NHS

Liberating the NHS:

An Information Revolution

A consultation on proposals

DH Department of Health

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Description	Equity and excellence: Liberating the NHS sets out a vision of patients at the heart of the NHS through an information revolution, which depends on transforming the way information is accessed, collected, analysed and used. This consultation document proposes and seeks views on the journey we all need to take so that information is managed for the benefit of all.
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Foreword

High quality health and care services depend on good information. The right person having the right information at the right time can make all the difference to the experience of a patient, service user or carer. Good information also enables care professionals to make the process of care safer and more efficient. Information is a health and care service in its own right: it must be freely available to all who need it.

Good information is also the basis for genuine shared decision-making: ‘no decision about me, without me’. We all know the difference between being informed by a service and being left in the dark, and we all know which we prefer. We also all know the experience of receiving volumes of inconsistent or poorly organised information, which can confuse as much as inform.

Information needs to be accessible to all, relevant and well-structured. At present, many people who use our health and care services do not get the information they need and are entitled to expect as part of the care process. Also, we sometimes fail to meet the information needs of our clinicians and care professionals. There are, however, a number of health and care services today where patients, service users and carers are being well-informed and supported to make decisions effectively - we want to build on these successes and on the good practice that already exists.

We need an information revolution to ensure that what is currently seen as good practice becomes the norm. We must not lose sight of the primary purpose of information in the health and care system: to ensure that every patient and service user receives high quality care. We must start by ensuring that accurate data is recorded at the point of giving care, as this forms the basis of information used for so many other purposes across our health and care system.

This consultation document builds on the commitments we made in the White Paper *Equity and excellence: Liberating the NHS*. It sets out the journey we all need to take - the public, patients, service users, carers, clinicians, practitioners, informatics professionals and health and care organisations - to change the ways in which information is managed for the benefit of all. We need to hear your views to help achieve that change. The challenges ahead are significant, but so is the prize: improved outcomes and services that fully meet the needs and expectations of the public.

Secretary of State for Health

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Executive summary

1. Our vision is of an information revolution in which 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. This includes an accurate record of their care, available to them electronically. Health and adult social care information will be liberated from a closed, bureaucratic system in order to serve patients and the public, and to help drive better care, improving outcomes, innovation and the better use of resources.

2. Transforming the way information is collected, analysed and used by the NHS and adult social care services will be critical to achieving this information revolution. This Government is committed to moving:

   - away from information belonging to the system, to information enabling **patients and service users to be in clear control of their care**;
   - away from patients and service users merely receiving care, to **patients and service users being active participants in their care**;
   - away from information based on administrative and technical needs, to information which **is based on the patient or service user consultation and on good clinical and professional practice**;
   - away from top-down information collection, to a focus on **meeting the needs of individuals and local communities**;
   - away from a culture in which information has been held close and recorded in forms that are difficult to compare, to one characterised by **openness, transparency and comparability;**
   - away from the Government being the main provider of information about the quality of services to **a range of organisations being able to offer service information to a variety of audiences**; and
   - in relation to digital technologies, away from an approach where we expect every organisation to use the same system, to one where we **connect and join up systems**.

3. Without fundamental changes to the data being collected and analysed, and the information made available, NHS and adult social care services will be held back in making the progress we all want to see. Our recent White Paper *Equity and excellence: Liberating the NHS*[1] set out a number of critical priorities for the years ahead, all of which rely on the information revolution in different ways. This consultation document considers and seeks views on the information implications of each of those priority areas in turn.

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[1] Referred to in this document as *Liberating the NHS* - See www.dh.gov.uk/liberatingtheNHS

Chapter 1 – An information revolution

4. Modern technology plays an ever-increasing part in our everyday lives. From online banking to searching the internet, we have come to expect more convenient services, supported by quick and easy access to information. Yet many parts of our health and care systems still rely on face-to-face contact and paper-based transactions, even when it is neither necessary nor appropriate. This introductory chapter sets out our thinking and seeks 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 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.

Chapter 2 – Information for patients, service users, carers and the public

5. 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 form the basis of information systems for patients and service users. Giving people control of their care records can also enable them to take greater control of their care. This chapter sets out our thinking and seeks 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.

Chapter 3 – Information for improved outcomes

6. The 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. This chapter sets out our thinking and seeks views on:

- 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 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 information available to GP and local authority commissioners can help secure the best possible services and outcomes for their local populations, relative to need.

Chapter 4 – Information for professionals

7. Clinicians and care professionals have a critical role to play in developing information systems, capturing data accurately at the point of care and ensuring the quality of that data. This chapter sets out our thinking and seeks 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.

Chapter 5 – Information for autonomy, accountability and democratic legitimacy

8. Transparency and openness are key to accountability. *Liberating the NHS* sets 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. This chapter sets out our thinking and seeks 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) programme, which seeks to harness and spread innovative best practice across the service.

Chapter 6 – Setting the direction – the information strategy

9. The information strategy, to be published following this consultation, will define the vision, set the expectations, describe the responsibilities, provide the timetable, and determine the routes by which the information revolution will be achieved. This chapter sets out our thinking and seeks views on a number of vital issues that will need to be addressed as we take the information strategy forward, including:

- improving data quality;
- 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.

The consultation process

10. This is a document for consultation. It is only by involving as wide a range of partners as possible that the information revolution will achieve its true potential. Consequently, we want to know about your ideas and practical proposals, as well as any issues that we need to consider, or other concerns you may have about the ambition and proposals set out in this document.

11. We have included three annexes at the end of this document:

    ### Annex A – Consultation questions

    shows all of the consultation questions asked throughout the document itself;

    ### Annex B – Glossary

    explains some of the words and phrases used in the document; and

    ### Annex C – The consultation process

    sets out the various ways you can become involved in this consultation.

12. We look forward to hearing your views.

1. An information revolution

The challenge and the opportunity

1.1 In a world where people are increasingly used to managing their own bank transactions online, using social networks and ordering goods and services over the internet, people are demanding information that puts them in control.

1.2 The current reality is that all too often those who use health and care services, or work in the organisations providing them, feel that they are not in control. Much of the frustration within today's care system has, at its root, information: the service user asked to give the same information for the third time; the worried patient waiting for a test result; the clinician filling out data returns that will not help improve care; the member of the public unable to compare one service with another.

1.3 The scale of the challenge in turning this situation around should not deter us. We can look to a number of practitioner-led initiatives which use information to support and to deliver care. We can look to best practice in other countries. We can also look to other sectors, where people use information and information technology to access, shape and tailor services. For example, the possibility of rapid price comparisons through the internet for basic utilities such as electricity has had a major impact on the experience of consumers[2]. For some time now, people have been using the internet to explore a diagnosis after (or before) they visit their doctor [3].

1.4 New forms of interaction and even new communities are emerging that would not be possible without the openings provided by information technology. Communities can now be defined by their needs, rather than where they live. The role of websites such as 'Mumsnet' in generating new ways of sharing insights and information – including health information – is having a lasting effect on our society. Carers, patients, service users, care workers and clinicians are increasingly able to access forums to discuss the issues that matter to them, and offer support from others with experience of their

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[2] Other sectors we might look to include the travel industry (three out of every four holidays in the UK are now researched or booked on line; there have been dramatic reductions in related operator and airline costs, many of which have been passed on to the consumer) and as another example, a bank suggests that over 1 million users log in every day - see http://www.onlinebankingreviews.co.uk/2010/09/lloydstsb-stats-show-increased-internet-banking-usage/ .

[3] For a study of patient use of the internet which showed 11% of patients for neurology outpatients at the Walton Centre for Neurology and Neurosurgery in Liverpool in 2001-5 accessing the internet prior to clinic attendance. Abstract available at http://jtt.rsmjournals.com/cgi/content/abstract/12/4/186.

condition[4]. The NHS, local authorities and care providers should be responding to and supporting these new approaches.

1.5 This is a document for consultation and we have asked some questions to help you to tell us about ideas and practical proposals, as well as any issues or other concerns you may have. The first of these consultation questions is shown in the grey box below**:**

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

1.6 An information revolution in health and social care has the potential to bring lasting benefits for people in all parts of society and of all ages, from children and adolescents through to older people - including:

- *patients, service users and their carers,* enabling them to take shared decisions with professionals and make informed choices;
- *the public*, supporting people to stay healthy, care for themselves and their families, and also in holding services to account;
- *clinicians and other care professionals*, giving them what they need to do their jobs well, improve quality and meet the needs and expectations of patients and service users;
- *health service commissioners and providers,* giving them the information they need to improve health outcomes and obtain the best value for the public money they spend; and
- *local government*, supporting its new role in public health and its expanded role in relation to health and social care.

1.7 To achieve lasting benefit, all of these different groups of people need to be able to access and use information that is:

- *informing*, so that they know it is comprehensive and can be trusted;
- *engaging*, so that they are willing and able to use it; and
- *empowering*, so that they know how it can make a difference.

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[4] Examples include www.healthtalkonline.org which shares the experiences of health and illness of more than 2,000 people, along with information about conditions, treatment choices and support; www.renalpatientview.org, the website of the Nottingham support group of carers of children with eczema (www.nottinghameczema.org.uk); and the International Still's disease forum (http://stillsdisease.org/stills_info). A number of examples exist in relation to adult social care demonstrating innovative use of the internet to share feedback and experience or to set up a virtual market place.

1.8 To have the maximum impact the information revolution needs to cover the many types of information used across health and social care, including information that:

- is recorded about the care of individual patients and service users;
- informs people about the availability and quality of services, and about the outcomes of care;
- informs people about particular illnesses, diseases or conditions;
- helps people live healthy and independent lives;
- supports clinicians and other care professionals to give the highest quality care, compare their performance with others, identify gaps in provision and develop their knowledge;
- supports researchers to advance medical and scientific knowledge;
- monitors how well health and care services are performing so that they are accountable to the public; and
- ensures services are well managed and providing value for money.

1.9 Information is also an essential resource to support policy makers. A greater availability of reliable, high quality information (which allows international comparisons wherever possible), as well as tools to support its use, will be vital for Government, regulators, and the NHS Commissioning Board in making major decisions about care.

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

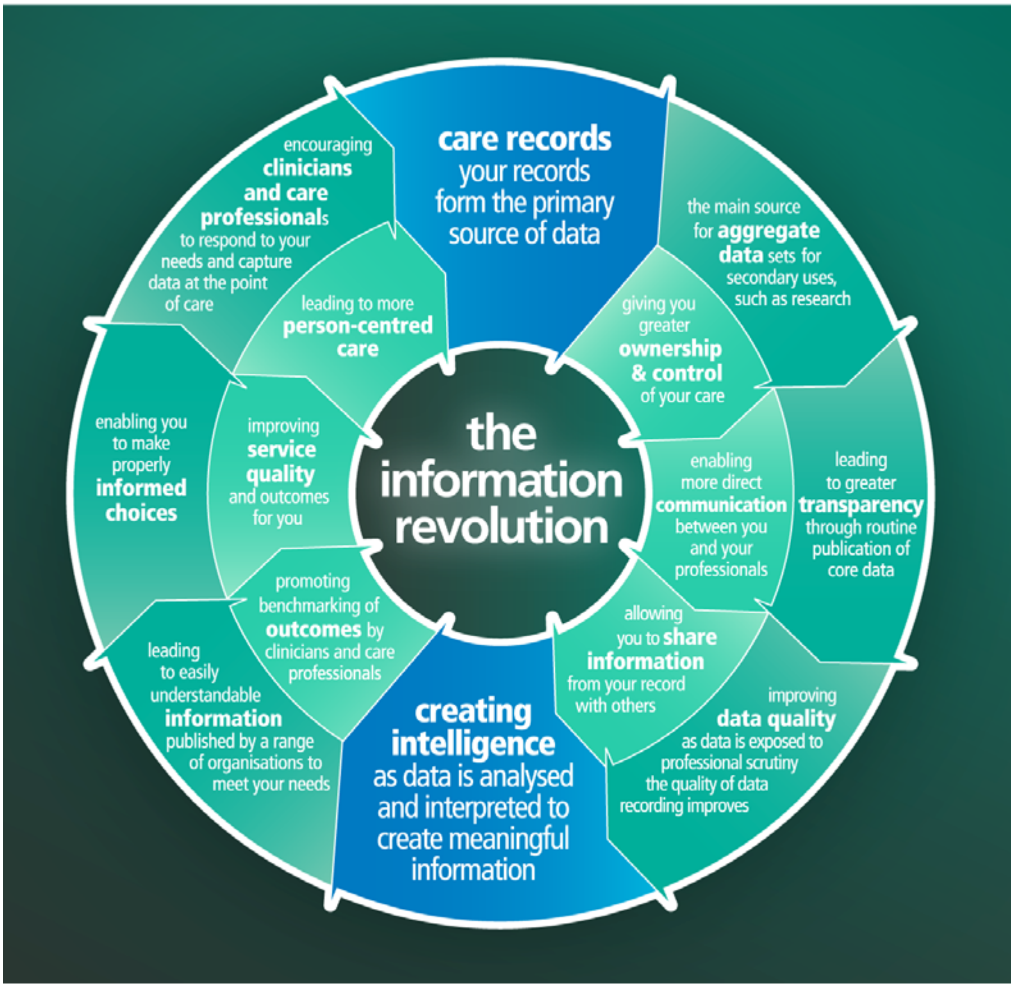
How will the information revolution work?

1.10 The information revolution starts from the premise that the primary use of information is to support the giving of high quality care. The most important source of data is the patient or service user’s care record, generated at the point of care. This record also provides much of the data needed for other, secondary purposes. In many cases, the way that data is recorded at the point of care and then moved around the system needs to change significantly.

1.11 The information revolution depends on a ‘presumption of openness’, which will mean routine publication of aggregate datasets built-up from data held securely in people’s records. This may mean publishing data in a relatively basic form, as close to the time of recording as possible, but will not mean releasing data that enables individuals to be identified. Personal information will, of course, continue to be subject to strict security arrangements.

1.12 Making centrally held datasets routinely and publicly available will encourage better data recording and thus drive up data quality. Allowing open access to centrally held datasets will inevitably improve understanding about what is really happening in care services and how they can be further improved[5]. This intelligence will enable meaningful benchmarking of performance and quality outcomes. When published in easily understandable forms, it can help people to make meaningful choices about how, when and where they receive care.

1.13 The diagram below summarises how the information revolution will work.



The outer circle (above) shows how data from the patient or service user's care record, leads to high quality information that gives people real knowledge and choice. The inner circle shows how giving patients or service users control of the data held within their record benefits them, as well as those providing their care. This is discussed in more detail in chapter two.

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

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[5] For example, making aggregated, anonymised data available to the university and research sectors has the potential to suggest new areas of research through medical and scientific analysis.

Can we afford an information revolution?

1.14 The information revolution will be implemented against the backdrop of a very challenging financial position. The Government has committed to an increase in health spending in real terms in each year of this Parliament. However, unprecedented efficiency gains will be needed to meet the costs of caring for an ageing population, funding new treatments and technological advances, and achieving the quality and outcome improvements we are determined to make. Whilst any associated costs will need to be met within the Department of Health's Spending Review settlement, there will be no additional central funding to pay for the information revolution. Therefore, we must focus on driving efficiency and making each pound we spend work harder and smarter. Unleashing information will support this by helping people to care for themselves and by driving up the quality of service provision through increased transparency and innovation.

1.15 Digital technology, too, offers opportunities for enormous efficiency gains within the NHS and adult social care services, especially when integrated with wider service design. Access to advice and support without the need to travel (with clear advantages in terms of convenience, outcomes and cost) is one example. The potential to deliver services directly, and to tailor them for different individuals and groups, is another. Commissioners and providers can also improve the quality of their financial information and use that to enhance efficiency. Whilst there will inevitably be costs, which could fall centrally and/or locally, the information revolution should, ultimately, pay for itself.

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?

Why the information revolution needs you

1.16 This is a document for consultation. We want to involve as wide a range of partners as possible from the NHS, adult social care, the voluntary sector, education, civil society, private enterprise (including IT and information suppliers), as well as interested, engaged individuals. It is only by engaging widely that the information revolution will achieve its true potential.

1.17 In the following chapters, we set out a description of the key issues as we see them, focussing strongly on the needs of patients, service users, the public, clinicians and other care professionals. We also recognise that there are a number of organisational and technical matters that need to be addressed as part of the process of developing a final information strategy through the consultation process. This document sets out the key issues and questions.

1.18 We have included three annexes at the end of this document**:**

Annex A shows all of the consultation questions asked in the document;
Annex B explains some of the words and phrases used in the document; and
Annex C sets out the various ways you can become involved.

1.19 A separate consultation on our proposals to give people greater choice and control is being published alongside this document[6]. After these two consultation excercises have been completed, we will use the responses and views from both of them to inform the Government's information strategy for health and adult social care.

1.20 We are fully committed to developing and publishing an impact assessment and an equalities impact assessment to accompany the Government's response to this consultation. As part of that process, we very much welcome your views on the potential economic and other benefits that the information revolution can bring - including sustainability, business, rural or equality issues - as well as any concerns that you may have.

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[6] *Liberating the NHS: Greater choice and control* - see www.dh.gov.uk/liberatingthenhs

2. Information for patients, service users, carers and the public

2.1 If we are to achieve the ambition of 'no decision about me without me', set out in *Liberating the NHS,* it will be vital to create an environment where people get the information they need, in a form they can use, when it matters. There are a number of areas where changes in practice and culture will be required - from patient and service user control of their records, to information for choice and healthy living. But we are not starting from scratch: we will build on existing good practice in the NHS and the voluntary sector.

2.2 In social care, personal budgets and direct payments put people in control of their own care - enabling them to make personal decisions about their care and use a wide range of local services, including those provided by the voluntary, social enterprise and private sectors. This personalisation agenda is being driven by local authority advocacy and advice services, which are already doing a great deal to use information to support choice.

Patient / service user control of records

Why would patients and service users want control of their records?

2.3 One of the most important sources of information for patients and service users to make choices is the information about their own condition and history contained in their health and care records[7]. Control of their records gives patients and service users a clearer understanding of their health needs, their treatments, their care and other options available to them and will help make shared decision-making a reality. Providing patients with greater control of their records is also symbolic of a new relationship between individuals and services. Patient control of records opens up exciting new possibilities for on-line health and care services, supporting patients and service users to directly access services and interact with them.

2.4 Research by The Health Foundation[8] indicates that giving people greater access to and control over their health records:

- improves relationships with clinicians by promoting informed discussions and engendering a sense of involvement;
- means patients are better informed about their care and medication and enabled to correct errors and omissions, thereby improving safety;

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[7] See "The Information Revolution" diagram in paragraph 1.13 above

[8] See - http://www.health.org.uk/publications/consultation_responses/health_records.html

- provides flexibility for patients, who don’t have to go to their general practice or hospital to access their records; and
- increases people’s ability to manage their own health care and their confidence to do so.

Wells Park Practice has been offering patients free online access to their GP records for some years. Patient and practice reactions include:

“Having broken my right shoulder twice and being treated by two different hospitals, I was able to take copies of discharge letters from the first hospital to the second hospital. It gave a base line for the physiotherapy department to work from.”

“I have been able to have some control over my illness rather then allowing it to control me - a very very important thing when dealing with long-term illness/pain.”

“I have a chronic disease and feel a real partner in the management of my health. Whether I am at home or abroad, I can monitor information and share it with any other health professional involved in my care. I would be lost without it now!”

“It reduced the number of phone calls to reception for copies of results and made patients much more responsible for their own care, which they liked.”

What does patient and service user control of records mean?

2.5 At present, there is no single overall record of a person’s entire health and care history. Records are kept electronically and on paper, in different care settings and different locations, and the quality of record keeping varies. Each record holds personal and clinical information, some of it particularly sensitive. In some areas, records are linked across organisations, but this is not consistent across the country. Health and care professionals and their organisations need to keep records for legal reasons as well as to provide good care. Therefore, patient and service user control of their record does not mean they will be able to remove the original record from the care provider, or alter or delete what a clinician or care professional has entered into their record unless it is incorrect.

2.6 The extent to which people will be able to have ‘control’ of their records will vary according to their circumstances and the nature of the record and its contents. A ‘one size fits all’ approach to control is unlikely to develop the high degree of engagement in shared decision-making, supported self-care and self-management that we are hoping to encourage. Mindful of the responsibilities involved, people will need to make informed choices about the extent to which they want to take control of their records.

2.7 Options open to people to control their records will, over time, include:

- having access to their various records, starting with those held by their GP, then extending to those held by all health and adult social care providers. There may be some information in a person's record that it would not be appropriate for them to see - such as personal information relating to a relative or carer - but this would be the exception;

- having routine access to their records will mean that people will be able to discover factual errors and notify the professionals responsible. The value of this is illustrated by a study undertaken in a general practice in 2004, in which 70% of patients found at least one error or omission in their electronic medical record, and 23% found an error or omission that could be described as important[9]. People will be able to correct errors and see changes when they are made, which will improve the safety of care;

- being able to access an electronic copy of their records and pass this, in standard format, to any organisation or person of their choice. This will enable people to share information with others, who can help them to understand and manage their health and care better, such as:

    - people with similar conditions, illnesses or care needs;
    - support groups that can help them understand their records and manage their conditions better;
    - patient or service user charities that provide advice and information to people with particular conditions and build up a better understanding of their needs; or
    - researchers (confidentially or in anonymous form), to play a part in building up the knowledge that leads to better health outcomes for themselves and for others in society.

2.8 We would like to see patients and service users having online access to the records held by their GP[10] and, over time, to extend access progressively to the records held by all providers, including but not restricted to:

- hospital letters;
- laboratory results;

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[9] Pyper, C., Amery, J., Watson, M., & Crook, C. (2004). Patients' experiences when accessing their on-line electronic patient records in primary care. *British Journal of General Practice*, **54**, 38-43.

[10] Direct access to full clinical records is already available for patients of a small but growing number of general practices; see, for example, the website of Haughton Thornley Medical Centres (http://www.htmc.co.uk), which explains how patients are taking advantage of this and other on-line services.

- centrally held patient-identifiable data;
- secondary care records (such as hospitals);
- community services (such as health visitors and district nurses);
- personal care plans for people with long terms conditions; and
- needs assessments and care plans relating to adult social care services.

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?

2.9 GPs and other care providers will also be encouraged to go further than simply providing information, and enable patients to interact with them through their records. This might mean people recording their symptoms, health status, self-testing results (eg. temperature, blood pressure, blood sugar levels) and medication they have taken.

2.10 Options for remote contact have the potential to extend choice and convenience, especially for people with long-term conditions who would otherwise have to visit health facilities frequently. It will also be a more cost effective and efficient use of patients' time, clinicians' time and NHS resources. People should be able to communicate securely with their health or care professionals on-line or by email wherever it is convenient, cost effective and feasible. Evidence from other countries is that, overall, this more flexible pattern of interaction frees up clinical time to meet the needs of those for whom face to face contact remains either desirable or essential[11].

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?

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[11] See Neville, Ron G; Marsden, Wendy; McCowan, Colin; Pagliari, Claudia; Mullen, Helen; Fannin, Allison *Informatics in Primary Care*, Volume 12, Number 4, December 2004 , pp. 207-214(8), http://www.ingentaconnect.com/content/rmp/ipc/2004/00000012/00000004/art00003#expand/collapse
Where children are very young and lack the competence to make decisions about their own healthcare, it will be necessary for healthcare professionals to share information with parents so that they can make shared decisions about the care needs of the child. However, as children get older it will be important to provide them with appropriate information so that they can participate in discussions about their own care. There may be circumstances where the child is competent to make decisions without his/her parents' involvement. Healthcare professionals will need to act accordingly and withhold information from the parents, while ensuring that the child is appropriately informed and supported to decide his/her own care needs. In a very small number of cases, healthcare professionals who have concerns about the welfare or safeguarding needs of a child may need to share information with other organisations or professionals involved with the child and their family to ensure that decisions about the child's care are in his/her best interests.

What needs to happen to enable patients and service users to control their records?

2.11 Opening up access to records and placing control firmly in the hands of patients and service users represents a significant and positive shift in the basis of the relationship between people and their care professionals. To make this shift does not require any legislative change (the European Convention on Human Rights, the Data Protection Act, confidentiality case law and the consequent right referenced in the NHS Constitution provide a sufficient legal basis), but it is a challenge to the culture and practices of some health and care organisations and professionals. Therefore, a phased approach will be adopted to enable all parties, including the suppliers of information systems, to adapt their arrangements in a considered manner. The importance of using records to support service integration across health and social care must be recognised, given the projected rise in complex need involving care from both NHS and adult social care services.

2.12 The Academy of Medical Royal Colleges has formally endorsed The Royal College of Physicians' case and vision for patient-focused records, stating that

> *"implementation of standardised, structured, patient focused records:*
>
> - *requires strongly led culture change, embraced by all medical and clinical staff*
> - *is an essential prerequisite for the safe, efficient and effective migration from paper to electronic patient records*
> - *will enable innovative development of services that cross traditional boundaries, and when patients themselves are given access to the record, empower them to take more responsibility for their own care"*

2.13 Comprehensive, professionally-assured record keeping standards will be needed to ensure consistency. The Royal Colleges are working to introduce comprehensive standards for record keeping, principles for shared records and guidance on good practice in giving people access to their own records[12]. It will be essential to ensure that all care records adhere to nationally agreed standards, including use of the NHS Number as the means of identification.

2.14 As patients and service users are given control of their records, the market will develop new products to bring together the information they need, in a form they expect, to help them manage their own healthcare and well being.

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[12] Royal College of Physicians - *The case and the vision for patient-focused records* (published 2009), *Generic medical record-keeping standards* (published 2007) and *A Clinicians Guide to Records Standards for the structure and content of medical records (*published 2008); Royal College of General Practitioners *Shared Record Professional Guidance* (published 2009) and *Enabling Patients to Access Electronic Health Records: Guidance for Health Professionals* (in final draft)

Measures to give people access to their records will be most effectively and efficiently delivered by exploiting the data held in existing systems.

2.15 Social care services have been working with NHS colleagues and their IT system suppliers to give service users web-based access and control of their own social care records. A number of local authority-led partnerships are beginning to share assessment, care and support planning information through Common Assessment Framework demonstrators. These are designed to identify and meet individual needs by effective information sharing. Projects will run to March 2012 and be subject to national evaluation. Emerging learning from the work of both the phase 1 and phase 2 demonstrator sites is published on the CAF Learning Network[13].

2.16 Ensuring confidentiality and security of data will be a key concern for service users, and, consequently, a fundamental issue for the success of our information revolution. Where organisations hold patient or service user records electronically, the systems used must meet appropriate standards of safety, security, reliability and resilience. The NHS Commissioning Board will be responsible for centrally developing and maintaining these standards for the NHS. Equivalent standards set by the Department of Health will also be required for social care and for public health services.

2.17 The Department of Health's Information Governance Toolkit[14] explains the controls and policies that organisations should use to manage the records held by them. These controls and policies are derived from legal requirements, mandated information standards, professional standards from the Royal Colleges and professional regulatory bodies and commitments set out in the published NHS Care Record Guarantee[15] and in the Social Care Record Guarantee[16]. Organisations will be responsible for ensuring that the systems they use meet the appropriate standards and they will be audited for compliance.

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.

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[13] See www.dhcarenetworks.org.uk/CAF/

[14] See http://www.connectingforhealth.nhs.uk/systemsandservices/infogov

[15] See http://www.nigb.nhs.uk/guarantee

[16] See http://www.nigb.nhs.uk/social

Shared decision-making and informed choices

2.18 The care of the future will, increasingly, be structured around a conversation between the patient or service user and the professional, either through face-to-face contact or remotely, such as through the care record. This will be a genuine dialogue in which each brings an important perspective to bear: the care professional brings knowledge about conditions and treatment options; the patient or service user brings individual needs, protected rights, values, preferences and personal circumstances. The principles, values and rights that underpin this approach are set out in the NHS Constitution[17].

2.19 A good example of this approach is the long term conditions model, which includes a personalised care planning discussion, focused on the needs and wants of the patient. The outcome is a care plan that is personalised to the individual rather then the service provider. There is strong evidence, both in this country and internationally, showing much better care outcomes when people are actively involved in shaping their own care. The appropriate involvement of carers in the dialogue can also be important in making a reality of shared decision-making.

2.20 For people to be able to take increased personal responsibility and fully participate in decision-making, they need information and support that enables them to understand clearly both their own situation and the options open to them. Many clinicians and care professionals are already skilled in shared decision-making and comfortable with patients seeking information and advice outside the consultation. They will support their patients, especially those with long-term conditions, to become their own first line of healthcare. As a routine part of their practice, care professionals should support and encourage self-care, signposting patients and service users to reputable information sources such as information prescriptions[18] and other resources such as patient decision aids. They should encourage people to explore such resources in their own time and, if they wish, with their family.

2.21 Many patients and service users will continue to look to their health and adult social care professionals to provide information and advice, and some will prefer this to be face-to-face. Getting the balance right between presenting options and offering views on the best option has always been a particular challenge for care professionals and is likely to become more so in the future.

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[17] See http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113613

[18] See http://www.nhs.uk/aboutnhschoices/professionals/healthandcareprofessionals/other%20resources/pages/information-prescription-service.aspx

2.22 Shared decision-making is not about imposing responsibilities onto people when they feel least equipped to deal with them. Often people find that they need to make decisions about health and care at a time of anxiety and uncertainty for them and their family. Getting the right information at the right time is not just a matter of matching information to individuals or groups, it is also about communicating with sensitivity and tact, and working with people to provide the support they need to make decisions and manage their own health and care.

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

Information for patient and service user choice

2.23 Informed decision-making, either alone or with a care professional, requires access to good quality information, presented in an intelligible way. The kinds of information that people will use depends on the choices they face and their personal preferences. As more information becomes available about the things that matter to patients and service users, we expect to see them using it to help them make choices about their care. Work carried out with users by NHS Choices indicates the breadth of information that people might be interested in, relating to:

- their own health status or condition;
- suitable medicines, treatments, and any risks, benefits and side effects;
- clinical outcomes and success rates, such as readmission or mortality rates;
- other indicators of quality and performance, such as infection rates;
- the availability of appropriate treatment or care in different locations;
- average and maximum expected waiting times for different aspects of their care or treatment;
- the track record, expertise and experience of clinicians or other professionals providing their care or treatment;
- for those with multiple care needs, how their package of care will be co-ordinated;
- the experiences of other patients, friends and relatives;
- the experiences of staff in the organisation providing their care;
- the views and advice of their GP or other care professionals;
- the care environment, particularly facilities, food and catering, and cleanliness; and
- the convenience of services, such as location, accessibility by public transport or availability and cost of car parking.

2.24 Much of this information can be recorded and presented in statistical and comparable ways, but we also need to recognise the power of qualitative information which, in its richness and detail, can support people in making choices about their treatment and care. Information prescriptions are an important means of providing this information, and we will explore how their use can be extended across health and social care services[19].

More than 30,000 people have heart surgery in the United Kingdom each year. Understanding the benefits and the risks associated with different types of heart surgery is important for all patients. The 'Heart Surgery in the United Kingdom' website (http://heartsurgery.cqc.org.uk/) provides important information about the rates of survival for patients who have had certain types of heart surgery at different surgical units across the UK. It also provides general information about different operations, the benefits of having heart surgery and details about what to expect after you have had an operation.

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?

2.25 Patients, service users and carers should be able to access the information they want through a range of media, to help ensure that no individual or section of the community is left out. External partners will be encouraged to provide information to support patient and service user choice in a range of formats. The availability of information and how it is accessed is discussed in more detail in chapter five.

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[19] See http://www.nhs.uk/aboutnhschoices/professionals/healthandcareprofessionals/other%20resources/pages/information-prescription-service.aspx

Information for carers, parents and guardians

2.26 Carers, parents and others play a vital role in supporting those with health and social care needs, but their own needs (including their information needs) can often be overlooked. Many will be caring for people who need a range of health and care services. Clinicians and care professionals can play a vital role in ensuring that those who care for others are identified at an early stage, and that they are signposted towards accurate, timely and useful information.

2.27 Health outcomes improve when carers and parents are better informed about the conditions of those they care for, the services available to them, and how to maintain their own life and health alongside their caring role. High quality information for those carers is, therefore, a critical element of the information revolution. We want to build on successful work, such as that of Carers Direct, in partnership with carers themselves and the organisations representing them.

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

Information for better prevention, self-care and healthier lives

2.28 There are some 300 million GP consultations each year, at an estimated cost of £2billion, involving patients with minor conditions. The majority will have a genuine need to see their GP, but if only a small proportion of the others were able to self-care, the benefits to them and their GP in terms of convenience, time and resource would be considerable. The availability of good information and advice is crucial to this. Services like NHS Direct, the new NHS 111 service[20] and NHS Choices[21] provide such information and advice, as do services from the voluntary sector and elsewhere.

2.29 The number of people in England with at least one long-term medical condition is set to grow from around 15.5 million to around 18 million in the next 15-20 years. The majority of this growth will be attributed to people with more than one long-term condition. The available evidence shows that where patients are able to develop self-care skills, service use reduces and quality of

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[20] The aim of 111 is to end the confusion over which services are available when and provide people with just two simple numbers to remember. For emergencies, people will continue to dial 999 ; for anything else, they will dial 111. When NHS 111 is rolled out nationally, it will replace NHS Direct's 0845 4647 telephone service. NHS 111 became available to people in County Durham and Darlington on 23rd August 2010. Later in 2010 we will launch the service in Nottingham City, Lincolnshire and Luton. This will help us understand what works best for patients and delivers value for money before rolling out nationally.

[21] See www.nhs.uk

life improves. People are more likely to engage appropriately with care professionals and receive the care they want and need. Good support, training and education - backed by relevant, accessible information and support - are the basis for improvements of this kind. The QIPP[22] long-term conditions programme is already working with local health communities to ensure patients have access to information and knowledge to help them manage their conditions and avoid inappropriate hospital admissions.

2.30 Assistive technologies, such as telehealth and telecare, support independent living. Through remote monitoring (eg. movement monitors), they support people with challenging long-term conditions to continue with their everyday lives[23]. Significantly, they help health professionals identify problems early and therefore avoid unplanned admissions to hospital. Devices, such as home-based blood-pressure monitors, can be an effective and, in some cases, relatively inexpensive way to support self-care, especially when deployed as part of a coordinated patient service. The Department of Health is currently managing the largest randomised control trial of telehealth and telecare anywhere in the world, with results expected in Spring 2011 that will influence service developments.

2.31 As the balance of health and care need increasingly shifts towards those people with long-term need, many of them will look to health and care services to be a part of the support network available to them rather than to provide a cure for a particular illness. The level, quality and variety of sources of information expected by individuals are likely to increase substantially.

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?

Information for healthier lives and the wider health of the population

2.32 We need to see information as a crucial resource for living healthy and independent lives. While, in some cases, it is enough to provide the basic

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[22] See http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPPworkstreams/index.htm

[23] **Telehealth** consists of electronic sensors or equipment that monitor people's health in their own home, for example equipment to monitor blood pressure or blood oxygen levels. These measures are then automatically transmitted to a clinician who can observe health status without the patient leaving home. **Telecare** consists of electronic sensors and aids that make the home environment safer so that people can live at home, independently, for longer. The sensor automatically raises the alarm by contacting a family member, friend, neighbour or warden (in sheltered housing). For further information on the 'Whole Systems Demonstrators' for telecare, telehealth and the management of long-term conditions see http://www.wsdactionnetwork.org.uk/.

facts, in others there is a need for the proactive, tailored provision of information. In the past, healthy-living information has been provided through large mass media campaigns, but there may be more cost-effective means. The Government is exploring new models that involve partnerships with industry, drawing on their resources and expertise. This new approach will be demonstrated first in the future direction of Change4Life. One of the benefits of giving people greater control over their records is the potential use of records as the basis for active personal health plans. Information, when used creatively and in a way that goes with the grain of human habits, can be genuinely transformative, and a means of helping people to take greater responsibility for their own health and well-being.

2.33 We also need to recognise that a great deal of the information that shapes our health and well-being decisions comes from outside the NHS. For children and young people, for example, schools are often far more significant channels for health information than health services. There is a role society as a whole to consider how the information we provide (and the ways we provide it) could be used to enhance the health and well-being of others.

2.34 The new Public Health Service will play a critical role in bringing together public health information to support local authorities, commissioners and policy-makers. Recognising and strengthening the links between the information generated by the NHS and by public health professionals and organisations will be at the heart of improving outcomes and population health, and will also help narrow health inequalities.

2.35 The creation of a new Public Health Service will provide the opportunity and leadership needed to help align those information systems that support the NHS with those geared towards prevention and public health functions. There are already many effective links in place, not least in relation to commissioning, but we believe there is further scope for using public health information to improve health service outcomes, and for using health service information to improve our responses to public health issues.

2.36 Further detail on our information, evaluation and evidence strategy for public health will be set out in the Public Health White Paper due later in 2010.

3. Information for improved outcomes

A new focus on outcomes: the role of information

3.1 Both *Liberating the NHS*[24] and the consultation document *Transparency in outcomes – a framework for the NHS*[25] signal a wholesale shift of focus away from improving processes and towards improving outcomes. This will free the NHS to work on what really matters to patients and clinicians. The NHS Outcomes Framework will focus accountabilities within the NHS on outcomes. True accountability can only be achieved if it is supported by transparency. People must be able to access information on how the NHS is delivering against outcomes.

3.2 The recent report of the National Quality Board *Information on the Quality of Services*[26] has been important in shaping this approach. We will also build on existing good practice, including the often-excellent work of the voluntary sector. The development of outcomes frameworks for adult social care and public health will provide complementary sets of outcome data that will also generate information. Improvements in the ways in which different forms of data are collected and linked will be necessary, in order to derive effective outcome measures. In some cases, this may mean not collecting more data but collecting different data. It will also be imperative that outcome indicators or measures derived from NICE Quality Standards are developed using approved national informatics standards.

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?

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[24] See www.dh.gov.uk/liberatingthenhs

[25] See www.dh.gov.uk/liberatingthenhs

[26] See http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_117318 for the NQB report.

Quality Accounts

3.3 A Quality Account is an annual report to the public from providers of NHS healthcare about the quality and outcomes of their services. It allows managers, clinicians and staff to demonstrate their commitment to continuous, evidence-based quality improvement. The first Quality Accounts have been published, covering providers of acute NHS services. Following the evaluation of the current pilots, we will consider extending them to other sectors. We are exploring how this approach could be applied to providers of care and support services.

3.4 We will consider how the mandated content of Quality Accounts can be amended to make it easier to compare outcomes. Once the Outcomes Framework and NICE Quality Standards are established, we could mandate providers to report on them in Quality Accounts. This would create a mechanism for transparent comparability of provider outcomes for patients and increased standardisation of Quality Accounts. We want Quality Accounts to evolve over time and, like financial accounts, become more standardised as organisations gain experience in this type of reporting. This will involve identifying and promoting the use of common standards, for example, best practice in benchmarking providers' performance against their peers - to encourage better local scrutiny.

A 'Clinical Dashboard' is a toolset of visual displays developed to provide clinicians with the relevant and timely information they need to inform daily decisions that improve quality of patient care. The dashboard gives clinicians easy access to a wealth of NHS data captured locally, in a visual and usable format, whenever they need it. By bringing together information from a range of sources, Clinical Dashboards save time and resources, as has been demonstrated at a Portsmouth hospital, where comments include:

> *"Clinical Dashboards have helped me as a clinician as I now have more finely tuned information available to me, without having to spend valuable time sifting through different charts and graphs."*
>
> *"This metric allowed us to make improvements to the way we managed neurology outpatients, that were based on actual clinical evidence rather than a trial and error method that has previously being used."*
>
> *"It was fantastic to see IT being intelligently used to benefit both staff and patients."*

Reviewing central data collections

3.5 In answering the question ‘how much does this service improve the lives of those who use it?’ the challenge is not necessarily to generate new forms of data. For example, in the proposals for the new NHS Outcomes Framework set out in *Transparency in outcomes*[27], we make it clear that the starting point will be data that is already collected by the NHS. This will also be the starting point for our approach to adult social care. The challenge is to take a comprehensive look at the information already circulating within the system to determine whether it is the right information to be capturing. That is why we are undertaking fundamental reviews of NHS and adult social care data returns. Over time, we will also need to review whether different data need to be collected that better reflect care outcomes. A public consultation in 2011 will lead to a set of data returns that meets one or more of the following criteria:

- is essential to and necessarily generated as part of the care giving process;
- helps achieve a key priority, focusing on outcomes/NICE Quality Standards;
- provides comparable information about the quality of services;
- supports and empowers patients and service users to make informed choices;
- is required to fulfil a statutory obligation; and
- supports more efficient stewardship of public money.

3.6 For adult social care, there is a twin-track approach. With immediate effect, we will conduct a rapid review of existing data to remove unnecessary data items and reduce compliance costs. This rapid review, conducted in consultation with local authorities, will determine the social care dataset from April 2011. Concurrently, we will launch a fundamental 'zero-based' review of social care data requirements, aiming to identify the social care data that should be shared beyond local level in the future.

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

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[27] See www.dh.gov.uk/liberatingthenhs

Patient and service user generated information

3.7 In order to rebalance health and care information in favour of outcomes, the NHS and adult social care will need to focus more strongly on a number of sources of information, and be innovative in using it. It will include information collected from staff and patients or service users through surveys, real-time feedback, ratings of services, and Patient Reported Outcome Measures (PROMs). With appropriate consent, it will also include information collated from individual care records. This will complement information from patients, service users and carers available on online services such as *iWantGreatCare*[28] and *Patient Opinion*[29].

3.8 Patient and service user-generated information provides a rich source of intelligence that can be used to improve services. The experience of other sectors clearly shows that strong user feedback can have a positive impact on the design of products and services. A number of organisations, particularly in the voluntary sector, have an excellent track record of providing patient and service user generated insight. This kind of information has the potential to improve services and, when used within a strong framework governed by the principles of human rights legislation, to improve autonomy and control.

3.9 Service user feedback, when used effectively, also provides a basis for people to enter into a dialogue with their care providers, involving them squarely in decisions about their care and the way it is delivered. This is already a reality in some parts of the NHS[30], where a range of service providers have well-used internet based comment services. In addition, a number of independent organisations are already supplying real time feedback at or near the point of care to providers of NHS services.

3.10 Patient Reported Outcome Measures (PROMs) provide information about the quality of care from the patient's perspective. We want to extend them to a far wider range of patients. In the past, patient quality measures were often limited to adult services and the patient's experience of care. Wherever possible, we want to use PROMs (and other patient reported information) in the NHS Outcomes Framework to judge not only the patient experience, but also how clinically effective care has been. Over time, we will ensure that the experiences and priorities of children and their families are captured in

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[28] See http://www.iwantgreatcare.org/

[29] See http://www.patientopinion.org.uk/

[30] Methods include both quantitative and qualitative feedback and range from 'prompt' cards, surveys, SMS texting, hand-held feedback devices to focus groups, interviews and video blogs. An important form of feedback is also available through the formal complaints arrangements and through the comments, concerns and compliments put directly to frontline staff or to the Patient Advice and Liaison Service (PALS).

consistent and comprehensive ways - eg. through national clinical audits, surveys, feedback at or near the point of care, expanded use of PROMs, and internet based approaches[31].

3.11 *Liberating the NHS* included a commitment to enabling patients to rate services and clinical departments. Current evidence suggests that patient and service user feedback has not yet reached a sufficient level in most settings to start shaping and influencing services, as envisaged in *Liberating the NHS*. We will explore how to encourage service users and their families to give feedback at or near the point of care and as close to real time as possible. We will also explore with the NHS and with social care bodies how feedback can be used more widely to compare services, and how we can incentivise use of this information to improve service delivery and design.

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?

Information for commissioning

3.12 Good commissioning involves using the resources available to secure the highest quality services and best possible care outcomes for a local population. It relies on high quality, timely data about needs and services. It also relies on being able to benchmark effectively against comparable areas. *The NHS Atlas of Variation*, to be published shortly, will be an important step in supporting this.

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[31] For the role of information in relation to services for children and young people, see
Sir Ian Kennedy's report *Getting it right for children and young people - Overcoming cultural barriers in the NHS so as to meet their needs*
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119445 - and
the Department of Health's engagement document *Achieving Equity and Excellence for Children*
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119449

3.13 *Liberating the NHS* proposes devolving responsibility for commissioning most NHS healthcare services to GP consortia[32], working in collaboration with other health and care professionals, with patients and with the public. Under these proposals, it will be vital to ensure that commissioners have the right information available to understand patient needs and provision options, and to monitor outcomes.

3.14 High quality commissioning will depend upon information provided as a by-product of individual clinician-patient decisions - eg. by combining information from the 300 million consultations that take place yearly within general practice with information from a wider range of healthcare services that patients receive. GP practices are well placed to use summary information (from their own records and other sources) to analyse the relationship between patient needs, services provided, resources used, and the outcomes achieved.

3.15 *Liberating the NHS* also proposes a stronger role for local authorities in relation to health improvement, and in leading work to promote integration of health and social care. Under these proposals, local authorities and local Directors of Public Health will play a vital role in leading the Joint Strategic Needs Assessment (JSNA) and in providing public health data that will underpin NHS commissioning decisions. Commissioners will be expected to link plans in the context of the JSNA. At a local level, the JSNA will continue to be the foundation process that provides the 'health and well being narrative' of an area, describing the health and well being needs of communities and how these are being met. It must be accessible to professionals, commissioners, elected members and members of the public as a key tool in the new arrangements for local democratic accountability in health.

3.16 We also envisage a stronger role for local authorities in promoting greater integration of care, particularly for people with more complex needs that cross the boundaries of health and social care, and for local authorities and the proposed local HealthWatch arrangements in helping provide accountability to local people and communities. Information will be a critical factor in making these relationships work: sharing data, intelligence and developing a better understanding of local needs and preferences across service boundaries will be vital to improving outcomes.

3.17 The NHS Outcomes Framework, the proposed Commissioning Outcomes Framework, NICE Quality Standards, and information relating to optimal care pathways will be important sources of information for commissioners. It is likely that the front-line perspective of GPs as commissioners will lead to new

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[32] See *Liberating the NHS: commissioning for patients - consultation on proposals* www.dh.gov.uk/liberatingthenhs

ways of looking at information for commissioning. This fresh perspective, combined with a more open environment for information providers, should foster innovative uses of information in both health and adult social care commissioning. Commissioners will be able to draw on national and local quality data in order to agree quality improvement goals with service providers (including through the Commissioning for Quality and Innovation (CQUIN) payment framework)[33].

3.18 *Liberating the NHS* proposes that the NHS Commissioning Board should commission GP services, other family health services (ie. dental, pharmacy and ophthalmic services), national and regional specialised services and maternity services. To undertake this role, the NHS Commissioning Board will need access to robust data to hold providers to account for quality and outcomes and to support people in making informed choices.

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?

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[33] Agreed CQUIN schemes will be publicly available through Quality Accounts

4. Information for professionals

Defining a common information agenda

4.1 The active involvement of clinicians and other care professionals is essential in developing information systems and requirements if we are to ensure that information improves quality.

4.2 For professionals and teams to offer high quality, safe, individualised care, they need access to a single source of information about patients and service users. One of the cornerstones of safe, high quality care is the account of the dialogues over time between the patient or service user and his/her clinician or care professional. It should include the decisions made, actions taken, and outcomes achieved. It should be accessible whatever the care setting. Information should be entered at the point of care by patients, service users, clinicians and care professionals.

4.3 Technologies in use today can simplify the recording of clinical information. Voice recognition software is used to great effect in a number of clinical settings. Significant improvements are expected in devices to allow touch and even gesture input of information into computers. Suppliers of information systems need to be encouraged to adopt these and other technologies so that clinicians can enter information at the point of care without interrupting the care process. Much has already been achieved and this work needs to continue to evolve, incorporating new standards as they emerge.

Improving data quality: the role of professionals

4.4 In order to achieve the benefits of the information revolution, clinicians and other care professionals need to continue to play an active role in developing information solutions that are safe, that work for patients and service users and that help improve outcomes. The new approaches need to be based on clinically governed standards and accurate recording of data. NHS and adult social care services have a vast amount of data flowing through them, but much of it does little to inform those who provide and use services about the things that matter to them. Given that we will only preserve data that is actually helpful for improving outcomes rather than simply the consequence of policy initiatives or historic collection exercises, there will be a strong incentive to make the data we continue to collect as powerful as possible. Such data should be generated at the point of care by clinicians and other care professionals, with a commitment to ensuring that it is of the highest quality.

4.5 More broadly, we know that the most innovative and authoritative forms of information are often generated by clinicians and care professionals themselves. A greater focus on outcomes relies on clinicians and other care professionals developing information of a new and powerful kind. The responsibility to ensure basic data quality will be accompanied by a real opportunity to turn that data into meaningful information for clinicians, care professionals and others.

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?

The use of evidence

4.6 In order to grasp the opportunities offered by the information revolution, clinicians and care professionals need to be able to access the best evidence (including international evidence) of outcomes, interventions and risks. Evidence needs to be user-friendly, up-to-date and available at the point of care, to inform discussions with patients and service users. Evidence is increasingly available in many forms, such as decision support, diagnostic interpretation, alerts such as those relating to drug doses and interactions and evaluation of therapeutic options. Individual professionals, teams and organisations need to be supported to access information of this kind, which can make all the difference in ensuring safety and effective outcomes.

4.7 Clinical and other staff need to use data to help improve the services they deliver and address inequalities, particularly in the outcomes of care. As the information strategy develops, it will need to take account of existing good practice in developing and using quality indicators as the bedrock of robust quality measurement. Such indicators should address key aspects of patient pathways including, where appropriate, looking at how efficiently services are being delivered. It will also be important to build on the Indicators for Quality Improvement library and other resources held by the Health and Social Care Information Centre (the Information Centre), by regional Quality Observatories, by other commercial data providers and by the Social Care Institute for Excellence (SCIE).

NHS Evidence is an on-line portal provided by the National Institute of Health and Clinical Excellence (NICE) that empowers staff with national and international best evidence and best practice information. The evidence is quality assured and made available both in its original form and through guidelines, pathways, tools and other resources. As NHS Evidence is expanded and developed all NHS staff, and others, will have free access to authoritative clinical and non-clinical evidence and best practice - available to support discussions and decisions at the point of care - as well as informing strategic planning and commissioning. It is an important addition to commercially provided data services (which are often subscription-based and aimed at particular specialist audiences). We intend to continue expanding and improving this service.

The Information Centre has been developing the ‘Consultant Team Summary Report’ tool. This web-based tool encourages consultants to share their hospital information, and provides hospital consultants with secure online access to twelve key indicators in three broad categories – inpatient information, outpatient information and information about Payment by Results (PbR). Each indicator enables consultants to compare their own performance to that of their peers benchmarked against the national average.

Clinical audit

4.8 The role of clinical audit in comparing the effectiveness of different clinical approaches and in identifying areas for quality improvement is critical and we expect to see participation in clinical audit as a professional norm. Data captured through national and local audit processes - wherever possible, through automatic processes - should be widely available (eg. to researchers, regulators, clinical professions, information providers) and also used to inform Quality Accounts. Clinical audit should support clinicians to develop a richer set of information relevant to patients. We will consider how to ensure that care providers recognise the importance of supporting participation in clinical audits (including making it more explicit that the cost of subscribing to national clinical audits is counted as a reference cost for the tariff).

Telling patients and services users if something has gone wrong

4.9 Open and honest communication with patients and service users is at the heart of high quality care and research in health has shown that being open when things go wrong can help patients and staff to cope better with the after effects of a patient safety incident. We have therefore made it clear that we will require hospitals to be open about mistakes and tell patients if something has gone wrong. We are working with external partners to develop options to build on existing good work to take this agenda forward. Listening to people when something has gone wrong, and learning from what they say, are also critical.

Staff feedback

4.10 There is a great deal that commissioners, care providers and users of health and care services can learn from staff feedback. The information about hospitals provided by NHS Choices, for example, currently includes staff survey indicators such as the proportion of staff agreeing that they would be happy for a friend or relative to be treated at that hospital. We plan to introduce greater transparency in the use of staff feedback. We want to work with staff, patients, service users, the public and interested organisations to identify the best forms of staff feedback to be used for national comparisons.

Research

4.11 Research is vital in providing the new knowledge needed to improve health and care outcomes and reduce inequalities. When resources are under pressure, research can identify new ways of preventing, diagnosing, treating and managing disease. Research is essential to increasing quality and productivity of the NHS and social care services[34] and supports growth in the economy. Outcomes will improve most rapidly when clinicians and care professionals are engaged so that creativity, research participation and professionalism are allowed to flourish.

4.12 Electronic care records and the wealth of structured data within them are potentially rich resources for applied research - for example, by making aggregated, anonymised data available to universities and other authorised researchers. There is also great potential to build new knowledge that will improve health outcomes and to identify new areas for research. The Government is considering how to provide a high quality research data service that will harness this potential.

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?

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[34] Social care researchers have been concerned for some time about the relative lack of data available to them at a national level, and the Department of Health is considering ways of improving this

Informatics workforce capacity and capability

4.13 It is staff who will lead the information revolution. Information management and IT capability will be essential. Strong leadership is needed from CEOs and Boards, clinical leaders and leaders of the information and IT professions. They will need to create a culture within their organisations where information is seen as the lifeblood. We will work with regulatory bodies, professional organisations and non-clinical training bodies to improve the skills of staff and also to embed informatics skills into the workforce and into professional regulation.

4.14 Information can not be seen as something that is the sole responsibility of the specialist. Information is a vital component of all care and business processes and all staff need to have the right capabilities to understand its relevance, adopt up-to-date practices and use new technologies. Developing these capabilities should primarily be a local responsibility, supported by easy access to best practice and other resources to create a momentum for change. Commissioners, general managers, clinicians and other care professionals will all need to have informatics skills to ensure that the information revolution is successful.

4.15 To improve the quality of care, those who collect, record, store, analyse and present data must understand the impact on care of poor quality data. All staff working in health and adult social care will need to understand and value the contribution data can make to improving outcomes. As a key component of assuring data quality, national education and training in approved informatics standards will need to be available.

4.16 Information and IT services vary in their size, structure and function as well as in their level of maturity. They range from mature health informatics services to relatively small IT functions whose primary focus is to keep the current infrastructure running as cheaply as possible. There is a need to raise standards by making informatics development part of core planning for health and care organisations as well as external providers of NHS care. Senior managers in these informatics functions will need high-level strategic leadership abilities to establish a business-based dialogue with their organisations.

4.17 Industry recognised competence frameworks will help identify the requirements for recruitment, development and retention of skilled informatics professionals, coupled with the developing Health Informatics Career Framework[35]. In the new environment of greater local autonomy and system choice, IT professionals will need to assume even more influential roles in helping to define local informatics strategies which are closely linked to local

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[35] See http://www.hicf.org.uk/

health strategies. They will need to deal with a plural supplier marketplace and the commercial and informatics complexities that arise.

4.18 The most important resources to drive the information revolution are the hundreds of thousands of people who work within our care services. As we embrace new information technologies and the principle of shared decision-making, we must recognise that many patients, service users and carers will either need or prefer face-to-face contact. It is clear that the communications skills of clinicians and practitioners will continue to be a central part of their practice and professional development.

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

5. Information for autonomy, accountability and democratic legitimacy

Information for shaping services and holding them to account

5.1 *Liberating the NHS* sets out our commitment to free NHS organisations and staff from the direct control of Whitehall. They will be autonomous and locally accountable. A fundamental requirement for this accountability will be a ‘presumption of openness’ across health and adult social care. NHS and adult social care organisations should deliver the fullest possible public access to the information they hold as soon as possible, adopting a ‘publish and improve’ rather than a ‘polish and publish’ approach. This will promote choice and shared decision-making, and will also enable improved scrutiny and accountability at local and national levels. Of course, personal information will continue to be subject to strict security arrangements.

5.2 Greater transparency and more widespread publication of information will provide valuable material to enable patients, service users, carers and the public to influence the shape and direction of local services. Their role in influencing local services starts with (but is not confined to) the care setting, where a culture of shared decision-making will increasingly make direct feedback to clinicians and practitioners a normal part of the care process.

5.3 As well as direct interaction of this kind to close the ‘feedback loop’, the development of a much stronger role for local authorities in holding the local NHS to account and improving integrated working (as set out in *Liberating the NHS: Local democratic legitimacy in health*[36]) will create a demand for information and insight. The publication of high quality information about services and outcomes will be critical to local authorities successfully discharging their new responsibilities. Where the published information gives cause for concern, the proposed Local HealthWatch will be able to draw it to the attention of commissioners and regulators.

5.4 At a national level, HealthWatch England will advise the NHS Commissioning Board about the information that will be needed to enhance accountability and support the shift to a patient-led NHS. Also at a national level, the Outcomes Framework will provide the basis for the Secretary of State for Health to hold the NHS Commissioning Board to account. Information requirements for the Outcomes Framework are being developed through the consultation process launched by *Transparency in Outcomes*[37] to support national accountability.

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[36] See www.dh.gov.uk/liberatingthenhs

[37] See www.dh.gov.uk/liberatingthenhs

The ‘presumption of openness’

5.5 Improving the supply and quality of information for all is not, however, simply a matter of compliance with legal or other requirements. It is also about radically altering the ways in which information products are supplied to different individuals and groups. For too long:

- data collected by the Department of Health and its Arms Length Bodies has been subject to variable access arrangements, impeding public scrutiny of health and adult social care services; and
- data that has not been formally published has become available in an ad-hoc manner, which has not facilitated meaningful comparisons between the performance of different services.

5.6 Government, therefore, has its part to play in making more of data. Making data more readily available to the public, to information ‘intermediaries’ and to innovators, will support the development of a far more vibrant and open environment for the provision of information products and innovative ways of exploiting data for the benefit of health and social care services. The more plural, market-based approach to information will foster the growth of a far greater range of digital services, supporting innovation, care closer to home and individual autonomy.

5.7 Routine and regular publication of nationally and locally held datasets will:

- encourage more accurate recording of data by clinicians and other care professionals as the data will be more likely to come under scrutiny;
- enable easier benchmarking of performance and learning between clinicians and care professionals, thus raising the standard of care;
- make it easier for organisations, such as those representing patients and service users, to access and analyse data about the quality of services and turn it into information that the public can readily access;
- encourage poorly performing health and care providers to improve their services as they come under increased public scrutiny; and
- stimulate a market for information providers who will develop new and innovative ways of presenting intelligible information to different audiences.

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?

Access to information for all

5.8 Many organisations - including hospitals, local authorities, charities and private sector bodies - already provide a wide range of information on health and social care topics for service users, such as on conditions, lifestyle choices, treatments and symptoms. However many people are put off by the sheer number of websites and are unsure which sources they can trust.

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

5.9 While there is already a range of providers of information on diseases, lifestyle etc, there are very few providers of numerical or rating information that allows people to make choices, for example, between hospitals. Our plans to make NHS-derived data much more freely available will allow new information 'intermediaries' to offer this kind of information in innovative ways that make sense to people. Drawing on models such as The Information Standard[38], we will work with interested parties to explore how we can ensure public trust in what they produce by considering schemes such as voluntary accreditation or industry-owned standards of good practice.

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?

5.10 Along with more diverse information suppliers, we need to encourage more imaginative use of different information and communication 'channels', particularly those enabled by new technology. From relatively simple technologies such as text reminders on mobile phones to more sophisticated web-based options, we are starting to see how people can manage their own condition and make healthy choices without relying as heavily on traditional health and care services.

5.11 To help avoid the overloading or under-provision of information, there will be a need for a 'channel strategy' to provide a coherent view of the nationally-managed channels needed to support access to information. This will need to combine the advantages of a single 'place to go' for health issues of the kind offered by NHS Choices, with the benefits from opening up the analysis and presentation of information to a wider range of information 'intermediaries'.

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[38] The Information Standard is a quality scheme which helps people to identify reliable and trustworthy sources of information on symptoms, diseases, healthy living, diagnostics and treatments, and disability issues - see http://www.theinformationstandard.org

This will also need to take account of the work to put in place the new NHS 111 service[39].

Helping people access information

5.12 Without dedicated action on the part of health and adult social care services, the benefits of greater access to better information will not be enjoyed equally across different groups in society. This is partly about tailoring information to the needs and preferences of different audiences but also about offering support to enable people to make full use of the information available. Social care service users and practitioners have developed a strongly ‘personalised’ approach by providing information and supporting people to use it. That approach must be built on so that people are equipped to make real choices using information that is accessible, reliable, and relevant.

5.13 The ability and willingness of individuals to access and use information about their own health and / or adult social care needs and the services available to support them will always vary greatly. This may be a matter of preference, capability or personal resources. Over a fifth of adults in the UK have never used the internet, so we can not assume that all or most services can be simply transferred online. There are, however, a number of measures that can be taken to enhance the digital reach of services within communities, including the better use of IT infrastructure that is already available in places such as schools, Citizens Advice Bureaux and Post Offices. As access grows, and the cost of basic technology continues to fall there are likely to be significant benefits for all if digital services are commissioned wisely and inclusively as part of a broader set of commissioning decisions[40].

5.14 As part of the information revolution, our ambition is for hospitals to be places where patients and their carers can access information easily - including their own record, as well as information sources to ensure they understand their condition and treatment options. Hospitals and other care providers will need to consider how they can most effectively deliver information to patients and

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[39] The aim of 111 is to end the confusion over which services are available when and provide people with just two simple numbers to remember. For emergencies, people will continue to dial 999 ; for anything else, they will dial 111. When NHS 111 is rolled out nationally, it will replace NHS Direct’s 0845 4647 telephone service. NHS 111 became available to people in County Durham and Darlington on 23rd August 2010. Later in 2010 we will launch the service in Nottingham City, Lincolnshire and Luton. This will help us understand what works best for patients and delivers value for money before rolling out nationally.

[40] For action to widen access to the internet, see *Manifesto for a Networked Nation* at http://raceonline2012.org/manifesto

service users. Increasingly, this could be through the bedside sets and infrastructure used for other media services.

5.15 There is a clear role for all in the ‘information economy’ to ensure that information, and the ways it is provided, are as inclusive as possible and that information is presented in ways that make it accessible to those who need it. The excellent work done to promote inclusion by voluntary organisations, such as the RNIB and Mencap, provides a helpful basis for future work. The relevant statutory duties set out in the Equality Act 2010 provide a clear set of obligations on the part of health and care services. Ensuring that the information needs of people of all backgrounds are adequately and sensitively met will be critical, not only for meeting the obligations of the law, but also in improving outcomes.

5.16 It is vital that the information revolution benefits everyone. Accepting that different people and groups in society access information differently, we need to respond actively to that diversity and ensure the right information is available and in a way that is relevant to those groups who have been, or could be, excluded. At the same time, we must recognise that many people (especially children and young people) are very comfortable using technology and would prefer to access information electronically - and that the information revolution will only take-off if the information and technology fit with people’s needs and attitudes.

5.17 We will publish an equalities impact assessment alongside the information strategy that will follow this consultation process.

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 can not access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages.

Collection and publication of national datasets

5.18 In our review of the Department of Health’s Arms Length Bodies (ALBs)[41], we set out that the Information Centre will become the focal point for national

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[41] See http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117691

data collections for health and social care, taking over data collection responsibilities from other ALBs and central data collectors such as the Department of Health itself. It will become the single, national repository for data collected from NHS and social care organisations, with roles in making health and adult social care data, including aggregated data in standard formats, more accessible. The Information Centre will also have powers to minimise bureaucracy and eradicate duplication in the data that is collected.

5.19 The Information Centre will routinely publish the aggregate data it collects in easy-to-use formats so that organisations presenting information to the public, health and social care organisations, researchers, professional bodies, policy makers and others can access this data for a variety of purposes. It will have the lead responsibility in assuring the accuracy and quality of aggregate data collections against the approved informatics standards set by the NHS Commissioning Board. It will not publish identifiable data, the use of which will continue to be subject to strict procedures to protect confidentiality.

5.20 The National Adult Social Care Intelligence Service (NASCIS) will have an enhanced and integral role within the Information Centre, publishing and disseminating data and developing national minimum datasets for adult social care. People want to receive integrated care across health and care services and do not expect organisational boundaries to impede joined-up care. It is therefore critical that the focus on outcomes is used as a means of driving integration for service users and patients, and we are exploring how we can most effectively link the approach to outcomes across health and social care to achieve this. The Information Centre can also play a role in helping to integrate information across these boundaries.

5.21 To ensure that published information about health and care services is comparable, we expect NHS, private and voluntary sector providers of NHS care to submit data to the Information Centre according to nationally defined standards, set by either the NHS Commissioning Board or the Department of Health. Commissioners will want to ensure through their contracts that the same obligations in relation to data collection are placed on service providers from other sectors as on the NHS.

Early release of national datasets

5.22 While a great deal of data and information is already published routinely about many aspects of health and social care, it is not always done using consistent standards or using formats which enable websites and computers to use this data effectively. For innovation and choice to be catalysts for improvement in health and social care, as it has been in so many other industries, we must enable our data to be used more effectively. That is why, over the course of the next few months, we will be looking to create the means to exploit data from a number of key data sources and to make this material available alongside the substantial body of other data now accessible via the Government's data.gov.uk website.

5.23 As a first priority, working closely with the Information Centre, we plan to release data as listed below.

Data already available includes:

- A significant amount of data from Department of Health Central Returns[42] and Hospital Episode Statistics[43]
- Healthcare Associated Infections data[44]
- Indicators for Quality Improvement data[45]
- Estates and Facilities[46]
- Prescribing costs and activity[47]
- NHS Performance data[48]
- NHS Organisational Reference Data[49]
- Patient Environment data, including hospital cleanliness[50]

Additional data to become widely available by April 2011 includes:

- Inpatient information at provider level (annual, November 2010)
- NHS Choices - Provider Quality Indicators (November 2010)
- Outpatient information at provider level (annual, December 2010)
- Maternity information at provider level (annual, November 2010)
- A&E - additional tables (January 2011)
- Ambulance Status reports (weekly, February 2011)
- Inpatient information at national level for procedures & diagnosis (by April 2011)

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[42] See - http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/DH_077094

[43] See - http://data.gov.uk/dataset/england-nhs-deliveries-by-length-of-gestation-and-method-of-onset-of-labour-2007-08 & via http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=1132

[44] See - http://data.gov.uk/dataset/mandatory_surveillance_of_mrsa_bacteraemia_and_clostridium_difficile_ http://data.gov.uk/dataset/nhs-meticillin-resistant-staphylococcus-aureus-bacteraemia-dataset-monthly

[45] See - http://data.gov.uk/dataset/england-nhs-measuring-for-quality-improvement & via https://mqi.ic.nhs.uk/

[46] See – www.hefs.ic.nhs.uk

[47] See - http://www.ic.nhs.uk/statistics-and-data-collections/primary-care/prescriptions/primary-care-trust-prescribing-for-april-to-june-2010

[48] See - http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/Performancedataandstatistics/index.htm

[49] See - http://data.gov.uk/dataset/england-nhs-connecting-for-health-organisation-data-service-data-files-of-nhsorganisations

[50] See - http://www.nrls.npsa.nhs.uk/patient-safety-data/peat/

Data to become available from 2011/12 onwards includes:

- Cancer Registries and Cancer Datasets
- Information about mixed sex accommodation
- National Clinical Audit
- NHS Choices Directories
- NHS Reference Cost data
- Financial Information Management (FIMS)
- Reference data (eg. population and demographic data in more useable forms)

5.24 More data is likely to become available from each of these sources over time. As one example, we will extend our system of Healthcare Associated Infections mandatory reporting to include Meticillin Sensitive Staphylococcus Aureus (MSSA) from January 2011, with others like E.coli to follow in line with expert advice. We will of course make sure that any data released is subject to strict information governance principles and does not allow access to person-identifiable or confidential information. This is simply the start of a sustained programme of making more central datasets routinely available in machine-readable form, which we believe will be a key enabler of the information revolution for health and adult social care.

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?

Using information technology to drive efficiency

5.25 Information and greater use of digital technologies offers the potential to deliver care more efficiently. As one example, the NHS, with encouragement from the Department of Health, is already implementing patient-level information and costing systems (PLICS). The implementation of PLICS is not mandatory but the Department of Health strongly supports the use of PLICS within the NHS. PLICS will provide organisations with the ability to understand their economic and financial drivers, benchmark their costs in detail against other providers and enable comparisons between different teams dealing with similar patients.

5.26 The implementation of PLICS will also help provide data for Service Line Management (SLM) - a combination of management and business planning techniques used by an increasing number of NHS foundation trusts. An SLM approach enables trusts to look at cost and profitability across a portfolio of services so that they can make informed decisions about how to manage existing services, prioritise new developments or plan investments. The robust reporting systems that underpin SLM give clinicians and managers the information they need to maximise resources and patient benefit.

Digital services

5.27 Modern technology and the more effective management of information offer enormous potential for improving outcomes and bringing greater efficiency to health and adult social care services. The opportunities that digital technologies bring for the direct provision of services are likely to be a particularly fruitful area for innovation and service development now and in the near future.

5.28 Given the financial challenges we face, it will not pay to be timid: these opportunities need to be grasped. But we also need to heed the lesson of recent experience. We must accept that large-scale uptake of particular technological innovations will not happen without local involvement and a clear understanding of the part particular technologies will play in local service redesign. Clinical and care professional involvement is critical, not optional.

5.29 We see the evidence of the transformative power of digital technology all around us. To take just one example, the extraordinary growth of social networking websites in recent years is altering how people interact and sustain relationships, and in ways that were not foreseen, even by the pioneers of the sector. While health and care services have made great strides in adapting new technology to improve outcomes for service users, there is widespread consensus that there is scope to go much further.

5.30 There are five key areas where digital technology could lead to major improvements in services and outcomes:

i) using digital technology to deliver services, and not just information;

ii) making services more convenient and accessible for users by removal of time as a barrier;

iii) making services more convenient and accessible for users by removal of geography as a barrier;

iv) tailoring information and services for particular groups; and

v) improving efficiency across supply chains.

A Yorkshire hospital is delivering care to 17 prisons through a video conferencing link saving on prisoner transport and escort costs.

The Picture, Archiving, and Communications System, which gives instant access to patient x-rays and scans regardless of location, has allowed local team working to be improved in cancer care.

A local innovation, the mobile clinical assistant pilots in the Salford phlebotomist service, has paid for itself within one year.

Service users and support groups can use social networking tools to set up personal portals detailing their needs and interests. They can use these tools either to provide networks across a service type, or in a geographic location, or to link to others with similar interests to share feedback and information which others might find useful. See www.adkc.org.uk (Action Disability Kensington and Chelsea), www.ecdp.org.uk (Essex coalition of disabled people) - a portal set up to support disabled people in Essex, or www.solnetwork.org.uk (Shaping our Lives network), www.ilanet.co.uk (Independent Living Association supporting personal assistants)

Local authorities are looking at ways of setting up virtual "market places" where service providers can publish information about their services. This has already been used successfully for services commissioned by local authorities, and is now being trialled for service users and carers - www.shop4support.com

5.31 The use of technology to support the delivery of care at or closer to home is on the rise, and set to increase further as demographic and service changes start to reshape the health and care system. The Whole System Demonstrator project, which is evaluating the costs of benefits of using telecare in a number of settings, is due to report in May 2011. It is taking a comprehensive look at the key elements for implementing effective telecare services (workforce development, quality and ethical standards, interoperability and integration, incentives and levers, awareness and market development). A number of other projects initiated as part of the Quality, Innovation, Productivity and Prevention (QIPP) programme have also started to show early promise[51].

5.32 There are clear benefits to both service users and service providers in the greater use of digital services as part of local service improvement and redesign. For service users, some of the key benefits are convenient access, reduction or removal of travel time, less time off work and more personalised care. For professionals, the key benefits relate to clinical effectiveness, the quality of care and efficiency. Even simple initiatives such as the use of text messages as appointment reminders can have a significant impact.

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[51] For example, the introduction of SMS appointment reminders at Addenbrookes Hospital which reduced non-attendance by 50%. The Picture, Archiving and Communication System has developed remote collaboration to support improvements in local team working in cancer care.

6. Setting the Direction - The Information Strategy

6.1 This document has set out some of the overall principles by which we plan to develop a comprehensive information strategy to deliver the information revolution as envisaged by *Liberating the NHS,* and has identified some of the associated challenges. Based on consultation and feedback resulting from this, we will then seek to put that strategy into action.

6.2 The information strategy can not be based on a philosophy of central control. The lighter touch governance approach will set the framework for the NHS and the wider marketplace, and help ensure accountability for the information provided. Underpinning this will be a vibrant, self-sustaining, information architecture that delivers value for citizens.

A new information architecture: standards, interoperability and market development

6.3 An 'information architecture' for the NHS and adult social care is the product of a number of interacting factors. They include standards set by central bodies (including professional standards) and the information needs of users and providers of services, commissioners, regulators and others. Standards need to be set to support innovation, improved outcomes, comparability and efficiency. Some of the key issues are set out in high-level form below.

6.4 For the information revolution to succeed, we will need to attract a far wider range of information providers. Information markets require agreed standards and rules covering basic matters. The key issues are:

- Ensuring basic data meets necessary standards;
- Use of a unique identifier - ie. the NHS Number; and
- 'Interoperability' - allowing information to move freely and meaningfully through the system.

6.5 The NHS Commissioning Board will set and maintain a portfolio of national information standards for the NHS, with the Department of Health setting equivalent information standards for social care and for public health services. Wherever possible, these national standards should be based on or adopted from international standards, to facilitate achievement of international best practice.

Accuracy of data as a bedrock for meaningful information

6.6 **Information needs to be based on accurate data**. Today, the majority of data collection relies on either paper-based processes or on entering data in different ways into electronic systems. It is not uncommon for the same information to be entered on multiple paper forms and then entered again into electronic systems long after the event. Inaccurate data collection contaminates the whole pool of information, and devalues even the good data in the pool. Poor data should be expressly barred from use, and actions taken to improve it.

6.7 We need to establish the principle of **recording data once and using it in many ways**. In the retail sector, sale of an item is recorded once at the point of sale and then used to update stock levels, trigger re-orders and provide information on buying habits. It can even be used to profile an individual customer’s buying habits. In the same way, recording the administration of a drug to a patient by a hospital pharmacist could be used to record the treatment for future clinical consultations, update stock levels for the drug, monitor drug usage for certain diseases, form part of the information that leads to optimum tariff structures for treatment and be used in research to determine clinical best practice..

6.8 Collecting data accurately need not be more expensive and difficult. However, it will often involve revising processes and making existing information more readily available. Airlines today can check passengers in and get them on a plane without any worker entering data on behalf of the passenger; similar approaches are being developed to smooth the admission of patients into hospitals. Automating the flow of information with patients and citizens in the health and social care system could, in many cases, save time and allow workers to focus more fully on the delivery of care.

6.9 There are other opportunities to improve efficiency. Describing quality standards in ways that computers can readily understand could help minimise both the burden of data transcription and mapping associated with implementing NICE standards, as well as the associated costs.

6.10 As well as improving efficiency, other critical benefits that will flow from accurate data include:

- increased availability of high-quality data and information to support research; and
- increasingly consistent coding; enabling:
  - better decision-support; and
  - greater choice for patients and service users.

Deriving information from data

6.11 In terms of information architecture and practice, rather than creating a special dataset for each type of use, the way forward will be to collect data routinely as part of care and use it for other purposes. Ultimately, all outcome and quality indicators should be derived from accurately collected data, wherever possible collected at the point of care. It should be possible, for example, to see how a particular set of diagnoses and interventions have been used by commissioners to arrive at a recommended tariff.

6.12 Some of the delays in gaining access to datasets will be reduced as publication of data extracts become automated and routine. It should not be unreasonable to expect the revised outcome framework[52] to be served by new datasets in weeks rather than years, with minimal investment.

Standardising patient and care records

6.13 To achieve efficiency, consistency and comparability, the structure of some key elements of the record of care need to be standardised. This means that the overall structure of records needs to be designed and the designs universally applied.

6.14 Professionally approved standards for the structure of records will be needed. A leading example of this in healthcare is the Professional Record Keeping Standards developed by the Royal College of Physicians on behalf of the Academy of Medical Royal Colleges, determining how key aspects of recording of patient care and transfer of care should take place. Such standards need to be developed and applied throughout the health and social care system.

6.15 Certain parts of the record need to be highly structured. An obvious and relatively simple part is the demographic part of a record. Name(s), date of birth, address(es) and so forth will need to be stored once in a structured form, and only re-entered if there are changes. However, that level of structuring needs to extend to other parts of the record, such as diagnosis or details of an operation.

6.16 The information strategy developed in the light of this consultation will identify key parts of the record that need to be structured in particular ways, and standards for this will be provided.

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[52] See *Transparency in outcomes - a framework for the NHS at* www.dh.gov.uk/liberatingthenhs

6.17 In the medical area, some key elements for early standardisation of recording would be:

- physiological observations;
- pathology and diagnostic imaging results;
- procedures, including surgery;
- medication;
- scheduling / disposition (is the patient admitted, discharged, awaiting a clinic appointment, if so, with whom);
- ‘diagnoses’, such as
  - in secondary care: discharge diagnoses - what the clinician felt was wrong with the patient at the end of the episode; and
  - in primary care: current problems.

The importance of terminologies

6.18 In the automotive industry, cars need to be assembled out of parts that fit together. This is achieved by catalogues of parts with precise specifications, each part having a unique product code. When recording a diagnosis, a clinician should be using precise ‘terminologies’. Terminologies are collections of definitions of anatomy, procedures, diagnoses, tests, medications, and so forth that are maintained and can be loaded into multiple record systems.

6.19 In primary care, the UK is a world leader in recording patient data using terminologies, and this has led to significant improvements in both care and care reporting. Other parts of the world, however, are ahead in the use of terminologies in the acute healthcare sector, though there are areas of good practice in the UK. The information strategy will seek ways of increasing the use of standard terminologies throughout health and social care services.

6.20 One of the challenges will be reducing the number of diverse terminologies in use to a small, consistent suite of terminologies. This is akin to suppliers in the automotive industry using a common parts catalogue. More often than not, it is expensive and difficult to translate between terminologies - for example, there are differences in the structure of some proprietary drug dictionaries. Harmonising the dictionaries or using only one would reduce the number of exceptions and also the extra effort required to manage multiple dictionaries and multiple maps.

6.21 The UK should maintain its leadership in the development and use of terminologies, and extend their utility. As one example, the Systematized

Nomenclature of Medicine (Clinical Terms), known as SNOMED CT, is managed by the International Health Terminology Standards Development Organisations (IHTSDO). It extends the use of Read terminologies, widely used in primary care in the UK, across much of the international healthcare industry. Continued development of SNOMED CT, in partnership with other nations, will standardise much of the content of clinical systems and maximise the opportunities for joint investment and system interoperability.

6.22 But terminologies alone are not sufficient. For example, the results of a pathology test might need to be grouped together with demographic information (eg. the NHS Number) and other information (eg. the requesting clinician and the laboratory that provided the test). There will need to be standards defined for the key parts of the patient record that we need to group in this way.

6.23 Other media will need to be integrated into users' care records, such as a photograph. The UK is a world leader in the electronic storage of digital imaging (eg. X ray images) and the information strategy will need to allow the movement of this type of data around the system.

6.24 Finally, a pragmatic attitude will be critical and not everything that can be structured should be. The information strategy should determine how guidelines are developed to make sure that the best does not become the enemy of the good.

Joining it all together - a unique identifier, the NHS Number

6.25 Because care is no longer restricted to individual organisations working independently, mandating complete adoption of the NHS Number is now more important than ever. We can not link the various parts of a patient's record from different organisations together if they are not stored with a consistent identifier. The NHS Number needs to become as important to care providers as the National Insurance number is to employers and employees. Social care services should also be encouraged to use the NHS Number as an identifier in social care settings so that health and social care can be better coordinated.

Interoperability

6.26 As more and more systems come into the market, interoperability (the ability of different systems to share information) will be more critical than ever. There are clear benefits to defining standards that support sharing between systems on a national basis in collaboration with key partners. We will work with key partners to build on initiatives such as the NHS interoperability toolkit to ensure that the right standards are in place, and that they meet current and future needs. It will be important to ensure that interoperability enables integration with other services such as adult social care.

Getting it right

6.27 The NHS Commissioning Board will be the prime authority for setting of standards for the NHS, and ensuring through the commissioning frameworks that these standards exist, are fit for purpose, and are applied. There is currently a large suite of standards that will be important for delivering the information revolution, and these will need to be developed and maintained. The Department of Health and NHS Commissioning Board will need to ensure the following functions exist:

- management of the whole portfolio of standards, from terminologies through to datasets and record standards;
- commissioning, developing, maintaining and retiring standards;
- assurance of standards as fit for purpose and implementable;
- assurance of the use of standards; and
- support for standards implementation and use, including advice (eg. a help desk), guidance, education and training.

6.28 Some standards will be national, some will be international and some will be specific to the NHS. Some may be developed by, or in conjunction, with the market. There will be a need to establish an overarching mechanism to oversee the range of standards and to ensure these support the information revolution.

6.29 We are not starting from scratch. The information strategy will need to take a view of how current systems and services can be used to help drive the information revolution including:

- Choose and Book, as highlighted in *Liberating the NHS*;
- Electronic Prescription Service, which relies on standardisation of prescription information, particularly through use of the dictionary of medicines + devices (dm+d) in primary care;
- The Personal Demographics Service, which is an important repository of information about NHS patients in England, indexed by the NHS Number;
- Casemix; and
- Payment by Results.

These systems and others will need to be reviewed and integrated into the strategy where appropriate.

Cultural change required to realise the information strategy

6.30 As well as considering more technical issues, the information strategy that follows from this consultation will need to cover cultural issues - eg. those for service users, professionals, commissioners and the public. As reflected in this document, the information revolution will rely on cultural changes to succeed.

What we should expect to see from the information strategy

6.31 Our ambition is that, by 2015, the information strategy will have delivered a number of key improvements, such as those listed below:

- Significant parts of patients' clinical and social care records, including the GP record, will be routinely available to them in electronic form; the information strategy will determine what and how these should be provided;
- Analytical data will move from ad hoc collections driven by policy to automated derivations from electronically stored care records using rigorous and standard transformations and aligned to outcomes;
- The public will have access to accurate information about the services available to them, and the quality of those services. The Information Centre will take a lead role in ensuring that this information is available and conforms to high standards of quality.
- Regulators will be able to monitor the performance of health and social care services, in order to take action in response to failings.
- Clinicians and care professionals will have the information they need to provide safe, high quality care and will adopt professionally-endorsed standards for record keeping.
- The quality and scope of information available for analysis and research will be considerably higher, more comprehensive and based on accurate recording.
- A set of information standards will be easily accessible by all staff and will include a description of all of the standards (including data, information governance, statistical, record keeping, business definitions, identity management, interoperability and security standards) that, for the NHS, have been approved by the NHS Commissioning Board. It will also be clear who is maintaining them, with key channels available so questions from the service and or public can submitted and answered.
- The market should innovate, and not stop at the minimum that the NHS expects. There should be a new culture, which promotes the creation of value through information, where patient choice and patient control of records becomes the driver for all stakeholders to raise their game.

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 A. Consultation questions

Your ideas and practical proposals can help make the information revolution a reality - one that benefits all users of health and adult social care services in England.

We want to hear your views on the consultation document as a whole and in response to any or all of the consultation questions - whether as a patient, service user, carer, clinician, other care professional, information professional, as an organisation or other representative body, or as a member of the public.

We are fully committed to developing and publishing an impact assessment and an equalities impact assessment to accompany the Government's response to this consultation. As part of that process, we very much welcome your views on the potential economic and other benefits that the information revolution can bring - including sustainability, business, rural or equality issues - as well as any concerns that you may have.

We look forward to all responses.

Consultation questions – Chapter 1

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?

Consultation questions – Chapter 2

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?

Consultation questions – Chapter 3

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?

Consultation questions – Chapter 4

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?

Consultation questions – Chapter 5

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 can not access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages.

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?

Consultation questions – Chapter 6

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. 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 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

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

Direct payments - payments given to individuals to choose, organise and pay for the social care services they need, rather than using the services offered by their local authority

Enterprise - an organisation, especially a business

Identifiable data - data that can be directly linked back to an individual

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 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

Interoperability - the ability of different systems to share information

JSNA - joint strategic needs assessment is the process of planning local health and care needs identifying current and future health and well being needs in light of existing services and informing future service planning taking into account evidence of effectiveness

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

Self-care - the care taken by individuals towards their own health and well being, including the care extended to their children, family, friends and others in neighbourhoods and local communities

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

Telehealth - the delivery of health-related services and information via telecommunications technologies

Telecare - remote care of elderly and vulnerable people, providing the care and reassurance needed to allow them to remain living in their own homes, using equipment and services that support their safety

Annex C. The consultation process

Criteria for consultation

C1. This document is for consultation. We want to hear from as broad a range of people and organisations as possible. The Information Revolution consultation document will be available to read and download at: www.dh.gov.uk/informationrevolution

C2. You can respond to the consultation by completing the response form and either emailing it to InformationRevolution@dh.gsi.gov.uk or posting it to:

Information Strategy Team, Department of Health,
7th Floor, New Kings Beam House, London SE1 9BW

Comments should be received by 14 January 2011.

C3. You can also respond to the consultation online, share your views and add comments on the consultation, in a number of ways. From the website above, you will be able access the online consultation space, and:

- read and respond to the consultation online
- read the introduction to the consultation document and leave comments
- see video and images of events and visits
- find links to related information on stakeholder websites
- read any features and updates on the consultation
- participate in a live webchat with the Secretary of State for Health

In addition, you can receive updates on the consultation and ask us questions through Twitter by following @dhgovuk

C4. The www.dh.gov.uk/informationrevolution website will also include a summary of the consultation document for download - including the consultation questions - available in Easy Read, in three common languages (Urdu, Punjabi and Polish), in large print, and in a word version that can be loaded for audio playback.

C5. The information revolution is for everyone. We will be working with a range of partners and organisations across sectors to ensure this consultation reaches as wide an audience as possible. You can help by hosting discussions for your own colleagues and networks on webpages, social media or through any meetings and events.

C6. Information about events and other opportunities to get involved will be available on the website above, together with material to support anyone who wants to host their own discussions. After these discussions, please feedback by using the response form or submitting an online response as mentioned above.

C7. Following the consultation process, we will publish an information strategy and further plans to put this information revolution into effect.

C8. We are fully committed to developing and publishing an impact assessment and an equalities impact assessment to accompany the Government's response to this consultation.

Criteria for consultation

C9. This consultation follows the 'Government Code of Practice'. In particular, we aim to:

- formally consult at a stage where there is scope to influence the policy outcome;
- consult for at least 12 weeks with consideration given to longer timescales where feasible and sensible;
- be clear about the consultations process in the consultation documents, what is being proposed, the scope to influence and the expected costs and benefits of the proposals;
- ensure the consultation exercise is designed to be accessible to, and clearly targeted at, those people it is intended to reach;
- keep the burden of consultation to a minimum to ensure consultations are effective and to obtain consultees' 'buy-in' to the process;
- analyse responses carefully and give clear feedback to participants following the consultation; and
- ensure officials running consultations are guided in how to run an effective consultation exercise and share what they learn from the experience.

C10. The full text of the code of practice is on the Better Regulation website at:

http://www.bis.gov.uk/policies/better-regulation/consultation-guidance

Comments on the consultation process itself

C11. If you have concerns or comments which you would like to make relating specifically to the consultation process itself, please contact:

Consultations Coordinator, Department of Health
3E48, Quarry House, Leeds LS2 7UE

or e-mail: consultations.co-ordinator@dh.gsi.gov.uk

Please do not send consultation responses to these addresses.

Confidentiality of information

C12. We manage the information you provide in response to this consultation in accordance with the Department of Health's Information Charter.

C13. Information we receive, including personal information, may be published or disclosed in accordance with the access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).

C14. If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we can not give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

C15. The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties.

Summary of the consultation

C16. A summary of the response to this consultation will be made available before or alongside any further action, such as laying legislation before Parliament, and will be placed on the Department of Health consultations website at:

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

Liberating the NHS: An Information Revolution
Department of Health
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