or care professional) already use?

Q15: What additional information about outcomes would be helpful for you?

Q16: 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?

Q17: For which particular groups of service users or care organisations is the use of information across organisational boundaries particularly important?

Q18: What are your views on the approach being taken and the criteria being used to review central data collections?

Q19: How could feedback from you be used to improve services?

Q20: What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?

Q21: 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?

Q22: Which questions, if asked consistently, would provide useful information to help you compare and choose services?

Q23: 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?

Q24: 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?

Q25: 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?

Q26: 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?

Q27: What are the key priorities for the development of professional information management capacity and capability to enable the information revolution?

Q28: 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?

Q29: What benefits and issues do you think will arise as a greater range of information providers offer information? How could issues be addressed?

Q30: 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?

Q31: 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 cannot 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.

Q32: 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?

Q33: 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?

Q34: Are there any critical issues for the future of information in the health and adult social care sectors that this consultation has not identified?

Annex B

Engagement activity throughout the consultation period

The consultation process included an extensive programme of engagement activity, tailored to facilitate meaningful discussion and dialogue with our identified stakeholder groups and to encourage patients, staff and all interested groups to put forward their views when responding to the consultation. This activity enabled contact with 479 distinct stakeholder organisations, of which 134 were patient or voluntary sector groups.

Stakeholder types	Count of stakeholder groups contacted
Patients, Public, Voluntary Sector	134
Clinicians	4
Informatics Professional	12
NHS Leaders and staff	13
Social care provider	22
Information intermediaries and suppliers	81
Policy/DH colleagues	28
Regulatory bodies	23
Commissioner	2
Healthcare provider	4
Think tanks	10
Academic / professional institution	125
Unions, member organisations	18
Public Health	3
	479

A detailed list of the some 150 centrally coordinated engagement events during the consultation period is shown below:

- 16 Sept 2010 LINKs Leeds Workshop for x35 LINKs participants
- 19 Sept 2010 PPE NHS Alliance Group event
- 20 Sept 2010 NHS Employers weekly bulletin
- 20 Sept 2010 Regional voices consultation event - Yorkshire & Humber (Leeds)
- 21 Sept 2010 Voluntary Sector strategic partnership session on White Paper
- 21 Sept 2010 East Midlands Regional HealthWatch consultation event, Derby
- 21 Sept 2010 Regional voices consultation event - North East (Newcastle)
- 23 Sept 2010 Regional voices consultation event - East Midlands (Nottingham)
- 23 Sept 2010 SHA Analytical Network
- 23 Sept 2010 Long-term conditions SHA Leads meeting
- 23 Sept 2010 QIPP follow up event with voluntary sector - covering White Paper, QIPP, HealthWatch and shared decision making. Range of charities attending.
- 23 Sept 2010 One day workshop with x18 LINKs participants from the South (London)
- 24 Sept 2010 Regional voices consultation event - East (Cambridge)
- 24 Sept 2010 Regional "Informed Conversations" on the implications of the WP for BME communities, North East, Sunderland
- 24 Sept 2010 Special Social Partnership Forum focused on White Paper for unions
- 28 Sept 2010 SHA Quality Leads meeting
- 28 Sept 2010 NHS Institute for Innovation and Improvement, Patient Experience Learning Programme Celebration Event
- 28 Sept 2010 Patient Safety Conference. Royal Society of Medicine.
- 28 Sept 2010 NHS Alliance/NAPC/RCGP White Paper event for primary care clinicians, Leicester
- 28 Sept 2010 Regional "Informed Conversations" on the implications of the WP for BME communities, East Midlands, Derby
- 29 Sept 2010 Regional "Informed Conversations" on the implications of the WP for BME communities, North West, Liverpool
- 29-30 Sept 2010 Primary Care Live London (practice manager and GP workshops)
- 30 Sept 2010 Event on Shared Decision Making – PPE team (providing DH speaker)
- 30 Sept 2010 Equalities focused White Paper Consultation Event
- 30 Sept 2010 QIPP regional engagement event, Yorks & Humber
- 30 Sept 2010 Public Health: Promoting Health and the Challenges Ahead conference, London
- 30 Sept 2010 Healthcare Technology 2010 conference (run by Inside Government)
- 30 Sept 2010 Conference on shared decision making - East of England SHA
- 01 Oct 2010 Society of British Neurological Surgeons Neurotrauma Group, Cambridge
- 01 Oct 2010 National event for PPE stakeholders to hear feedback on HealthWatch proposals. Wellington House
- 01 Oct 2010 Regional "Informed Conversations" on the implications of the WP for BME communities, Yorkshire & Humber, Bradford
- 04 Oct 2010 Workshop for PPG Participants in Leeds
- 04 Oct 2010 East of England Public Health and Social Care Directorate engagement and consultation event to inform development and future implementation of the Public Health White Paper. Cambridge
- 07 Oct 2010 King's Fund: Engaged and informed patients - the potential of shared decision making
- 7-9 Oct 2010 RCGP annual conference
- 08 Oct 2010 QIPP regional engagement event, South Central
- 08 Oct 2010 Eastern region Public Health Observatory
- 11-13 Oct British Computer Society Primary Health Care SG 30th Annual Conference
- 11 Oct 2010 West Midlands Dental Conference (workshop run by West Mids SHA)
- 13 Oct 2010 Royal Association of Disability Rights AGM
- 13 Oct 2010 Engagement Roundtable: Royal College Surgeons
- 14 Oct 2010 Social Partnership Forum
- 15 Oct 2010 Workshop with Think Tanks to get feedback on latest HealthWatch thinking
- 15 Oct 2010 Directors of Public Health advisory group on public health, first meeting
- 19 Oct 2010 Transforming the NHS Summit 2010: Building a 21st Century Health Service. Westminster Briefing
- 19 Oct 2010 NHS Norfolk Supporting the information revolution event -
- 20 Oct 2010 CIO/DCIO Session
- 20 Oct 2010 Joint Medical Consultative Committee Council Meeting
- 20 Oct 2010 Strategic Partner Programme Meeting
- 20 Oct 2010 Meeting with MacMillan
- 25 Oct 2010 NHS Employers weekly bulletin
- 25 Oct 2010 Transforming Community Services Pathfinder Sites event
- 26 Oct 2010 International Implementation of Health records
- 27th Oct 2010 National Centre for Independent Living AGM
- 27th Oct 2010 Carol Clark RSG Team Briefing
- 01 Nov 2010 PiF Session
- 01 Nov 2010 Doctors.net podcast
- 01 Nov 2010 Future of Informatics DH Staff Workshop
- 02 Nov 2010 Intellect Roundtable event
- 03 Nov 2010 South Central SHA Choose and Book forum
- 03 Nov 2010 Engagement Meeting with Royal College of Surgeons
- 04 Nov 2010 Yorkshire and Humber Choose and Choose Book Network
- 04 Nov 2010 NME Clinical Leads Meeting- discussing IS
- 04 Nov 2010 RiO User Group
- 05 Nov 2010 London Acute IT Directors
- 08 Nov 2010 Future of Informatics DH Staff Workshop
- 08 Nov 2010 SHA Senior Lead Scientists Network
- 8-9 Nov E Health Insider Live
- 09 Nov 2010 Inside Gov conference - Public Health: Healthier Lifestyles, Healthier Nation
- 09 Nov 2010 DH webchat on Choice and Info Strategy
- TBC AVECO workshop on Choice and IS consultation
- 10 Nov 2010 Future of Informatics DH Staff Workshop

- 11th Nov 2010 NHS Choices Operations Board
- 11 Nov 2010 Quality Observatories
- 11-12 Nov 2010 In Practice, Vision User Group
- 11-12 Nov 2010 Individuals affected by Thalidomide related group
- 12 Nov 2010 Y&H Conference for Health informatic professionals
- 15 Nov 2010 Future of Informatics DH Staff Workshop
- 16 Nov 2010 Chief Scientific Officer's White Paper consultation meeting 16 November for Healthcare Scientists
- 17 Nov 2010 Event on Shared Decision Making – PPE team (providing DH speaker)
- 18 Nov 2010 The GP IT forum
- 18 Nov 2010 National Information Governance Board
- 18 Nov 2010 Information Centre
- 18 Nov 2010 AHP Service Improvement Board
- 22 Nov 2010 BCS Hosted Engagement Event
- 23 Nov 2010 Choice / Info Strategy Consultation Learning Event
- 23 Nov 2010 Kings Fund Annual Conference
- 24-25- Nov 2010 IMS Health Meeting
- 24 Nov 2010 HSJ Healthcare Informatics 2010- Reducing costs and raising quality of care through effective healthcare informatics (London)
- 24 Nov 2010 NMC
- 24 Nov 2010 GMC
- 24-25 Nov HSJ: The Health White Paper: Interpreting and Implementing a 'liberated' NHS
- 25-26 Nov NHS Medical Directors' Conference, London
- 26 Nov 2010 Webinars focus on bringing the 'information revolution' to life: The Health White Paper and the Information Strategy- overview and discussion
- 29 Nov 2010 Seminar on 'Coding and structuring of clinical information in electronic health records'.
- 30 Nov 2010 Race Equality Foundation
- 30 Nov 2010 National Clinical Leads
- 30 Nov 2010 NHS WM Webchat
- 30 Nov 2010 NPSA
- 30 Nov 2010 National Stakeholder Forum
- 30 Nov - 02 Dec 2010 Health Informatics Benchmarking Club Masterclasses
- 30 Nov 2010 Public Health White Paper - Published 30 Nov 2010
- 01 Dec 2010 Information Centre Session
- 01 Dec 2010 MENCAP
- 01 Dec 2010 Monitor
- 01 Dec 2010 NICE
- 01 Dec 2010 CQC
- 01 Dec 2010 National Council of Palliative Care Forum
- 01 Dec 2010 Mental Health Strategy Board
- 01 Dec 2010 HSJ Event: Information for GP Commissioning
- 01 Dec 2010 Race Equality Foundation
- 02 Dec 2010 HPC
- 03 Dec 2010 Regional Voices event
- 03 Dec 2010 BCS Hosted Engagement Event
- 03 Dec 2010 Y&H Conference
- 06 Dec 2010 NCB Workshop
- 06 Dec 2010 IQPC Healthcare It Exchange (Panel discussion)
- 06 Dec 2010 Race Equality Foundation
- 07 Dec 2010 EoE SHA - Information for GP Commissioning Event
- 07 Dec 2010 NHS West Midlands Webchat
- 08 Dec 2010 Macmillan Stakeholder event
- 08 Dec 2010 DH Policy Session: Glenn Mason
- 08 Dec 2010 Choose and Books user group meeting
- 08 Dec 2010 Learning Disability Today
- 08 Dec 2010 National Council of Palliative Care full day conference on end of life care for ppl with dementia
- 08 Dec 2010 PiF Partners consultation
- 08 Dec 2010 Public Sector Procurement Event
- 08 Dec 2010 Race Equality Foundation
- 8-10 Dec 2010 HFMA Annual Conference, London (representative body for finance in healthcare)
- 09 Dec 2010 Y and H Regional Voices Network
- 09 Dec 2010 Race Equality Foundation
- 09 Dec 2010 BCS Health Professional Development group
- 09 Dec 2010 Intellect
- 10 Dec 2010 SHA Analyst Network
- 10 Dec 2010 South Central SHA Event (AM)
- 10 Dec 2010 South Central SHA Event (PM)
- 10 Dec 2010 NE SHA event
- 10 Dec 2010 ASSIST supported consultation event
- 13 Dec 2010 ASSIST supported consultation event
- 14 Dec 2010 MS (CS) Social Care Stakeholder Forum
- 14 Dec 2010 ASSIST supported consultation event
- 14 Dec 2010 NHS WM Webchat
- 16 Dec 2010 IC Information Services Supplier Forum: The Role of Information Intermediaries
- 22 Dec 2010 SLaM Hosted Session
- 21 Dec 2010 ACEVO Roundtable
- 04 Jan 2011 NHS WM Webchat
- 04 Jan 2011 Liberating the NHS: an information revolution consultation, public & patient event
- 11 Jan 2011 NHS WM Webchat
- 13 Jan 2011 South Central NHS workshop
- 13 Jan 2011 Equalities Event
- 14 Jan 2011 Webinars focus on bringing the 'Information Revolution' to life: Commissioning excellence in Health and Care

Annex C

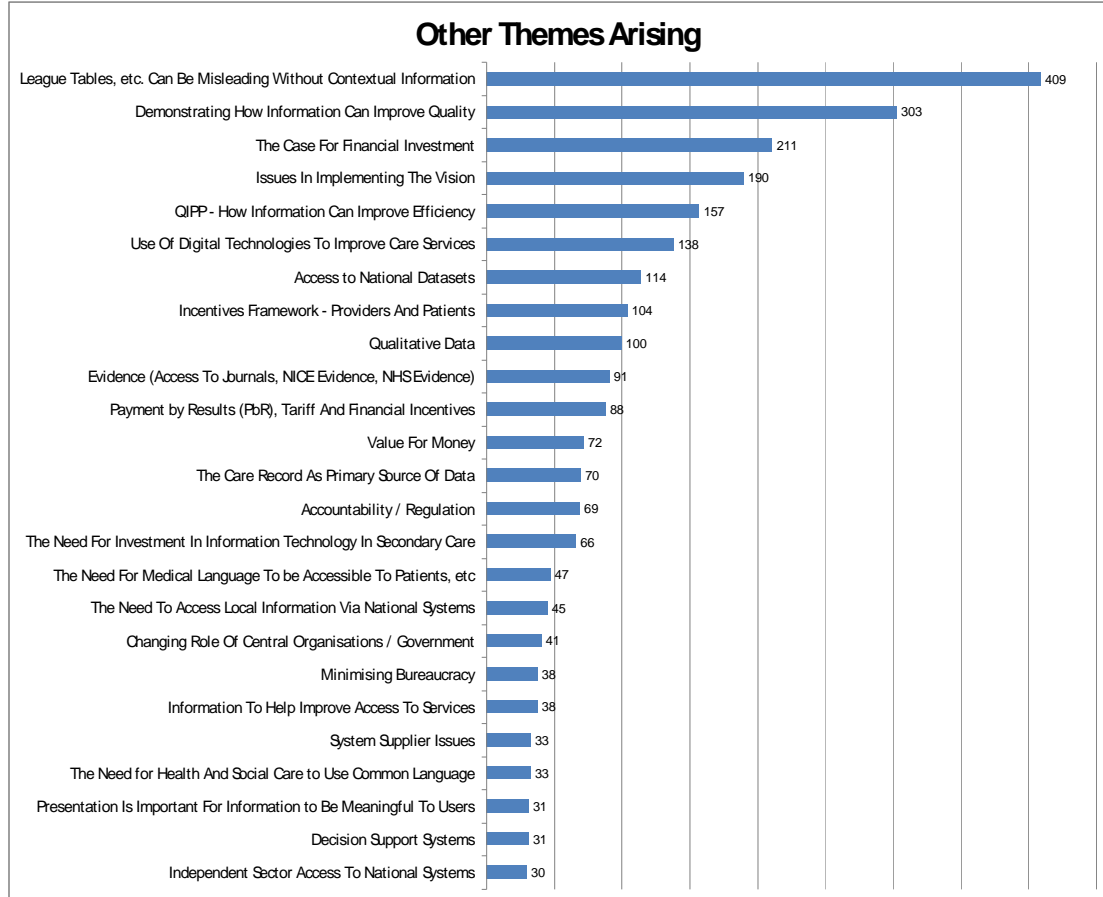
Analysis of themes identified in consultation responses

The figure on page 9 shows a breakdown of points made or issues raised within consultation responses, grouped into the main themes discussed in chapter 3. These main theme groupings included points made or issues raised in consultation responses within a number of further sub-themes, as shown below.

main theme	sub-themes
<p>ensuring that the information revolution benefits everyone and does not increase inequalities</p>	<ul style="list-style-type: none"> • culture change; • education of staff; • promoting equality (including digital divide issues); • the importance of face-to-face contact; • vulnerable people; • information advisers (support for people to use information); • information for carers; • libraries; • professional support; • health literacy; • peer support; • the need for datasets to include equalities information; • advocacy; • eliminating discrimination; • specific issues for elderly groups; • promoting good relations between groups
<p>information for improved outcomes</p>	<ul style="list-style-type: none"> • patient reported outcome measures (PROMS); • user-based feedback as a mechanism to improve services; • other user-reported information; • information to support commissioning; • outcome measures by clinical team; • complaints; • feedback captured at the point of care
<p>the need for information to be linked across health, social care and also public health</p>	<ul style="list-style-type: none"> • linking data using the NHS number; • interoperability; • information for public health, prevention and screening; • local authorities' information services
<p>information for professionals</p>	<ul style="list-style-type: none"> • culture change issues; • data quality; • education of staff; • developing and retaining informatics capability and skills; • ensuring information systems 'work' for care professionals; • recording information at the point of care

<p>people’s control of and access to information held in their own care records</p>	<ul style="list-style-type: none"> • control of people’s own care records; • access to people's own care records; • information governance (including sensitive information); • data security; • consent models; • confidentiality; • audit trails within care records; • the balance between security and accessibility of information held in care records; • accountability for the record; • carers being able to access care records; • people adding information to their own care records
<p>the need for clear routes (or “channels”) to information</p>	<ul style="list-style-type: none"> • a single online 'portal' into information; • signposting for local, regional and national information sources and also support services; • the need for multiple media for communications to suit individual needs; • the need to not ‘re-invent the wheel’ but build on current things that work well, including the NHS Choices website and The Information Standard; • issues of ‘information overload’; • the ‘111’ telephone service.
<p>information for patients, service users, carers and the public</p>	<ul style="list-style-type: none"> • information to support choice; • information for patients to help them care for themselves; • shared decision making; • people using public health, prevention and screening information; • information about specific conditions; • information prescriptions; • education of patients; • information for or about children and young people; • information issues for people with long term conditions; • personal budgets
<p>information for autonomy, accountability and democratic legitimacy</p>	<ul style="list-style-type: none"> • how people can trust data (including issues on accreditation or kite-marking of information sources); • transparency; • opening up a market of information ‘intermediaries’; • information for research and development; • voluntary sector organisations as information ‘intermediaries’; • private sector information ‘intermediaries’; • issues around the potential for commercial use of care data
<p>the need for clear information standards across health, public health and social care</p>	<p>this main theme did not include any further sub-themes</p>

In addition to the main themes discussed in chapter 3 (and as shown in the figure on page 9), the figure below shows a further breakdown of other particular points made or issues raised within consultation responses:



Annex D

Glossary

Anonymised data - data concerning an individual which has been stripped of personal details, so that the identity of the individual cannot be determined

Care pathway - the path that a patient goes along from their first contact with a healthcare professional to talk about symptoms, through to diagnosis, treatment, aftercare and their final follow-up appointment with a healthcare professional

Care records – information, however recorded, which relates to the physical or mental health or condition of an individual, to the diagnosis of his condition, to assessment of need for support, to his or her care or treatment and to other practical assistance provided.

Care professional - a person who is registered with a professional body as qualified to provide care to a patient or service user

Carer - a carer spends a significant proportion of their life providing unpaid support to family or friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems

Channel - Medium through which a message is transmitted to its intended audience, such as print media or broadcast media.

Clinician - health professional, such as a physician, psychiatrist, psychologist, or nurse, involved in clinical practice, as distinguished from one specialising in research

Commissioning - the process of assessing the needs of a local population and procuring or buying services to meet those needs

Data - a series of facts, and figures, measurements or observations that require analysis and/or interpretation to convey meaning and derive knowledge

Data quality - the state of completeness, validity, consistency, timeliness and accuracy that makes data appropriate for the purpose intended

Datasets - a collection of related data records on a storage device

Digital technology - computer or communications technology

Informatics - the knowledge, skills and tools which enable information to be collected, managed, used and shared

Information - the ‘real-world’ meaning conveyed by data, usually after a process of analysis and interpretation, when presented within a context that gives relevance

Information intermediaries - a channel that provides specialised information on behalf of providers to service users, carers, the public and others

Information architecture - information architecture defines what information needs to be shared, the flow of information between organisations, systems and people and the standards and technical constraints that apply

Information governance - a standards based approach for supporting the provision of high quality care through the effective and appropriate use of information. It provides a set of rules that organisations must comply with in order to maintain comprehensive and accurate records and keep those records confidential and secure

Information prescriptions - are designed to give people with long-term conditions or care needs information to help them manage their health more effectively and live more independently. They contain information, and signposts to further sources of advice and support, such as how to find local support groups

Information standard – a document containing standards in relation to the processing of information

Interoperability - the ability of different systems to share information

Kite-marking – a sign of conformance to a standard

NHS Choices - is the online 'front door' to the NHS. It is the country's biggest health website and gives all the information you need to make choices about your health

NHS Commissioning Board – subject to Parliamentary approval of the current Health and Social Care Bill, the NHS Commissioning Board will hold consortia to account and for allocating and accounting for NHS resources

Patient Reported Outcome Measures (PROMS) - measure quality from the patient perspective. Initially covering four clinical procedures, PROMs calculate the health gain after surgical treatment using pre and post operative surveys

Practitioner - someone who practices a learned profession

Provider - a person or organisation that provides healthcare services, whether by running a hospital, or an independent treatment centre, by providing services in the community, or in any other way

Service users - someone who uses health and/or social care services because of illness or health problems

