

# The power of information:

Putting all of us in control of the health  
and care information we need

## DH INFORMATION READER BOX

<b>Policy</b> HR/Workforce Management Planning/Performance	Clinical Commissioner Development Provider Development Improvement and Efficiency	Estates IM & T Finance Social Care/Partnership Working
<b>Document purpose</b>	Policy	
<b>Gateway reference</b>	17668	
<b>Title</b>	The Power of Information Putting all of us in control of the health and care information we need	
<b>Author</b>	Department of Health	
<b>Publication date</b>	21 May 2012	
<b>Target audience</b>	SPCT Cluster CEs, NHS Trust CEs, SHA Cluster CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Audit SSs, PCT Cluster Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of HR, Directors of Finance, GPs, Communications Leads, Emergency Care Leads, Directors of Children's SSs, Allied Health Professionals, Information Professionals, The Public, Information and Information Technology System Suppliers, CCGs, Commissioners	
<b>Circulation list</b>		
<b>Description</b>	This document provides the formal Government response to the 2010 consultation 'Liberating the NHS: An Information Revolution'	
<b>Cross reference</b>	Equity and Excellence: Liberating the NHS	
<b>Superseded documents</b>		
<b>Action required</b>	As in Annex A of this document	
<b>Timing</b>	As in Annex A of this document	
<b>Contact details</b>	Information Policy Team Fifth Floor Skipton House 80 London Road London SE1 6LH	
<b>For recipient use</b>		

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# Foreword

Information and technology are changing almost every aspect of our lives: how we shop, how we work, how we communicate with our friends. We can access information on almost any subject, from almost anywhere.

Information can encourage positive changes to the way we live our lives and also to the way public resources are used on our behalf. Information also feeds the research that improves care services for us all and will play a key role in creating a public health system that is locally owned, locally led and able to reflect the needs of the local population. This is about putting us all in control and enabling a culture of 'no decision about me without me'.

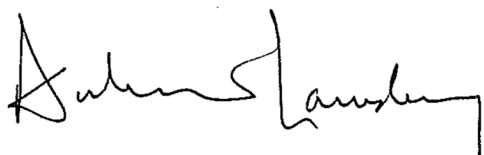
This strategy embraces that change and marks a shift in the way information must drive better health, care and support – to improve our experience, quality and outcomes of health and care services, putting people truly at the heart of care.

Using digital and online services can simplify the more routine aspects of care, such as booking appointments, requesting repeat prescriptions, or self-assessment for social care. The strategy sets out ways to reduce the frustrations we experience, such as repeating or recording the same information many times for different staff, or travelling long distances for services that could be delivered better in other ways. Not only is this more convenient, but it can also help care professionals to focus more time on face-to-face aspects of care and provide more support for those who need it to benefit from technology and information.

Clear direction from central Government is vital. So too are the standards that allow different systems to communicate with each other and to enable us to access the trusted information and services we need to improve our health, wellbeing and care. Equally, and in some areas, progress will be greater with the centre 'getting out of the way' so that local organisations, system developers, information specialists, voluntary sector organisations and others can innovate.

I am grateful to the NHS Future Forum for the excellent work it undertook throughout its listening exercise, which has shaped this document, and to the many people who provided valuable input into the consultation *Liberating the NHS: An Information Revolution*. Those responses have set a clear direction to take this agenda forward and have also highlighted the solid foundations we have to build upon – providing one of the most successfully and universally computerised primary care systems in the world and national information flows that are the envy of many developed countries.

This strategy spans public health, social care and healthcare in England. Building on the wealth of experience, viewpoints and insights gained through the consultation and the NHS Future Forum's work, this document sets out the ambition, clear direction and early actions required to transform our health and our care services to meet our needs and expectations, for now and for the future.

A handwritten signature in black ink, appearing to read 'Andrew Lansley'. The signature is fluid and cursive, with the first name 'Andrew' and the last name 'Lansley' clearly distinguishable.

Andrew Lansley CBE

# Executive summary

This strategy sets a ten-year framework for transforming information for health and care. It aims to harness information and new technologies to achieve higher quality care and improve outcomes for patients and service users. Underpinned by the Health and Social Care Act 2012, it covers public health, healthcare and social care in adult and children's services in England.

As citizens, patients and users of care services, this strategy sets out how a new approach to information and IT across health and care can lead to more joined up, safer, better care for us. The strategy spans information for patients, service users, carers, clinicians and other care professionals, managers, commissioners, councillors, researchers, and many others. Information and transparency can drive up standards, leading to safer, more integrated care and more effective prevention of ill health.

Information can bring enormous benefits. It is the lifeblood of good health and wellbeing, and is pivotal to good quality care. It allows us to understand how to improve our own and our family's health, to know what our care and treatment choices are and to assess for ourselves the quality of services and support available.

Information can also be used by regulators and by local organisations to head off issues before they become the next major incident.

Information also allows professionals to understand the needs of the population they serve, how well different services and treatments work, and the needs and health history of the people they treat. Information about local areas allows residents to understand how the use of public funds matches local care, support and health needs, and whether vulnerable groups are getting a fair share of the benefits.

Yet too often, the information picture is disjointed. Paper records get lost. The Accident and Emergency doctor does not always have the information needed, such as details of important allergies or information about vulnerable children at risk, to be able to treat the sick person in front of them safely. On discharge to a care home, the busy care worker has inconsistent paper medication records to interpret. Links often cannot be made to the underlying causes of ill health, such as the impact poor housing might have on a person who is asthmatic. Local councils and commissioners are often unaware of major variations in delivery of services or health outcomes between areas.

Unlike previous information strategies, this strategy does not reinvent large-scale information systems or set down detailed mechanisms for delivery. Rather, it provides a framework and a route map to lead a transformation in the way information is collected and used. It takes the needs of us as patients, carers, users of care services and citizens as the key driver for change. It provides the infrastructure to support the things that need to be done system-wide but – recognising that information technology is always advancing – it promotes flexibility and local innovation.

This strategy focuses on information in its broadest sense, including the support people need to navigate and understand the information available. This is about ensuring that information reduces, not increases, inequalities and benefits all.

## The strategy's main ambitions

To realise the enormous potential benefits of information to improve our care and our health outcomes, this strategy sets the following ambitions:

- ***Information used to drive integrated care across the entire health and social care sector, both within and between organisations;***
- ***Information regarded as a health and care service in its own right for us all – with appropriate support in using information available for those who need it, so that information benefits everyone and helps reduce inequalities;***
- ***A change in culture and mindset, in which our health and care professionals, organisations and systems recognise that information in our own care records is fundamentally about us – so that it becomes normal for us to access our own records easily;***
- ***Information recorded once, at our first contact with professional staff, and shared securely between those providing our care – supported by consistent use of information standards that enable data to flow (interoperability) between systems whilst keeping our confidential information safe and secure;***
- ***Our electronic care records progressively become the source for core information used to improve our care, improve services and to inform research, etc. – reducing bureaucratic data collections and enabling us to measure quality;***
- ***A culture of transparency, where access to high-quality, evidence-based information about services and the quality of care held by Government and health and care services is openly and easily available to us all;***
- ***An information-led culture where all health and care professionals – and local bodies whose policies influence our health, such as local councils – take responsibility for recording, sharing and using information to improve our care.***



- ***The widespread use of modern technology to make health and care services more convenient, accessible and efficient;***
- ***An information system built on innovative and integrated solutions and local decision-making, within a framework of national standards that ensure information can move freely, safely, and securely around the system.***

If we can access, contribute to and choose to share our health and care records, it will support a culture of ‘no decision about me without me’. Better use of information and innovative technology can help professional teams to prioritise more face-to-face support where that is needed, and can also enable local areas to design integrated health and care services, and improvement strategies that reflect local need.

We need to have confidence in the quality of the information we use. Improving and enhancing our access to our own health and care records and facilitating the accurate recording and use of information by clinicians and professionals will lead to much needed improvements in the quality of information. This will, in turn, promote greater confidence in the quality of information collected and used for our care, as well as the nationally aggregated information used to support the planning and commissioning of services, research, quality and safety, and for accountability.

The success of this strategy depends as much on a culture shift – in the way patients, users of services and professionals think, work and interact – as it does on data or IT systems. It depends on making the shift to give us more control of our health and care and on recognising that collecting and sharing good information is pivotal to improving the quality, safety and effectiveness of our care, as well as our own experiences of care.

Each chapter in this strategy begins with a highlighted box summarising the chapter contents. This executive summary and the chapter summaries give a general overview of the strategy.

**Chapter 1** sets out the case for change, including the way information can fundamentally improve our health, wellbeing, services and the outcomes of our care. Because the benefits of information are potentially so great, information must be seen as core to the business of care.

**Chapter 2** covers the information held within our individual care records. It sets out a vision in which being able to access and share our own records can help us take part in decisions about our own care in a genuine partnership with professionals.

- Increasingly, we will be able to interact with health and care services online, for example to book appointments or communicate electronically.
- Letters from health and care professionals about our care need to be available electronically to us, and to other professionals involved in our care.
- It will become normal for us to be able to access health and care services – including our own records – online.
- Electronic access to our own care records where we request it will start with GP records by 2015 and our social care records as soon as IT systems allow. Work with patient, service user and professional bodies and with industry will enable this access to expand progressively to our records across health and care.
- Increasingly, we will be able to obtain personalised information on opportunities to improve our own health or manage the consequences of any illness.

**Chapter 3** focuses on how our health and care professionals can use connected information and new technology to join up and improve services, to inform the decisions they make and to help deliver safer, more integrated care, e.g. through faster access to test results in hospitals or by ensuring a care worker gives the right medicines to the right person in a care home. This chapter also outlines a future in which our electronic care records become a source of core professional information.

- Health and care professionals will be able to access relevant records online – simply, securely and all in one place (eg. via ‘clinical portals’ or other solutions).
- Information standards will be set nationally for the whole health and care system, so that different parts can connect and communicate with each other and to improve the consistency and quality of information.
- The NHS number will be used consistently.
- The Department of Health and NHS Commissioning Board will pilot new ways to incentivise the use of integrated barcode medication administration systems in care homes by 2014, with the results informing wider implementation planning.
- Professionals will lead better, more standardised and useful recording of information in our records, wherever possible capturing data at the point of care.
- Data from our records will be combined and linked together with other data in a secure environment, then made anonymous. This data will be used to audit quality, improve services, guide commissioning, and identify trends and patterns of health.

- The research and life sciences community will have access to a greater wealth of information to help drive improvements in health and care.
- Over time, the information from combined records will replace cumbersome national data collections.

**Chapter 4** outlines how we will access information, including a new, single, website 'portal' provided by the Government from 2013, and one 'routine' number. It sets out moves towards a new culture of transparency, where we will be encouraged to provide instant feedback about services, and where information about the quality and performance of health and care services is easily accessible.

- There will be a single comprehensive online 'portal' provided by Government from 2013, as a link to trusted information on health, care, support and public health.
- Alongside the Government's core role, a wide range of organisations will be encouraged to take a broader role in making information accessible and usable for people.
- More information will be publicly available about care at clinical or professional team level and information that enables us to 'benchmark' services, such as clinical audit data.
- Similarly, more information will be available to help us see and compare the quality of care provided by local services, to help us choose which best meets our needs.
- We will be encouraged to provide more feedback, instantly wherever possible, which will be used to improve our services – making each encounter count.
- We can all expect information about the quality and performance of health and care services to be publicly available (unless there is a strong reason not to publish it), as part of a wider drive to increase public-sector transparency.
- The NHS and local government will do more to offer support for those who need it to access, understand and use information.

**Chapter 5** covers the organisational elements and the culture change that will underpin the strategy.

- Better use of information – and more innovative use of technology – will drive more effective and efficient services. Better quality and outcomes information will drive service improvement and encourage professionals to use information to improve the quality of care.
- Leadership at all levels will support more efficient and effective use of information to improve health care and outcomes.
- Lead clinicians or care professionals within individual organisations will be responsible for organising and interpreting information in support of better care.
- To ensure anonymised information is available to improve health and care, the Health and Social Care Information Centre will become the focal point for national data collected across the health and care system in England. The Centre will set up a secure data linkage service, with a more specialist data service serving research and life sciences needs.
- An independent review of information governance will ensure the right balance between sharing and protecting information across health and care.

**Chapter 6** sums up the approach and the next steps needed to make the information revolution outlined in the strategy a reality. Above all, the strategy is a framework to support local innovation and empower us all as service users, citizens and professionals to drive change.

**What the information strategy means for me:** Throughout the strategy, the highlighted boxes at the beginning of the chapters also pick out key messages for specific groups. These summarise what the information strategy means for:

- patients and service users;
- carers;
- citizens and communities;
- health and care professionals;
- commissioners of health and care services, including local councils;
- service providers (people and organisations that provide health and care services);
- information and IT specialists;
- system suppliers;

- information ‘intermediaries’ (who take information and present it in useful ways);
- researchers and academics.

The online version of this strategy includes links to relevant information and to a much larger bank of evidence and case studies that support the local delivery of this shared vision.<sup>1</sup>

**Annex A** provides a summary of specific commitments and recommended actions.

**Annex B** sets out a ‘presumption of openness’ and transparency for information about the quality and performance of health and care services, and specific open data commitments.

**Annex C** sets out the roles and responsibilities of different bodies in relation to information. It highlights the role of the NHS Commissioning Board, Public Health England and the Department of Health, working with the Local Government Association, the Association of Directors of Public Health and the Association of Directors of Adult Social Services in taking this agenda forward.

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<sup>1</sup> <http://informationstrategy.dh.gov.uk/>

# 1. Introduction

**Summary:** This chapter sets out the case for change and the strategy's overall ambition.

Better quality information and sharing information is critical to modernising the NHS and care services. Information can be used to:

- improve the quality of care;
- improve our health and care outcomes;
- reduce inequalities; and
- increase productivity and efficiency.

Rapidly advancing information technologies have revolutionised the way we interact with each other. Industries such as banking, retail and travel have changed profoundly; today's information world has the potential to cause a similar revolution in health and care services, shifting the relationship between patient and professional towards one of shared decision-making.

Information is an essential service in its own right, allowing us to understand our own health, adopt healthier lifestyles and choose treatment and care that is right for us. Information technology can also improve the use of health and care resources, for example through mobile working, paperless hospitals and applying business intelligence and analysis to the way services are run.

Rather than expect every organisation to use the same technology, the Government is committed to an approach that connects and joins up local systems, unleashing innovation at a local level. This strategy covers healthcare, care and support, and public health in England.

- 1.1 Information can fundamentally improve our health, our wellbeing, our care services and the outcomes of our care. Improved information quality and information sharing is critical to modernising care through raising the quality of that care, improving outcomes and reducing inequalities, as well as improving productivity and efficiency<sup>2</sup>.

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<sup>2</sup> see [www.dh.gov.uk/liberatingtheNHS](http://www.dh.gov.uk/liberatingtheNHS)

- 1.2 This strategy covers healthcare, care and support, and public health in England, setting out the case for change, the ambition and next steps.<sup>3</sup> The strategy aims to transform the quality of information and the way it moves freely and securely around the system to:
- improve health outcomes and safety;
  - empower service users and support shared decision-making;
  - facilitate and drive integration, within and between organisations and care settings;
  - inform local health and wellbeing strategies; and
  - drive greater efficiency and productivity.
- 1.3 This strategy is the Government's response to the consultation on *Liberating the NHS: An Information Revolution*<sup>4</sup> and to the information report from the independent NHS Future Forum<sup>5</sup>. It aligns well with European Union (EU) plans to improve electronic information: the EU Digital Agenda for Europe 2010-2020<sup>6</sup>, and the objectives outlined in the voluntary eHealth Network group of article 14 of the cross border directive<sup>7</sup>.
- 1.4 The strategy builds on the intention of *Healthy Lives Healthy People: Our strategy for public health in England*<sup>8</sup> to 'harness the information revolution to make the best use of evidence and evaluation and support innovative approaches to behaviour change throughout society'. It responds to themes raised through the *Caring for our future* engagement about the power of information to drive more integrated care – within and between organisations, and across the health and social care sector as a whole. It also takes account of the recommendations on information within the *Law Commission report on adult social care*<sup>9</sup> and *Fairer Care Funding: The Report of the Commission on Funding of Care and Support*<sup>10</sup>.

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3 Whist primarily aimed at publicly funded NHS services, including health care in prisons and other criminal justice or secure settings, at public health services and at the social care sector, the strategy will also have relevance to independent healthcare providers in England.

4 see [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_129405](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_129405)

5 see <http://healthandcare.dh.gov.uk/forum-report>

6 The Digital Agenda for Europe 2010-2020 [http://ec.europa.eu/information\\_society/digital-agenda/index\\_en.htm](http://ec.europa.eu/information_society/digital-agenda/index_en.htm)

7 see <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:01:EN:HTML> Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare

8 see <http://www.dh.gov.uk/en/Publichealth/Healthyliveshealthypeople/index.htm>

9 see <http://lawcommission.justice.gov.uk/publications/1460.htm>

10 see <http://www.dilnotcommission.dh.gov.uk/our-report/>



- 1.5 The forthcoming care and support White Paper will take forward the ambition for meaningful information and evidence routinely captured and used by professionals and service users, and where care records link across the services we use. Across social care, public health and healthcare, the intention is for combined then anonymised data from individual records, along with other sources, to become the main source of the information used to drive system improvement, our health and care choices, integration, efficiency, research, support growth and allow robust measurement of care outcomes.
- 1.6 Across health and care, there are already many good working examples of the power of information to improve experiences and services, a few of which feature in this document. But as yet we are only scratching the surface of what is possible. Arguably, it is more important than ever to address this challenge, with more and more people experiencing complex and ongoing needs for support and health services – and with increasing opportunities to prevent poor health.
- 1.7 Today's information world is fast, flexible and portable, revolutionising how we can interact with each other and with the services we use. Industries such as banking, retail and travel have changed profoundly; for example, people now build their own personalised travel itineraries online informed by the views, experiences and recommendations of other travellers rather than opting for package deals on the high street. People now use forums to discuss, share, and solve common problems, and to offer their own reviews and opinions. The social networking generation demands and expects a more interactive, personalised relationship with health and care services.
- 1.8 Greater transparency and information availability is shifting the relationship between patient and clinician, service user and care professional, towards one of shared decision-making. Information is an essential service in its own right, allowing us to understand our own health, choose healthier lifestyles, and choose the treatment and support that is right for us.
- 1.9 In time, implementation of this strategy will mean that:
- I will get the information I need when I need it in a form I can use and, if I need help, I will be signposted to people who can help me;
  - My doctors, nurses and other professionals will be even better at communicating;
  - I will be able to make informed decisions about my care and about the treatment I will receive, advised and supported by those who are looking after me;
  - I will not have to tell my medical or care history over and again;
  - I will be able to get an electronic copy of my referral letters;



- I (and, when appropriate, my carer) will be able to access a copy of the discharge summary shortly after I leave hospital;
- NHS and other care services will share the information about me with all those who need to look after me (with my appropriate consent), will protect my data and respect my confidentiality;
- I will be able to contact my health and care team electronically for routine support;
- I will be able to see my health and care records and other information online;
- It will be easy for me to tell the NHS and other care services what I think – good or bad. I will be confident my views will be considered and, if appropriate, something will be done to improve services;
- I will understand how services are being developed in my area and how priorities are set;
- As set out in the NHS Constitution, I will have easily accessible, reliable and relevant information enabling and supporting me to participate fully in my own health and care decisions and to support me in making the right choices for me; and
- I will understand better what I can do to improve my own health or cope better with any long-term condition or disability.

1.10 A broad range of new and innovative technology is already available to support these overall aims. Services will operate with us, as individuals, at their centre. We will be offered online and mobile access to records, electronic communication with our professional teams, health and care transactions online, and the ability to rate services and provide feedback in ways which are convenient to us.

1.11 Particularly when our individual problems and care are complex, integration across different care settings and departments need to be supported by better information and better communication. Systems will be more joined up, underpinning efforts to integrate care, offering telehealth solutions (health and care services and support online or via the telephone) and case management approaches that enable improved access and involvement for patients, clients and carers. Technology can also enable better use of health and care resources, for example through automated processes, mobile working, wireless and paperless hospitals, and business intelligence and analytics.

1.12 Whilst this country has achieved successes, such as in computerising primary care systems, and in setting national information flows, previous approaches to health information have often pursued perfection at the expense of progress, through detailed national programmes. Programmes have been too slow to evolve with

changing service needs, and there has been too great a separation between the needs of frontline care and the negotiations around the specific contracts.

- 1.13 As set out in *Liberating the NHS: An Information Revolution*, the Government is committed to an approach where we connect and join up systems (rather than expecting every organisation to use the same technology), and to enabling a range of organisations to offer service information to a variety of audiences.
- 1.14 The information technology industry can deliver IT solutions such as portals<sup>11</sup>, online and mobile access to records, secure electronic communication, transactional services online, e-medicines management, e-prescribing, clinical decision support, telehealth and many others. These technologies will facilitate the efficient recording, synthesis, summarising and presentation of clinical and other care information to improve the safety, quality and efficiency of our care and to enable greater access to and greater engagement in our care for all of us.
- 1.15 Through its recently established partnership with the Department of Health, Intellect – the UK technology industry body representing over 850 SME and multinational companies – is providing crucial feedback from the technology industry into the development and implementation of the strategy. Indeed, Intellect's 2012 report *Health and Care Information Strategy: proposals from the information technology industry* is an output from one of the work streams that form an overarching programme designed to foster a healthy and vibrant IT market. This partnership has informed the development of not just this strategy, but also the implementation plans that will follow.
- 1.16 This strategy is deliberately and unashamedly aspirational. Because the benefits of improved information are so great, information must consistently be seen as being core to the business of health and care.
- 1.17 Delivering the information strategy will depend on the leadership of care professionals and clinicians within individual organisations, using local innovations and adopting solutions that have been shown to work elsewhere.
- 1.18 But, success will also rely on us as citizens and service users demanding better quality information, greater transparency, convenience and experiences that meet our expectations of a 21st century health and care system.

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<sup>11</sup> Portals bring together information from diverse sources in a unified way. Usually, each information source gets a dedicated page for displaying information. Portals provide a way for enterprises to provide a consistent look and feel for information that is on multiple applications and databases.

## 2. Information about me and my care

**Summary:** This chapter covers the information held within our own individual care records.

### Key ambition

- ***A change in culture and mindset, so that our health and care professionals, organisations and systems recognise that the information in each of our own care records is fundamentally about us – and so that it becomes routine for us to be able to access our own records online.***

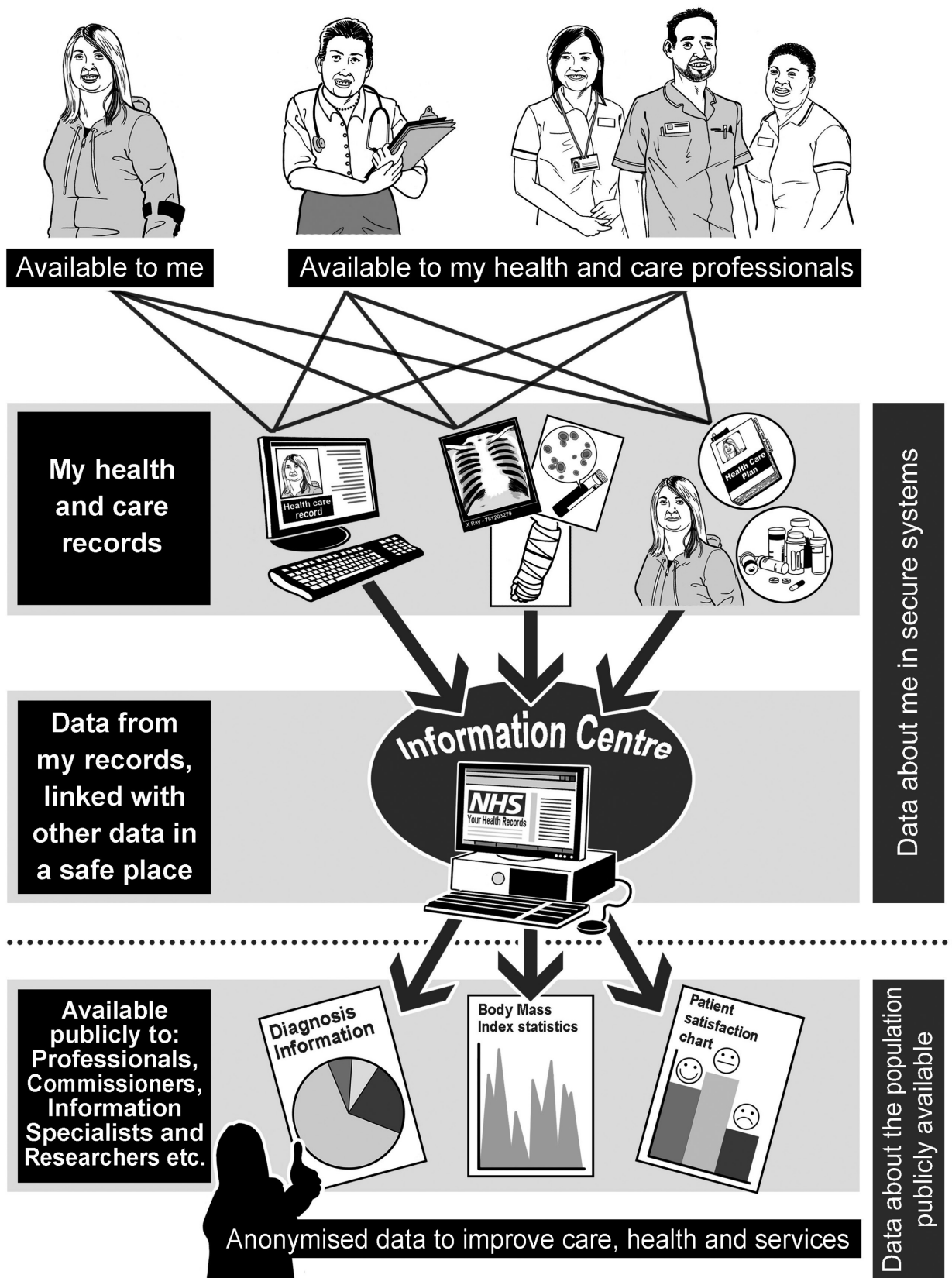
The accelerating pace of technological change offers unprecedented opportunities to interact with health and care services in ways that are convenient, cost-effective and reliable. In taking advantage of this transformation – as many of us have already done in so many other areas of our lives – we should be confident that personal support is available when needed.

The primary use of information is to support high quality care. The most important source of information is the information held in our own health and care records. The information in our records can help make sure our health and care services join up efficiently and effectively, with us at their centre. Being able to access, add to and share our health and care records electronically can help us take part in decisions about our own care.

This chapter sets out the steps to make this a reality, beginning with electronic access to our GP record. These changes will support us as individuals to take more control of our own health and care and to work with professionals to ensure that there really is 'no decision about me without me'.

## What 'information about me and my care' means for me:

- **As a patient or service user** – I look forward to being able to book appointments and order repeat prescriptions online, communicate electronically with my health and care professionals and use IT and online services to improve my health and better care for myself, where appropriate.
- I look forward to being able, by 2015, to access my general practice record, including my test results, online, as well as some of my other health and care records as more care providers make these available to me. It will be important that I can share my information with others who care for me, both professionally and informally. I will know how the information from my health and care records, together with information about my own needs and preferences, will be shared securely between the professionals providing my care, so that my care can be more joined up, safer and better, and so that I won't need to repeat important information to different staff.
- **As a carer** – I will be able to access services and health and care records online, according to the access authorised by the person/people for whom I care, helping me carry out my responsibilities safely, conveniently and effectively.
- **As a health and care professional** – Greater and better use of IT will help me improve the efficiency and quality of my practice of care, and I will be able to prioritise more of my time for those who need face-to-face care. I recognise that it is my duty to ensure people can access their records online if they wish and have the support they need to understand information in their records.
- **As a commissioner of care services** – I will ensure all patients and service users have the opportunity and support to benefit from online access to their own health and care records, and from a growing range of other beneficial online services. I will outline a clear and agreed timetable for providers to deliver this.
- **As a service provider** – My organisation will outline a plan and timetable for all of our patients and service users to have online access to their care records and to other beneficial services. Also, we will provide appropriate support to enable everyone to understand and take proper advantage of all these services.
- **As an information or IT specialist** – I will treat the provision of online access to records and other beneficial services for patients and service users as of equal importance as professional access to electronic records, and promote both equally.
- **As a system supplier** – I will ensure over time that patients, service users and professionals can have convenient and safe access to their health and care records stored in the systems which I supply to providers of state-funded health and care services, whichever system they use to access these records.



with thanks to CHANGE for the images on this diagram

## What we want

- 2.1 Through feedback to the Department of Health's *Liberating the NHS: An Information Revolution* consultation exercise, through the NHS Future Forum listening exercise and the *Caring for our future* engagement, it is clear that, as service users, patients and citizens, we want:
- online access to our personal health and care records – where we have already seen the benefits it brings to us as a patient or user of services and also where this can be linked with 'transactional' services (for example bookings) online;
  - information recorded in our health and care records to be clear and understandable;
  - clear rules and protocols to be observed by those health and care providers who maintain our records to protect our confidential information;
  - clear guidance as to who could, would and should have access to our health and care records;
  - face-to-face and personal support, whenever necessary, to continue to be readily available; and
  - safeguards to protect vulnerable members of the community from potential abuse that could occur through others accessing their care records inappropriately.

## Where are we now?

- 2.2 There is no single overall record of our entire health and care history. Our records are kept electronically and on paper, in different care settings and different locations, and the quality of record keeping varies. In some areas, records are linked across organisations, but this is not consistent across the country.
- 2.3 Many different systems, using diverse data structures and definitions are in use across primary, secondary, community and social care, and by individual specialties in secondary care. As a result, the quality of the data held is variable, often conflicting in content, and difficult to synthesise into a safe and useful record that is focused on us as the individual at the centre of that care.
- 2.4 We have the legal right to access information in our health and care records, but currently this is not easy to do when it means requesting paper copies, and we may be charged. Easily accessing records online does not require changes to the law, but it is a challenge to the culture and practices of some health and care organisations and professionals. The NHS Future Forum has emphasised this cultural shift and the importance of health and social care operating 'as if it is the patient's or service user's data'.



- 2.5 Currently, although over half of general practices use IT systems with the technical capability to provide us with electronic access to our own records, less than 1% offer this service. The picture is more advanced for practical online services that can make interacting with the health and care services simpler. Around 70% of general practices currently use IT systems that include options for booking appointments and ordering repeat medication online, and around 30% already offer these services. However, most of us still rely on face-to-face or telephone contact for booking appointments, repeat prescriptions and similar routine transactions, when we would find other mechanisms more convenient.
- 2.6 An increasing number of social care systems have developed to support personalisation and the introduction of personal budgets – so that we can be much more in charge of the specific care services we need. These initiatives increasingly allow us to carry out transactions on self-assessment, assisted assessments of need and indicative budgets, as well as providing links to the organisations providing specific services for us.
- 2.7 Some of the Common Assessment Framework (CAF) for Adults demonstrator sites are implementing citizen portals to provide us with specific aspects of online access to information and advice, self-assessment, identification of needs, access to our own records or data from our records, access to areas where we can start planning our own care and support and, in some cases, access to brokers and to a marketplace of specialist service providers.

### Case study: Patient access to records – Renal PatientView

Renal PatientView was set up by the Renal Information Exchange, a partnership of patient groups, professional bodies and renal registries. It provides online access to renal patients' diagnosis, treatment, and their latest test results. Patients can share this information with anyone they want, and view it from anywhere in the world.

Renal PatientView has more than 17,000 registered users in 43 of the 52 kidney units nationwide, with 9,000 visitors making 25,000 visits a month. It is now developing a two-way information exchange between patients and clinicians.

<https://www.renalpatientview.org/>

[http://www.kidneycare.nhs.uk/\\_Ourworkprogrammes-Treatmentoptions-Renalpatientview-Toolstohelpyou.aspx](http://www.kidneycare.nhs.uk/_Ourworkprogrammes-Treatmentoptions-Renalpatientview-Toolstohelpyou.aspx)

## The evidence and benefits

- 2.8 There are significant benefits to both patients and GP practices from offering us access to our own GP records online and to other online services, for example online appointment booking and repeat prescription services.
- 2.9 The significant benefits for us as patients include:
- identifying mistakes in records – there are huge benefits to us as patients if treatment errors are avoided as a result;
  - being able to manage our own health and care better; and
  - the ability to share records with our other health and care professionals and/or carers, therefore improving the experience and continuity of care.
- 2.10 The significant benefits to GP practices come from modest investments of time to offer support services to those of us who wish to access our own record online, and from offering online access to other services. These lead to significant increases in productivity that far outweigh the initial investment. Such improvements have meant that online access to records is already happening in general practice and beyond.
- 2.11 Some specific benefits for GP practices include:
- reductions in ad hoc contacts with some patients, allowing more time to be spent with those of us who have a greater need for face-to-face contact with practice staff;
  - reductions in staff time spent on administering repeat prescriptions; and
  - patients being more likely to cancel unnecessary appointments if able to do this online.
- 2.12 The Impact Assessment supporting this strategy further analyses these benefits and the supporting evidence.

## The vision

- 2.13 The shared vision set out in this strategy is for all of us to have secure electronic access to services and to our own health and care records. This will include access to letters, test results, personal care plans and needs assessments. A first step towards making all this information accessible will be for us to have access to our own records held by our general practice.



## Case study: Wells Park Practice

Wells Park Practice has been offering patients free online access to their general practice 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 than 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."*

<http://www.wellsparkpractice.co.uk/>

- 2.14 To enable access to our health and care records for all health and care professionals, organisations need to recognise and operate on the fundamental principle that the data in each of our own care records is fundamentally about **us** and for **us** – as the person at the centre of that care. As such, we have a 'say' in that information and our ability to access and use the information in our own health and care records should be the normal 'default' position.
- 2.15 As well as providing access to our information, we want our health and care services to make it easy for us to contact and interact with them electronically – for example, by enabling us to have secure electronic communication with our care professionals or teams, provide feedback and, in time, ensure that other information is shared with them – for example, about our symptoms, our health status, medication, or our own information needs and preferences. We should also be able to book appointments and order repeat prescriptions electronically, which will be convenient, efficient, and go a long way to reducing the frustration we sometimes currently experience when interacting with services.

- 2.16 The health and care system fully supports the cross-Government approach to 'digital by default', but health and care needs to take a 'digital first' rather than 'digital by default' approach. 'Digital first' makes a firm commitment to adopting digital methods to deliver healthcare, but makes clear that face-to-face contact with our health and care professionals will remain an essential, core part of our care. Where there are high quality, low cost alternatives to face-to-face contact with our health and care professionals then, increasingly, we should have the choice to use them.
- 2.17 Many of us will need some support to access, use and benefit from technology and information, such as online access to our records. Over time, the use of digital and online technologies will simplify services for most of us, and will enable care professionals to focus more time on face-to-face care when it is really needed, reaching out to those who have the greatest need for support. Using technology to improve services – and reaching out to the most vulnerable and disadvantaged – can help ensure that face-to-face and personal support can be made available.
- 2.18 Access to our own care records, as and when we want it, supplemented by interacting with professionals electronically will enable more informed discussions and genuine involvement in decisions about our health and care, as well as helping us manage our own care, leading to a better experience of our care. We will be able to review our records, including test results, before engaging with services, we will be able to refer back to them during the course of our care, and benefit by sharing (if we choose) our information with a range of people – people with similar conditions or needs, support groups, patient and service user organisations or charities – to help us with the care and support we need, when we need it.
- 2.19 Advances in technology can also help more of us to manage illnesses or long term conditions and to continue living in our own homes, using devices and equipment that can help monitor things such as blood pressure and glucose levels, thus reducing the number of visits we need to make to GPs and hospitals.
- 2.20 Once we have chosen the treatment option that is right for us, increasingly comprehensive information on organisations and our own health options will be available to help us make decisions about where we can get that treatment and care.

## Case study: SLaM Mental Health Open Patient Record – MyHealthBox

South London and Maudsley (SLaM) foundation trust has launched an online health record that gives service users meaningful access to their records as well as allowing them to contribute to the system directly. The open patient record has been developed as a web portal using Microsoft's HealthVault platform. The aim is to allow clinicians and patients to work collaboratively on care and treatment rather than it being an isolated experience.

<http://www.slam.nhs.uk/media-and-publications/latest-news/health-minister-launches-myhealthbox---a-world-first-for-mental-health-care.aspx>

[www.myhealthboxlondon.nhs.uk](http://www.myhealthboxlondon.nhs.uk)

## The journey

- 2.21 We need to be able to communicate with our health and care professionals in ways that suit our own circumstances. Electronic access to our own records is a vital step. But this forms just part of the expansion we need to see of practical and secure electronic services, such as: booking and cancelling appointments, ordering repeat medications, viewing test results, contributing information into our electronic records, and electronic communication with our health and care professionals.
- 2.22 Those general practices which already have the systems in place to provide us with online access to these services, and to our own health records are encouraged to do so as soon as possible.
- 2.23 From April 2013, we will be able to see which general practices make available online access to records and other transactional services on the NHS Choices<sup>12</sup> website or via the national online portal described in Chapter 4.

## Case study: Patient access to records – Haughton Thornley Medical Centres

Dr Amir Hannan has actively pioneered patient access to records in his practice in Greater Manchester in order to be completely open and transparent with his patients. There have been other advantages. Research with Tameside and Glossop PCT shows that accessing records online at the practice reduces need for GP and practice nurse appointments, gives patients the opportunity to view test results and other aspects of their records when travelling as well as from home, and supports shared decision-making.

<http://www.htmc.co.uk/>

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<sup>12</sup> See <http://www.nhs.uk>

- 2.24 By 2015, all general practices will be expected to make available electronic booking and cancelling of appointments, ordering of repeat prescriptions, communication with the practice and access to records to anyone registered with the practice that requests these services. Some GPs may decide that they can only provide online access to records and to attached letters from a specific date onward, rather than to give access to historical information (which may not have been written with patient access in mind).
- 2.25 In line with the recommendations of the NHS Future Forum, the Government has engaged with the Royal College of General Practitioners (RCGP), to work in partnership with patient groups and other professional organisations to lead development of a plan to support people to access services and their records electronically. The NHS Commissioning Board will be asked to work with the RCGP and other partners to promote this work from 2013 onwards.
- 2.26 As well as considering what support GPs and their patients may need, and to what extent access to historic records is practical, particular issues to be addressed through this partnership might include:
- secure but straightforward means to identify and authenticate us as patients or services users, in conjunction with other initiatives to develop secure citizen access to public services;
  - appropriate processes for those of us who need particular support in accessing our own care records;
  - standards for us to control access to our own electronic records by health and care professionals beyond those in the organisations which created them and also by others who care for us; and
  - ways of accessing electronic copies of our records and sharing them with people and organisations who can help us to understand and manage our health and care.

### Case study: Patients Know Best

Patients Know Best is a patient-controlled medical records system. Patients can use the system to create a personal electronic health record account and grant clinicians access to that account. The system also enables patients to be given online access to records such as clinic and discharge letters, prescriptions and test results. Patients can consult online with clinicians, use structured email messaging and Skype video calls and work with their clinicians to create personal health plans.

<http://www.patientsknowbest.com/>

- 2.27 Electronic access to services – and to our own records in general practice – is only a first step. We also need mechanisms for sharing our own care plans, our own preferences or our support needs, so that these can be shared with all of those who provide care for us. Progressively, as patients and service users, we should be able to access more and more of our health and care records online. An early priority is to be able to access maternity records and the ‘red book’ online, since the evidence shows that parents and parents-to-be find these immensely useful.
- 2.28 The Department of Health will work with relevant parties to identify and set ambitious but deliverable dates by which we, as users of health and care services, and our health and care professionals, will be able to access the different aspects of our own records online – simply, securely and all in one place (for example via ‘portals’ or other solutions).
- 2.29 In practical terms, the spread of online access to services and records beyond general practice will be led by professional, patient and service user and commissioning initiatives, both driven for particular specialities (for example, kidney services’ Renal PatientView) and by organisations (for example, South London & the Maudsley NHS Foundation Trust’s MyHealthBox.com). As electronic access to our health and care services and to our records becomes more widespread, and as more and more organisations adopt these, the need for standards and for consistent mechanisms will become increasingly important. These will include, for example, developing the capability to enable us and our professionals readily to ascertain the location and readiness for access of our own records, as held by the services we have accessed.
- 2.30 Electronic access to social care records will include assessments of need and our care/support plans. All local authorities will be encouraged to provide clients the choice of accessing their assessment and care plan information online as soon as IT systems allow. It will be possible to build on work under way to provide access to our social care records to support personalisation – to give clarity and control about who (e.g. family members, carers, advocates) can access these records. Online portals, apps or other innovative means would also enable interactions, such as self-assessment questionnaires, making enquiries, obtaining information and advice, accessing an online service directory and support plans. Much of the momentum will be driven by local innovation, enabled by national information standards, and by sharing the lessons from organisations that do this first.
- 2.31 Industry has a role to play in developing and delivering the IT solutions that enable us, our care professionals and also those people that we choose to allow access (e.g. trusted carers or family members) to see our collected health and care records in a single place.

- 2.32 Intellect (representing health and care information systems suppliers) has been invited to prepare a compelling case demonstrating the benefits and value for money of secure online portals and related solutions for patients, service users, local providers, and commissioners of health and care services. These solutions should enable us – as well as the professionals who care for us – to see our health and care records in a simple online ‘view’. The Department and the NHS Commissioning Board will work with Intellect to promote these solutions and share information about local implementations and benefits realisation to support more widespread investment.

### Case study: Online care plans in Graham Care Group homes

Following initial trials at Rodwell Farm Nursing Homes, all residents in the Graham Care Group homes, their relatives and friends can now access securely current care plans and daily reports via email, internet, iPhone etc. Designated contacts can receive text alerts or emails notifying them that updates have been uploaded. The newest and most innovative part of the system allows families and friends to use a text-based system to supply information, photographs etc., which designated care staff will share with residents. The system is being evaluated by the University of Surrey.

<http://www.grahamcare.co.uk/index.html>

- 2.33 As well as access to services and to our records online, we should all expect to receive information electronically – starting with hospital discharge summaries being made available electronically to us as well as to our GP.
- 2.34 Expansion of our access to electronic services and to our own health and care records will need to be accompanied by appropriate safeguards – such as confirming our identity, ensuring there is appropriate support for those of us who particularly need it, and in the protection of our personal information. The British Computer Society is leading work to support people in understanding how to access personal health and care information safely and securely.
- 2.35 There are particular elements of risk in access to records for vulnerable people – for instance, people in abusive relationships where access could mean that their partner sees their record and may use this knowledge against them. The Royal College of General Practitioners has agreed to review guidance on access to records, including reference to safeguarding.



### 3. Connected information for integrated care

**Summary:** This chapter outlines how the professionals providing our care can use connected information to support safer, more integrated care for us, for example, through online access to GP records in hospitals, electronic prescribing and barcode-scanning in care homes and hospitals to reduce medication errors, and electronic access to results, X-rays and scans.

#### Key ambitions

- *Information used to drive integrated care – within and between organisations, and across the health, care and support sector as a whole;*
- *Our electronic care records progressively become the source for core information used to improve our care, improve services and to inform research, etc. – reducing bureaucratic data collections and enabling us to measure quality;*
- *Information recorded once, at first contact, and shared securely between those providing our care – supported by consistent use of information standards that enable data to flow whilst keeping our confidential information safe and secure.*

Many benefits and efficiencies can flow from information being recorded once, at first contact with health and care services, and shared securely between those providing our care. National standards will allow information to move freely through the health and care system, and will inspire trust in that information. Nationally adopted open information standards will be the 'building blocks' for the information infrastructure. This means that systems will be able to connect and join up, rather than every organisation using the same technology – and that innovation can flourish.

Our NHS number will be used to connect our records across the whole system as we move between services. This, as well as professionals being able to access relevant records online, simply, securely and all in one place (for example via 'clinical portals'), will enable more joined-up care. By 2014, pilots for the use of integrated barcode medication administration systems in care homes will inform future plans for implementation across England.

Information will be taken from our records, combined and made anonymous. This will become a key source for all health and care service information, used in many ways: to assess clinical and professional performance, to plan and target services, research new treatments, improve the quality and safety of services and ensure value for money for taxpayers.

This information will also be a vital resource for local councils and Public Health England to take on new leadership roles in health.

### What 'connected information for integrated care' means for me:

**As a patient or service user** – Wherever I go for my care services, such as my GP, pharmacist, care home or local A&E, professionals will be able to access the information they need about me to provide safe and coordinated services that work round my needs and wishes. They will have access to important information to make safe decisions – such as any allergies I have, or about the support I need. They will have access to my own care plan, my support needs or my expressed preferences at a glance. The results of important tests will be available rapidly and electronically, to provide faster diagnoses and treatment and reduce the anxiety of having to wait. If I know my own NHS number, I can help ensure that my care, and information about my care, can be better joined up and more efficiently and effectively coordinated.

**As a carer** – Good information for professionals will ease the burden on me as a carer, making it easier and quicker for me to explain to professionals what is going on and what other services are being provided.

**As a citizen and member of the community** – I will increasingly have useful information available on which services are available and how well they work. This will help me make the right choices. Information from my care records will be used (with my confidential information properly protected) to improve everyone's health, to improve care services, to support research leading to more effective treatments, and to ensure money is being well spent on health and care.

**As a health and care professional** – I will understand better the needs of the people I work with and understand more about the impact my care is having on them. This will rely, in turn, on my recording data directly into their care records and sharing it. I will record accurate information, as close to the point of contact as possible, in line with national information standards, and linked by the person's NHS number. I will share it with other professionals along care pathways and with the Health and Social Care Information Centre, where it can be held and linked securely to support broader health and care improvements. IT will support safer handling of medicines in care homes.



**As a commissioner of care services** – I will have powerful data about the local population I serve, about how money is spent, and about the performance of providers. This will support good planning and good management of services.

**As a service provider** – I will have detailed information about my organisation and the people within it to support continuous improvements in care.

**As a system supplier** – National information standards, used consistently across health and care, will give clarity and will provide new opportunities for me to develop technology to support 21st century care. Government and central organisations will work closely in partnership with me to support and coordinate systems, but give me freedom to innovate and improve.

## What we want

- 3.1 In responses to the Department of Health's consultation on *Liberating the NHS: An Information Revolution*, professional groups argued for a 21st-century person-centred electronic health and social care system, with information recorded once at the first appropriate contact with health and care services and shared across boundaries safely. They argued for a changed national role, allowing greater local innovation and market development in IT. There was also clear consensus that national standards are needed to allow information to move freely through the health and care system and to inspire trust in that information.
- 3.2 The NHS Future Forum made a series of recommendations building on this issue – including the need for systems to support joined-up care across the whole health, care and support sector. Service providers and commissioners should ensure that information integrates around the needs of the individual. The NHS and social care must use IT systems to share data about service users electronically – and develop a consent model that safely facilitates this. How this is achieved should be for individual providers to decide, but with common standards. The key requirement is interoperability – IT systems talking to each other – including the adoption of the NHS number across health and social care.

## Where are we now?

- 3.3 The nature of care, support and health is becoming more complex; 15.4 million of us in England live with a long term condition, and this number is set to increase, with the greatest increase coming from people with multiple, complex conditions. This requires ever-increasing collaboration of professionals across boundaries and over long periods.

- 3.4 Meanwhile, a genuine information revolution is happening, changing the nature of the way we communicate, the way businesses are organised and making more complex information exchange ever easier. Retail, banking and other information-intensive industries have embraced this to improve efficiency and service quality. However, this revolution has not occurred in social care and in health in the same way, despite the huge potential benefits to safety, quality and efficiency.
- 3.5 Many parts of the social care and health system are still reliant on paper records systems. These systems tend to be designed around specialist service areas, not around the users of those services. Systems currently work in isolation and are not designed to interact with other systems across health and social care. As data cannot be shared and is entered many times, data quality and professional decision-making are compromised, there is duplication of recording and a poorer experience of these services for us. This can be unsafe, for example leading to errors in emergency care and medication management.
- 3.6 Across social care, a myriad of paper and electronic systems have been designed primarily to monitor administrative activity. Our care records have typically been paper-based and cannot be received or shared electronically, leading to inefficiencies and safety issues. Local authorities typically have electronic records, but the information they contain cannot be easily shared with other authorities or health services. Across the health and social care system as a whole, data tends to be entered multiple times and the information collected is often of very limited use to professionals.
- 3.7 A major Audit Commission report<sup>13</sup> noted that local authorities often do not have the capacity or capability to use the data they have and highlighted the inefficiencies and impact on quality of poor information systems. Informatics is not a part of social care professional training and is typically not well understood. The traditional focus of local authorities on pre-determined central data returns has constrained their ability to unlock the value of their information resources. Although now changing, attention has focused on numbers of people getting assessments and services, rather than meaningful information on the impact of those services. Even major multi-national social care providers do not have electronic care records systems that offer standardised data on their business or support quality improvement.
- 3.8 In many cases, IT systems have their own 'standards' that often do not work with other systems. This is analogous to telecoms companies having their own sets of phone numbers for their network and their own SIM cards that only work with their own phones. Important information tends to be communicated on paper, often after

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13 Audit Commission – Is there something I should know? July 2009 – see <http://www.audit-commission.gov.uk/nationalstudies/localgov/istheresomething/Pages/Default.aspx>

a delay. Systems are often detached from routine professional care, which can lead to frustration and to poor recording of data.

- 3.9 Concerns over security and privacy issues – and a lack of clarity for professionals in understanding what level of information sharing is permitted – can lead to a culture that is overly risk averse and reluctant to share information at all, even where it would improve our care. The NHS Future Forum work has heard the clear message that ‘not sharing information has the potential to do more harm than sharing it’.
- 3.10 There are, of course, numerous examples of technology that is transforming care and where professionals are already championing effective information use. Simple examples include the use of secure electronic communication for sharing information between people, as well as more advanced solutions that allow systems to join up. There is a clear need to build on these and free up professionals to innovate and lead, seeing improving and using information as core elements of their job.
- 3.11 Joined-up care needs information systems that talk to each other. This approach, based on nationally set information standards, will enable information to be captured once and shared right across the health and care system. National standards and implementation guidance provide the foundation for the joining up of systems so that health, care and support can move away from solutions that work only in their area. Rather, our information will be able to follow us across organisational boundaries as we move between services, and new innovations and ideas can be taken up.

### Case study: Tower Hamlets joins up social care and health data

The London Borough of Tower Hamlets has been integrating information from health and social care in a partnership with the local health service supported by the Cass Business School. It has created a comprehensive database of area-referenced information by joining elements from the general practice register, land and property gazetteer, school pupil census and social and hospital care records. The remarkably rich intelligence created is helping to shape commissioning and delivery of services in the borough by targeting them where they are most needed.

[www.nkm.org.uk](http://www.nkm.org.uk)

## Common Assessment Framework Programme for Adults

The Common Assessment Framework (CAF) for Adults programme highlights options being taken for sharing information and working towards fully joined-up systems. Running from 2009 to 2012, the programme will provide a national evaluation, expected to be published in 2012, on cost and cost-effectiveness of integrating health and social care information around the individual.

The programme has tested different approaches to sharing information across different agencies to support the implementation of personalisation across a number of sites in England. It has placed an emphasis on maximising individuals' control over their care and on the importance of the co-production of services and support

Through their developmental work the CAF sites working individually and as a collective, have looked to capture their practical experiences which have been pulled together into a suite of practical lessons supported by examples. These CAF 'Lessons Learnt' documents cover:

- Redesigning systems: what an organisation might need to know,
- Technical approaches: IT operations and
- General programme issues.

Lessons Learnt documents and more information are available at:

<http://www.networks.nhs.uk/nhs-networks/common-assessment-framework-for-adults-learning>

Information sharing, within the NHS and between the NHS and Social Care, has too often relied on post or the fax. NHS London's 'Secure email Project' is engaging all London Boroughs and NHS Trusts in London to encourage culture change. Another project, the 'Adapter Project' is building on the secure email project to enable patient-level information to be sent using the interoperability toolkit (ITK) standards across health and social care systems. These projects have a focus on Admission and Discharge Notifications between Hospitals and Social Care Departments but also support other workflows such as Continuing Care, End of Life, GP Referrals, Care Plans, etc.

Please see Page 38-40, in the Department of Health's 'Developing standards for health and social care records: report of the Joint Working Group', 2011

<http://www.rcplondon.ac.uk/resources/developing-standards-health-and-social-care-record>

CAF for Adults sites in other parts of the country are looking at options for sharing information between systems that provide additional benefits to users. Examples include the sharing of common IT systems across organisational boundaries, area based hubs, clinical portals and citizen portals allowing client access and control of sharing of care records and support plans.

<http://www.networks.nhs.uk/nhs-networks/common-assessment-framework-for-adults-learning>

<http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/CommonAssessmentFrameworkforAdults/index.htm>

- 3.12 It is also important to consider how sharing information appropriately between agencies can improve outcomes for children and young people. This is one of the key messages arising from consultation during the development of the Children and Young People's Health Outcomes Strategy, launched by the Government in January to consider the outcomes which matter most to children, young people, their families and carers and the professionals responsible for their care. The ability to share information following assessment between all the agencies involved in a child's care would greatly improve joining up of services around the child, and help parents and children better manage the child's condition and retain as much independence as possible.
- 3.13 This has particular importance where the child has a long term or complex condition or disability. The Government's Green Paper *Support and Aspiration: a new approach to special educational needs and disability*<sup>14</sup> sets out plans to develop a new birth to age 25 assessment process and a single plan incorporating education, health and social care assessments. This information strategy will enable services and systems to share information and provide better outcomes overall for children and young people.
- 3.14 Children and their families also consider that transition to adult services, at age 18, is a particularly important transition point in terms of improving outcomes. The individual, family and carers of a young person should feel confident about next steps and that they will not fall through gaps in provision. Professionals from both children's and adult services should be involved in transition planning so that they have a shared understanding of the outcomes the young person is working towards. The information strategy will help enable better sharing of information and joining up of services.
- 3.15 From the perspective of looked-after children, it will be essential that professionals in health and social care are absolutely clear about information being shared (on a 'need to know' basis) so that looked-after children get the health and care services that they need in a way that is timely, sensitive to their wishes and feelings and takes account of their views as appropriate, according to their age and understanding.
- 3.16 The statutory guidance *Working Together to Safeguard Children*<sup>15</sup> emphasises that effective information sharing underpins integrated working and is 'a vital element of both early intervention and safeguarding'. Child protection is everyone's responsibility. The Government is committed to developing a co-produced work programme with NHS, local government and other partners, to ensure that effective

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14 see <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/CM%208027>

15 see <https://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-00305-2010>

arrangements to safeguard children are central to this Government's health and care reforms.

## The evidence and benefits

- 3.17 There are significant benefits from connected information and more integrated care – to providers of health and care services, to commissioners of those services, and to us as patients and service users.
- 3.18 Providers of health and care services will be able to increase their efficiency, for example from reduced duplication of work, by being able to view all of the relevant health and care records for those of us in their care. This ability to view all relevant health and care records will also enable providers to improve the quality of services, for example by minimising the risk of errors and improving the continuity of services provided.
- 3.19 Commissioners of health and care services will be able to make more informed decisions on the services they commission, on behalf of and with us. This will enable commissioners to maximise the benefit received by us as users of services for each pound they spend commissioning our care.
- 3.20 We will benefit from the quality improvements in the services provided to us by both providers and commissioners of health and care services, as well as experiencing increased continuity of care and better experience of those services. As patients or services users, we are also likely to benefit, in the longer term, from the research outputs which will become possible as a result of better, more useful information on the quality of health and care services.
- 3.21 The Impact Assessment supporting this strategy<sup>16</sup> further analyses these benefits and the supporting evidence.

## The vision: connected information enabling safer, more joined-up care

- 3.22 This strategy's vision is to record and collect high-quality data in our health and care records for the primary purpose of ensuring we receive high-quality care, to link our records and data electronically, to share it appropriately and to extract from it data that is combined and then made anonymous, to be used for a wide range of secondary purposes.

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<sup>16</sup> <http://informationstrategy.dh.gov.uk/>



- 3.23 There are many benefits for us as users of health and care services from joining up information, using appropriate technology, along our health and care pathways. We will have access to a more complete record of our own care. The professionals providing our care will have more complete information. Errors or cases of lost or delayed data will be reduced, as will the need for us to repeat the same information to different professionals. In addition, sharing test results quickly in an understandable way will become an integral part of joined-up care.
- 3.24 But there are other, broader benefits to be gained. This strategy aims to move the NHS and also care services from a reliance on specially collected data<sup>17</sup>, which is often recorded a second or third time alongside our main clinical or other care notes, to recording routine clinical and care information in such a way that it also fulfils the needs of national datasets without the need for duplicate data entry. This information, recorded at the level of the interaction between us and our care professionals, will be the most accurate, reliable and efficiently recorded, as this is the data required for our actual care.
- 3.25 Information generated by health services, and increasingly by care and support, is used in a variety of ways. Its primary purpose is to ensure that we receive the best care and treatment possible. But it is also used for a wide range of secondary purposes, principally to plan and develop health and care services to ensure they are capable of meeting our needs – both now and in the future – and to allow professionals to understand different conditions and the links between them, as well as to develop new and improved treatments and services.
- 3.26 Over time, data drawn directly from care records will become a core source for much of the information that is used to improve our care services: the patient activity data (rather than parallel data collections) which, when combined with data from other management systems, such as finance, estates, supplies and HR, will provide more timely and accurate information to improve planning and delivery of our care services; for research, as well as providing a rich source of information for local organisations and regulators to identify issues and intervene before they become serious problems. These kinds of information can also be of enormous value in terms of planning public health – for example, in identifying correlations between disease and demographic factors. This linked, then anonymised data will help lead to better quality, safer care and improved outcomes for us, as well as new treatments and a better understanding of our health at the population level.
- 3.27 Commissioners of care health and care services, with better access to information about what is happening now, and the quality of care being commissioned, will lead

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<sup>17</sup> sometimes collected specially to fulfil national datasets

to better informed commissioning decisions in the future. The Atlas of Variation<sup>18</sup> has already shown the power of reflecting information back to the service in a way which highlights where changes could be made to improve our care. A default position of open access to easily understandable information about health and care provision will also allow us as citizens, patients and service users – and others who represent us (e.g. health charities and journalists) – to hold both service providers and those who commission those services for us to account.

- 3.28 Research has always been and remains an essential aspect of the health and care quality agenda. The day-to-day information produced within the NHS alone is of vital importance to researchers as they seek to develop new, better, more reliable and effective treatments, diagnostics, procedures, medical equipment, devices and ways of delivering our care. The data generated within our care records helps researchers identify potential areas of research and, in very strictly controlled situations, identify patients that could help with the research. Without research and without our participation, many of the treatments now available to us would not have been possible.
- 3.29 There is also enormous untapped potential from joining up information at the population level. Our individual information, when combined securely at a population level, gives researchers the opportunity to have greater confidence in the accuracy and outcome of their research. This is essential if new treatments are to be brought into everyday use quickly and efficiently to improve our health and our care.
- 3.30 In social care, the vision is for sharable electronic assessments to drive integrated care across boundaries. This approach has been used in New Zealand to deliver nationally portable and transparent assessments, not only for social care but for a range of connected health services New Zealand use InterRAI for health and social care needs assessments. This has, in turn, facilitated multidisciplinary working and integration at a local level. Also, assessments captured in a consistent way electronically enables the use of these assessments and reviews to track outcomes at an individual, provider and national level. This both promotes integration and utilises the untapped information potential of electronic care records, including assessment and review, to drive system improvement and to provide accurate data for outcomes and research.
- 3.31 Aggregated, anonymised data drawn from care records, when combined with other sources of data such as vital statistics, demographic trends and information on risks to health in local communities, will provide the core of local Joint Strategic Needs Assessments – to provide confidence that local commissioners are addressing the right priorities. These assessments will allow Health and Wellbeing Boards to publish

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<sup>18</sup> see <http://www.rightcare.nhs.uk/index.php/atlas/atlas-of-variation-2011/>



clear evidence-based Health and Wellbeing Strategies that we, as local citizens, will be able to review.

### Case study: cancer registries and National Cancer Intelligence Network

All cancers diagnosed in England are registered by the network of Cancer Registries (eight across the country, with an additional one covering childhood cancers), which collect a range of data about the cancer patients, their treatment and their outcomes. This provides a vital database to allow comparisons of incidence, services and outcomes. This allows commissioners, providers and clinicians to assess the needs of their populations and to benchmark their services and outcomes, and therefore to identify areas where there is scope for improvements. Cancer Registry data enables assessment of survival rates for different cancers, by different groups of people, and assessment of variations in survival rates.

<http://www.ukacr.org/registration-organisation>

- 3.32 The NHS Future Forum highlighted that this vision has been achieved in some areas within other countries, such as the USA's Veterans Health Administration (see next page). Within primary care in England we are beginning to see this vision realised with data captured as a part of the care process and used for a growing number of purposes. For example, this data is being used to target front-line services at those people at highest risk of future hospital admissions, to provide a wealth of data for clinical research, for financial payments systems and national data collections.
- 3.33 Being able to derive increasing amounts of information from underlying records will contribute to the reduction in expensive and inefficient parallel data collections and manual submissions of information to the Health and Social Care Information Centre, or to those organisations commissioning our health and care services. The Department of Health has estimated eliminating the use of paper across the NHS could save £200m.

### Case study: the Department of Veterans' Affairs (VA) electronic system (VistA)

The VA provides health care to over 20 million ex-service people and is regarded as one of the safest and highest performing systems in the USA<sup>18</sup>. The VistA system was developed in-house by clinicians, aimed at supporting them to deliver safe and effective care. It includes computerised ordering of tests and viewing of results, bar coded medicines administration, electronic prescribing, clinical guidelines and reminders. It is built on a standardised care record for each person. This record is accessible online and can be shared by professionals across primary care, social care and hospitals nationwide. VistA reduces duplication and improves care coordination, and saves the VA over \$3 billion a year from improved efficiency. The database of care records has provided data for over 30,000 published research articles. The software is available free of charge as open-source software. Other countries are now adapting VistA for their own use, including Jordan, Finland and Mexico.

[http://www.va.gov/vista\\_monograph/](http://www.va.gov/vista_monograph/)

### The journey: safer care

- 3.34 Local innovation and market development will drive much of the progress, facilitated through sharing and showcasing technology and IT solutions that are already in use in some health and social care services. These include clinical 'portals', which bring together information through a secure online site. Other innovations include recording information through mobile devices such as digital pens and integrating this information directly into local systems (see Chapter 5).

### Case study: clinical portal at Basingstoke & North Hants NHS Trust

The Trust has used a clinical portal solution to unite data from five separate IT systems into a single portal that doctors and nurses can view via a wireless connection from anywhere in the hospital. Using this clinical portal, clinicians can review patient information and medical records, order lab services such as radiology and pathology, view test results, prescribe medication and prepare discharge documents and correspondence, instantly and in real time, without leaving the patient's bedside.

<http://public.dhe.ibm.com/common/ssi/ecm/en/wsc14289gben/WSC14289GBEN.PDF>

<sup>19</sup> Ash et al (2004) Comparison of Quality of Care for Patients in the Veterans Health Administration and Patients in a National Sample. *Annals of Internal Medicine* vol. 141 no. 12 938-945

- 3.35 Whilst there are clear drivers for improved information sharing, the time and cost involved in developing reusable approaches to joining up systems can discourage organisations from doing this work. Too often, bespoke solutions are implemented by one organisation, but good ideas fail to spread, and different organisations repeat similar work. The main benefit of standards-based approaches come when the whole health and care system is joined up around us as patients and reusable approaches reduce the time and cost involved in deployment.
- 3.36 Proposed national investment in 'information sharing' will help address this issue, focused upon stimulating a market to use open approaches to information sharing. The aim is for a reusable standard to become the fastest and most effective means of addressing local information sharing needs.

### Case study: integrated care in Worcestershire Health Economy

Worcestershire Health Economy has developed a new automated approach using the Interoperability Toolkit standards to support the electronic communication of clinical information seamlessly into the GP clinical systems for outpatient letters and discharge summaries. This means paperwork can be completed online and shared between teams across care settings.

Every week hundreds of patients are discharged from Worcestershire Acute Hospitals NHS Trust and for some, a comprehensive package of continuing care provided by health and social care teams within nursing or patients' homes is essential. Worcestershire has developed an integrated electronic solution that makes the process of completing all the associated paperwork much easier at the acute trust, by integrating the production of clinical information into the operational systems. It has also been integrated with primary care information systems used across the county using PCTI docman, which enables the e-correspondence to be directed around the practice ensuring the right information, is received by the right GP. This can then be passed to community, social care teams, patients and carers alike.

The solution, which incorporates the Interoperability Toolkit standards, allows staff to complete continuing care paperwork electronically and share it with relevant parties via secure messaging. The solution was developed by the acute trust and GPs working in partnership, ensuring the workload/productivity benefits are achieved by all organisations involved.

<http://www.connectingforhealth.nhs.uk/systemsandservices/interop>

- 3.37 New technologies and improved information flows have the potential to transform health and social care safety and efficiency in many areas – including within care homes.

- 3.38 Barcode-based drug administration systems have been developed for care homes. These address safety problems, such as administration errors, can support optimal prescribing, automatically control stock and reduce waste. These systems give the pharmacist oversight of the whole system from prescribing to administration, to resolve problems working with the key partners of GPs and care-home staff.
- 3.39 The Department of Health will continue to collaborate with key partners such as the National Care Forum, the Royal Pharmaceutical Society and key Royal Colleges, building on existing work, to improve the use of medicines in care homes, including considering the role of technological innovation and commissioning incentives in transforming safety and efficiency.
- 3.40 The Department of Health and the NHS Commissioning Board will work to pilot new ways to incentivise the use of integrated barcode medication administration systems in care homes by September 2014, including exploring the use of Social Investment in the sector, with the results informing future plans for implementation across England.

### Case study: Bristol care homes use barcode medication systems to transform safety and save the NHS money

Medication safety systems have been transformed in a number of Bristol care homes with the introduction of pioneering barcode technology, due to an innovative collaboration between NHS Bristol, Pharmacy Plus and the care-home sector. National research suggests 52% of care-home residents have a serious medication error, such as being given another resident's medication, in any three-month period<sup>20</sup>. The technology developed stops care workers from making these mistakes, ensuring that the right medication is scanned and then can only be given to the right person at the right time. The system, developed by Pharmacy Plus, also integrates the prescribing and dispensing process, automating care-home stock management and alerting the pharmacist to sub-optimal prescribing. Drug over-use and waste is a recognised problem in care homes with up to £50 million of drugs returned to pharmacies each year by care homes for disposal<sup>21</sup>. A percentage of the money saved in reduced NHS drug costs in the care homes is being returned by NHS Bristol to Pharmacy Plus to support the costs of the technology over the start-up period.

20 Szczepura et al (2011) Medication Administration Errors in long term Residential Care. BMC Geriatrics 11:82

21 Trueman, et al. (2010) *Evaluation of the scale, causes and costs of waste medicines*. York Health Economics Consortium and The School of Pharmacy, University of London

3.41 The table below highlights priority areas, where progress should be made locally to drive safer more efficient care, supported through national partnership working.

Encouraged local action	Recommended approach
Medicines management for safer, more effective care	<ul style="list-style-type: none"> <li>• Building on the roll-out of NHS Electronic Prescription Service, delivery of ePrescribing outside GP practices (for example, hospitals) including the electronic exchange of medication information inside and outside organisations.</li> <li>• Roll out Automatic Identification and Data Capture (AIDC – barcodes / scanning) for hospital medication, including hospital manufactured medicines. Trial with IV medication first. Offer to independent sector care home providers.</li> </ul>
Test results, X-rays and scans exchanged safely between all settings	<ul style="list-style-type: none"> <li>• Building on national information standards (such as the National Laboratory Medicines catalogue), ensure test orders and results are communicated in a standard, interoperable, electronic format.</li> </ul>
Letters about patients and service users can be sent electronically between professionals for safer, quicker, more efficient care and as a building block for secondary applications in records	<ul style="list-style-type: none"> <li>• Transfer all correspondence electronically rather than on paper</li> <li>• Code electronic outpatient and discharge letters from inpatient stays, emergency departments, mental health, paediatrics and maternity.</li> <li>• Share discharge notifications, medication, assessment and arrangements for continuing health care by secure email or other electronic means.</li> <li>• Deliver accurate and timely coded discharge diagnoses. These can then feed national datasets, national statistics (such as Hospital Episode Statistics) and national outcome metrics.</li> <li>• Capture routinely asked outcome data and code it in outpatient and discharge letters and over time in social services care assessments.</li> </ul>
Systems for easy viewing of records	<ul style="list-style-type: none"> <li>• Support innovative mechanisms at appropriate geographical level that build on the joining up of systems, giving end-to-end access to records where appropriate consent is given (such as clinical and citizen portals)</li> </ul>

Encouraged local action	Recommended approach
Electronic care plans for health and social care	<ul style="list-style-type: none"> <li>• Share multi-agency assessment and care plans and Common Assessment Framework (CAF) information electronically across the country.</li> </ul>
On-line professional access to shared records in non-GP settings	<ul style="list-style-type: none"> <li>• Explore how GP system suppliers can develop equivalents for professional viewing, just as they can offer the functionality for online patient viewing of records.</li> </ul>

## The journey: standards to support joined-up care

- 3.42 We need national information standards (including agreed terminologies and coding definitions) and interoperable systems – across health and social care services in England. This will become increasingly important as local organisations look to procure IT systems locally, following the end of the National Programme for IT. Minimum 'standards' will be systematically adopted; a shared language to allow systems to talk to each other, phased over ten years.

## Case study: doctors unlocking the untapped potential of care records

The Royal College of Physicians has led pioneering work to agree professionally-led standards for care records. Doctors originally saw the need to come together and standardise key records to provide higher quality clinical care and communicate effectively with other professionals.

Subsequently, the Royal Colleges have outlined a wider vision for standardised care records to become a rich source of information for other purposes, such as clinical audits, research and essential management and financial data. Ultimately numerous separate management data collections and national data returns will become unnecessary, as anonymised data is automatically extracted from the care record itself. RCP standardised care records have been trialled in a number of areas. For example, the Academy of Medical Royal Colleges endorsed standard Discharge Summary is being introduced in Newcastle to support the development of an electronic discharge summary. Local GPs have welcomed the early implementation and have requested further content improvements supported by the standard headings.

*References:* 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 Professional.

- 3.43 In developing standards, ensuring that these are prioritised and 'person-centred' will be crucial – focused squarely around improving care for us as users of services. It will also be important not to over-complicate or pursue overly 'perfect' standards at the expense of making concrete progress. Setting standards must be done in conjunction with value for money assessments of the benefits expected vs the costs, feasibility and risks of implementation.
- 3.44 To accelerate progress on integrated care, this strategy recommends a pragmatic, modular approach to making standards as straightforward as possible. An early priority will be to unify and standardise the recording and use of information that links to demographics (such as age, sex, and ethnicity), including the NHS number as the default unique identifier and the information used for hand-over between services. Similarly, it will be important to ensure other identifiers are used consistently, for example for the health and social care provider organisations registered by the Care Quality Commission.



- 3.45 From 2013 onwards, the legal provisions within the Health and Social Care Act 2012 will come into force. These will ensure that standards, to which all providers of health and social care should have regard, can be set once across the health and care system in England (by the NHS Commissioning Board for the NHS and by the Department of Health for public health and for care and support).
- 3.46 A fundamental part of setting those standards will be comprehensive and consistent use of the NHS number across health and social care services, at the point of care and in 'real time', as care is delivered. The NHS Future Forum recommended action to make the consistent use of the NHS number a reality across health and care records.
- 3.47 All of our health and care data should, wherever it is held, use the NHS number as the default patient identifier by 2015. This should be recorded as care is delivered, not in retrospect. Local authorities are committed to working with health colleagues towards much better integration of our health and care information and working towards the consistent use of NHS numbers.
- 3.48 There will remain a limited number of cases in which the immediate use of the correct NHS number is not possible and local temporary identifiers will still be needed for these instances. Examples include where small or voluntary organisations do not have the capacity or infrastructure, or for some services such as drug treatment or sexual health services, where patients may wish to remain anonymous or where using the NHS number may act as a deterrent to treatment.
- 3.49 Our NHS number will become far more visible to us, for example, on every letter or appointment. As users of health and care services, and as members of the public, we should become increasingly aware of our own NHS number and its ability to ensure that we are always correctly identified – and how it can help ensure that our care and our records are appropriately reconciled and coordinated.
- 3.50 We can help those providing our care by, wherever possible, knowing and being ready to quote our own NHS number. Some of us may not remember or know how to access this, and, for those reasons our records will always be identifiable in other ways. But, by increasing the use of the NHS number we have the opportunity to connect our own records reliably and quickly across the different health and care services we use, helping to drive more integrated care services more generally.
- 3.51 All e-mail communication about our care must be appropriately secure and protected. Work will continue to improve access to and use of NHSmail within the NHS, and social enterprises and other qualified providers of care services, as part of their commissioning contracts with the NHS, will be given access to a limited number of NHSmail accounts. Similar incentives for social care will be made available that

make the process and cost of connecting social care providers, local authorities and other care providers via secure electronic communication easier, cheaper and less bureaucratic.

- 3.52 Consistent adoption of national information standards will underpin the success of this strategy, and the success of truly integrated care services. This will require not only taking the opportunity offered by the new legal status of information standards, but also a different approach to their adoption – crucially, an approach that builds clinical and professional buy-in into the process and that promotes adoption by the market so that the systems and solutions that can be procured and used across health and care already have national standards ‘built in’.
- 3.53 To this end, recognising the NHS Future Forum’s specific recommendations, by April 2013 the Department of Health and the NHS Commissioning Board will need to agree:
- the single process they will use to set consistent information standards across healthcare, public health and social care, which engages with relevant organisations including Public Health England, the Care Quality Commission, Monitor and NICE, as well as with Royal Colleges and other professional organisations, with bodies such as the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS), and also with industry bodies; and
  - the 2013-18 ‘route map’ for setting and implementing information standards and for following up their adoption across the health and care system in England.
- 3.54 The Department of Health and the NHS Commissioning Board may wish to consider setting further steps such as:
- using regulation or enforcement, where information standards are not adopted in reasonable timescales (for example by 2018); and
  - standardised care plans to support integrated services across care pathways and between health and social care (by 2016-18).
- 3.55 The Care Quality Commission has a significant role in influencing the uptake and use of these national mandated information standards. This includes consistent use of the NHS number by health and care provider organisations, where failure to comply increases the risk of unsafe or poor quality registered services. Included in this is the appropriate, effective sharing of information between provider organisations that reduces the risk of unsafe or poor quality services.

- 3.56 Similarly, Monitor will explore how its existing regulatory functions can support the information requirements needed to deliver more integrated services. This is consistent with Monitor's primary duty to protect and promote the interests of people who use healthcare services, and its supporting duty to enable the integration of health services.
- 3.57 In the meantime, there are staging posts along the way, during which current datasets, like HES and the mental health minimum dataset, will be made more relevant to clinical need and, increasingly, to align data collected nationally with outcomes rather than with processes. This will heed lessons from the Department of Health's Fundamental Review of Data Returns to ensure that the data collected across the system is the information that is actually needed.
- 3.58 At the moment different areas of the health and care system use different coding terminologies – this means that information cannot flow around the system well, and the way data and terminologies are described is often inconsistent. Reducing the number of inconsistent or incompatible terminologies from 2015 (via the 'route-map') will allow better integration between systems and across health and social care, and better information to support care and improvement of care. In due course, for patient care purposes, all relevant systems should use the same terminology to exchange coded information; SNOMED CT, adapted to fit all necessary uses, is the appropriate terminology to base this on. Similarly, to allow drugs to be consistently referenced, systems will consistently use the electronic drugs dictionary (dm+d).
- 3.59 In prioritising the development of specific consistent standards needs to be prioritised and how they will be implemented, draw on best practice and consensus and, noting of the work of Royal Colleges to date, the 'route map' will also need to cover both the cultural (human, educational and preparatory) elements prior to the adoption and implementation (electronic and systems) – i.e:
- *cultural preparatory phase* – enabling professionals, organisations and system developers to prepare to implement a specific standard. During this phase, professional and industry bodies set guidelines, procedures, coding mechanisms, implementation guidance, etc. to help the system to prepare for and adopt the specific standards (published in outline form); followed a couple of years later by; and
  - *adoption* – when the information standard is 'switched on' and from when records and other systems – and the clinicians, professionals and others staff recording data, as well as system suppliers – will be required to adopt the standard.

- 3.60 As such by April 2013, clinicians and other professionals, systems suppliers and developers, should expect to see an agreed 'route map' setting out provisional dates for specific information standards, prioritised according to need – for instance, including:
- **unique identifier** – NHS number;
  - **professional record keeping** – Academy of Medical Royal Colleges Records Standards, Social Care Assessment;
  - **terminology** – Pathology & diagnostic imaging, medicines and devices, clinical coding language; and
  - **equalities data** – considering ways to ensure we fill the gaps that currently exist in relation to protected characteristics equality data.

### Case study: spine mini-services – University Hospital of North Staffordshire NHS Trust

University Hospital of North Staffordshire NHS Trust has become the first to go live with a 'spine mini-service' accredited under NHS Connecting for Health's Interoperability Toolkit.

The Trust has implemented Quicksilver's new orQestra service to enable direct, automatic access to the personal demographic service held on the NHS data spine. Staff can now verify NHS numbers while patients are on site, which saves time, makes it easier to obtain reimbursement from commissioners, and avoids potential penalties for holding inaccurate data.

The Trust has shown significant early benefits from this approach. There has been a five-fold increase in the ability to trace patients on a daily basis. Each week, the Trust has updated 1,400 records with the patient's NHS number, in a process that previously resulted in just nine numbers being traced and updated. With around 1.3 million patient records on their system, in the first month of operation there was a 1.1% improvement in the number of patient records with a verified NHS number.

<http://www.ehi.co.uk/news/EHI/7457/staffs-trust-first-on-spine-mini-service>

### Case study: StrokeNav – data capture and communication across systems and teams

Stroke Nav is a web-based system that supports clinicians and managers involved in stroke care. Users can enter and review data via tablets such as the Apple iPad. The system offers data collection modules for each aspect of treatment, including multidisciplinary team meetings, handover lists, therapy assessments and goal planning. Where possible, the modules share data to avoid duplication. The information is transferred between acute and rehabilitation hospitals, and within the multidisciplinary care team, supporting continuity of care and providing a real-time graphical dashboard of service performance.

<http://departmentofhealth.ideascale.com/a/dtd/51856-15482>

- 3.61 Over time we will see a systematic move to industry adoption of open standards, greater interconnectivity and interoperability, and greater competition between system suppliers to support local service requirements. This will allow data to be captured once at the first contact and used for much wider purposes which, in turn, will help drive more integrated, modern, safe and effective care for us as patients and service users.

### Case study: e-consultations for chronic kidney disease at Bradford Teaching Hospitals

The chronic kidney disease e-consultation service allows GPs to share a patient's electronic health record with a renal specialist after first obtaining and recording the patient's verbal consent. The specialist can review the electronic health record and decide whether a patient should be referred to clinic or undergo tests or interventions in primary care. Responses are saved in the electronic health record and also sent as tasks to alert the referring GP. The service enables GPs to obtain specific management advice or request virtual review of patients before making a hospital nephrology clinic referral. e-consultation services have subsequently been deployed in Bradford and Airedale in other long term conditions, including cardiology, endocrinology, hepatology, rheumatology and haematology. Further emulation of the model is being facilitated in several health communities across Yorkshire and the Humber and hospital-based clinicians are actively exploiting the potential of shared electronic records with primary care to enhance the care of patients with more advanced disease.

<http://www.kidneycare.nhs.uk/Library/nephrologyposter12.pdf>

## 4. Better access to better information

**Summary:** This chapter outlines how we will access information, including a new, single, website 'portal' provided by the Government from 2013, and one 'routine' number. It sets out moves towards a new culture of transparency, where we will be encouraged to provide instant feedback about services, and where information about the quality and performance of health and care services is easily accessible.

### Key ambitions

- *A culture of transparency, where access to high-quality, evidence-based information held by Government and health and care services about services and about the quality of care is openly and easily available;*
- *Information regarded as a health and care service in its own right for us all – with support for those who need it to access and use available information, so that information helps reduce inequalities and benefits everyone.*

Access to good quality information, and being supported to use it effectively, is an important health and care service in its own right. Useful, accurate information that is based on evidence is essential for us to make choices about our care and hold services to account. This chapter focuses on the range of information available to us. It sets out a radical simplification of the way we will be able to access trusted information – about other people's experiences of care, hospital and care-home performance, symptoms, treatments and information that can help us make healthier lifestyle choices.

### What 'better access to better information' means for me:

**As a patient or service user** – I will be able to find the information I need through a single trusted place. I will be able to use the national information portal on the internet to understand my symptoms and what I can do to manage them, and also to identify services that I may want to approach. I will be able to access information relating to different services or clinical teams to make an informed choice about my care. I will be confident that the information available through the national portal is of high quality, whether this comes from the NHS, local authorities, national bodies or from trusted third parties, including patient organisations.

If I need it, I will be able to access support, provided by the NHS or my local authority, which helps me to locate and make best use of the available information.



I will be able to leave feedback about my health and care experiences whenever I use services, in a way which is convenient and feels more like my experience elsewhere on the internet. I will feel confident that my feedback and complaints will be used to improve services.

**As a carer** – I will have access to the information I need through a single portal to help the person I care for, reducing the complexity and confusion of navigating the system. I will be informed about the options available to the person I care for. I will know what support is available to me, such as for breaks and financial assistance.

**As a citizen and member of the community** – I will be able to use the information portal on the internet to understand my symptoms and identify services available to me. I will know about local support groups and networks. I will be able to see clearly which organisations and professionals are performing better than others. I will expect health and care services to make information freely available to support accountability.

**As a health and care professional** – My patients and service users will be increasingly well informed about their conditions, needs and the services available to them, what good quality care looks like, and the experience of others like them. I will be able to recommend information resources available via the national portal to the people in my care, being confident in their quality.

**As a commissioner of care services** – Through having far more detailed experience and equalities data available to me, I will be able to make better informed commissioning decisions about the services that people in my area want and need. I will ensure all patients and service users have the support to benefit from online access to their own health and care records, and from a growing range of other online services. As a Council Cabinet Member for Health, I will be able to download an integrated analysis about my community, a short list of cost-effective ways to address local problems and ways to share experiences online with councils with similar challenges.

**As a service provider** – With transparency as the default position, there will be more information about parts of my organisation in the public domain, including better quality user experience data, which I can use to improve my services. I will be able to hear the views of people who use my services, including comments and ratings, and use these to identify areas for service improvement.



**As an information ‘intermediary’** – The services I offer will be increasingly recognised as contributing to people’s health, extending reach and utility of information through innovation. National information standards will give me clarity and if I meet the requirements of the new national portal, this can provide a potential ‘shop window’ to my services. I will have an increasing range of open data and content made available for me to re-use and add value. My business will be expected to be self-funding, but I will know ‘the rules’ by which the system will operate, the role of the centre, and where there may be opportunities to innovate.

## What we want

- 4.1 Clear messages from responses to the Department of Health’s consultation on *Liberating the NHS: An Information Revolution*, and also from the NHS Future Forum listening exercise and the *Caring for our future* engagement were that, as users of health and care services and as citizens, we:
- support a single, trusted health and care portal acting as a bridge to quality-assured information from third parties, including patient organisations – we would like to find information quickly, in one place and in as few clicks as possible;
  - want as much comparable information as possible to be available in order to make good choices and to build a partnership between us and our care providers;
  - recognise the value of more independent sources of information to complement Government provision, but have concerns over confusing information of varying quality and accuracy, particularly in respect of clinical content;
  - want information to benefit everyone and reduce (not increase) health inequalities – with appropriate support for the many of us who need it in understanding and using information effectively – in particular, we are clear that not being able to access the internet should not be a barrier to information;
  - want more information on clinical outcomes, with a clear plan for publishing all currently available information by 2015, and developing further new measures;
  - want to be able to feed back on treatment and services to inform others, shape better care delivery, and understand and manage our own care;
  - want a new generation of citizen-reported experience measures that evaluate experiences across a person’s entire experience of care, within and between services.
- 4.2 Work carried out with users by NHS Choices indicates the breadth of information that we want to see, relating to:
- our 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 our care or treatment;
- the track record, expertise and experience of clinicians or other professionals providing our care or treatment;
- for those of us with multiple care needs, how our package of care will be coordinated;
- the experiences of other patients, friends and relatives;
- the experiences of staff in the organisation providing our care;
- the views and advice of our 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.

## Where are we now?

- 4.3 Over the 'digital decade' of the past ten years, we have seen an explosion in our take-up and use of mobile phones and other mobile devices (hand-helds, tablets and so on). There are now more active mobile phone subscriptions (80m) than people in the country, with over 90% of us having at least one mobile phone. Although many of us still use simple mobile phones for voice and text, increasingly our devices are smartphones that can search the internet and access a range of web-based services. Over a quarter of UK adults now have a smartphone, and 23% of our online surfing is now via a mobile device<sup>22</sup>.
- 4.4 Even with the expansion of access to the internet, there remains a core of us who do not go online. Three quarters of all homes have broadband access to the internet, but that still leaves a quarter that does not. Those of us who are not online are likely to be those who could most benefit from health information and services – older people, people with low incomes, people with disabilities and long-term conditions, people with transient lifestyles. However, many are likely to have a mobile phone, if not necessarily a smartphone.

<sup>22</sup> see Communications Market Report UK, Ofcom, 2011 – <http://stakeholders.ofcom.org.uk/market-data-research/market-data/communications-market-reports/>

- 4.5 There are around 2,000 major providers of health information in the UK alone. Quality is very variable and compares poorly to travel, financial services or utilities. There are over 4,200 NHS websites, some duplicating information, others poor quality and not updated. Many of us are confused between the national NHS online services currently available, such as NHS Choices ([www.nhs.uk](http://www.nhs.uk)) and NHS Direct ([www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)), and how these relate to information on other NHS or local authorities' websites. The amount of information available about health organisations can be overwhelming.
- 4.6 Government, its arm's length bodies and other agencies and health and care providers already publish a wide range of data and information about the health and care services that are available, their performance and the quality of the care they give. But this is not always easy to find, published in easily accessible formats or easy to compare.
- 4.7 The NHS Institute for Innovation and Improvement has brought together the evidence base for improving patient experience, 'how to' guides, and examples of practice in one place under 'Transforming Patient Experience: the essential guide'.<sup>23</sup> Research commissioned from the King's Fund and King's College London into what matters to us as patients has informed the National Quality Board's NHS Patient Experience Framework, published in February 2012.<sup>24</sup> It outlines those elements that are critical to our experience of NHS services. NICE has published patient experience Quality Standards<sup>25</sup>, one for Mental Health and one for Adult Services, which for these elements describe what high quality patient experience looks like and how it might be measured. Our experience should be measured in terms of our 'journey', to capture transitions between different services.
- 4.8 Good information and advice are only useful to us if we have some understanding of the health or care issues and options open to us, i.e. our health literacy. We know that health literacy levels are not high for many people, so initiatives such as health trainers can provide that additional advice and support required to make healthy living choices and decisions about our own care.

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23 Transforming Patient Experience: the essential guide

[http://www.institute.nhs.uk/patient\\_experience/guide/home\\_page.html](http://www.institute.nhs.uk/patient_experience/guide/home_page.html)

24 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_132786](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132786)

25 NICE Quality Standard – Patient Experience in adult NHS services

<http://www.nice.org.uk/guidance/qualitystandards/patientexperience/home.jsp>

NICE Quality Standard – Service user experience in adult mental health

<http://www.nice.org.uk/guidance/qualitystandards/service-user-experience-in-adult-mental-health/index.jsp>

## Case study: the health trainer workforce

The health trainer workforce in England has been developed over the last five years in a unique collaboration between the National Team at the Department of Health, regional teams and local services. An enormous amount has been learnt about how to recruit, train and support a lay workforce to engage people from some of the country's poorest communities and support them to make the changes in their lifestyle that they want to make.

From the outset they were intended to offer 'support from next door' rather than 'advice from on high' and to:

- target 'hard to reach' and disadvantaged groups;
- increase healthy behaviour and uptake of preventative services;
- provide opportunities for people from disadvantaged backgrounds to gain skills and employment;
- reduce health inequalities.

The website below brings together information from across the country about health trainers. <http://www.healthtrainersengland.com/home>

- 4.9 The Care Quality Commission currently runs the Patient Survey Programme, which captures feedback from patients on NHS services.<sup>26</sup> Similarly, the annual Health and Social Care Information Centre user survey<sup>27</sup> provides information on adult social care service users. The annual Staff Survey provides information on staff experience, which we know from research drives better patient experience. Taken together, these information sources provide a rich picture of how a provider is functioning.
- 4.10 As users of health and care services, we can already rate and comment on providers (hospitals, GP practices, dental practices and community pharmacies) via NHS Choices. All NHS organisations have the opportunity to receive feedback via NHS Choices at no local cost, but some feel that, in addition, other services can provide added value.
- 4.11 Research demonstrates a link between our good experience of care as users of health and care services with organisations or teams where staff themselves have a positive experience<sup>28</sup>. For the NHS, staff views and experiences of their organisations are

<sup>26</sup> see <http://www.nhssurveys.org/>

<sup>27</sup> see <http://www.ic.nhs.uk/services/social-care/social-care-collections/user-surveys>

<sup>28</sup> see research carried out by Aston University in 2009 to 2010 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_129643](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_129643)

collected through the annual NHS Staff Survey<sup>29</sup>. Selected staff survey and patient survey indicators for all NHS trusts are currently presented on NHS Choices, allowing side-by-side comparisons of any two organisations.

## The vision

- 4.12 The Future Forum emphasised that: *“Information for patients and service users is an integral part of care. Like medicine, good information can heal but poor information or poor handling of information can harm.”* This chapter covers how we access broader information about health and care and making more information available to us, in ways which we can understand – information about services, about specific conditions and treatments, and about our health, lifestyle and wellbeing options.
- 4.13 This includes making information available to us on the performance and quality of our services, in particular on individual clinical and other care outcomes at a more detailed level. This can include clinical audits down to individual clinician or clinical team, staff feedback and views, and patients’ and service users’ opinions, feedback and complaints.
- 4.14 We want to have access to clear information and advice that helps us understand and make informed decisions about the type of care and support we need, the care available to us locally and how the different options compare. In terms of social care services, we also need information and advice on what our responsibilities are in maintaining our own wellbeing, planning and paying for our own care, and what we can expect from the state and our local authority in terms of support (financial or otherwise).
- 4.15 Rich information on quality can improve our conversations and interactions with those providing our care, either through face-to-face contact or remotely. The aim is for everyone to benefit – irrespective of whether we can access the internet, have other translation, communication or support needs – and for information to improve health and care and to reduce inequalities. This will mean that some of us will need extra support to use information as a core part of our care services.
- 4.16 For those of us with carers, our own health outcomes can improve when our carers and parents are better informed about our conditions, the services available to them, and how to maintain their own life and health alongside their caring role. Care professionals can play a vital role in ensuring the people we trust to care for us are identified at an early stage, and that those who care for us are signposted towards accurate, timely and useful information.

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<sup>29</sup> see <http://www.nhsstaffsurveys.com>

- 4.17 Information can and should enable us to make better choices about our own health and about our care services, have a better experience of care, improve our outcomes and also help the service operate more efficiently.

## The evidence and benefits

- 4.18 Evidence suggests that transparency can have a positive effect in improving our care services and our health outcomes. As one very powerful example of this, the Society for Cardiothoracic Surgeons reported that mortality in coronary artery surgery had fallen by a fifth and in aortic valve replacement surgery by a third over five years – with this result attributed to public reporting of outcomes by individual surgeons. Overall, savings outweighed the costs of data collection more than threefold<sup>30</sup>.
- 4.19 Independent research published in February 2012<sup>31</sup> found that hospitals recommended by patients on the NHS Choices website tend to have lower death rates and lower readmission rates. Hospitals rated as cleaner by patients have lower MRSA rates.
- 4.20 Lay-led and disease-specific patient education courses, such as The Expert Patient Programme<sup>32</sup>, DAFNE/DESMOND<sup>33</sup>, Challenging Arthritis<sup>34</sup> and Breathe Easy<sup>35</sup> currently use high quality information and tools to train and educate people about their own condition, build confidence and support them to manage their own condition. Building consumer knowledge helps to increase ownership of the decisions we make that affect our health.
- 4.21 The case for embedding shared decision-making throughout NHS practice has been strongly made<sup>36</sup>. Not only is there a strong ethical imperative driving the case for us to be partners in our own care, but evidence shows that involving us in making important decisions about our own lifestyle or treatment options improves our experience of care and the quality of our lives. Research shows strong proven benefits for us as patients from shared decision-making, including:
- better treatment adherence – we stick to our treatment plans;
  - we have improved confidence and coping skills;
  - fewer of us choose major surgery, creating cost savings;

30 <http://www.guardian.co.uk/lifeandstyle/2009/jul/30/heart-surgery-death-rates-fall>

31 [http://www3.imperial.ac.uk/newsandeventspggrp/imperialcollege/newssummary/news\\_14-2-2012-10-30-40](http://www3.imperial.ac.uk/newsandeventspggrp/imperialcollege/newssummary/news_14-2-2012-10-30-40)

32 see <http://www.nhs.uk/Conditions/Expert-patients-programme-/Pages/Introduction.aspx>

33 Education programmes created for people with type 1 and type 2 diabetes

see <http://www.dafne.uk.com/> and <http://www.desmond-project.org.uk/>

34 see <http://www.arthritiscare.org.uk/>

35 see <http://www.lunguk.org/supporting-you/breathe-easy/>

36 *Leading the way to shared decision making; summit report* Health Foundation, February 2012



- our health behaviours improve, such as increasing exercise and reducing smoking; and
- we use services more appropriately, particularly with fewer emergency admissions.

4.22 Evidence<sup>37 38</sup> also indicates that when we are given good information and advice, we are more likely to opt for social care personal budgets and direct payments, we are more likely to stay with them and achieve better outcomes.

### Case study: NHS Information Service for Parents

Information and advice for parents-to-be and new parents is a key part of the care and support which the NHS provides to families. From May 2012, all parents-to-be and parents of new babies will be given the opportunity to sign up for a new digital service, the NHS Information Service for Parents. The new service will use evidence-based NHS content, including new videos, to provide messages of advice and actions to take, throughout pregnancy and after birth. The service will be provided by email, but importantly, also by text message to ensure the service reaches as many people as possible. Increasingly the core information from the NHS will be augmented by quality-assured information from voluntary sector and independent information providers.

To sign up for text messages and emails go to [www.nhs.uk/parents](http://www.nhs.uk/parents)

4.23 We need the right information to take part in decisions about our care. Patient Decision Aids<sup>39</sup> and Information Prescriptions<sup>40</sup> are tools that can help us to understand our options, consider the importance of possible benefits and harms, and facilitate our communication with our care professionals. The best of these, and of any other tools or innovations that can support genuine shared decision-making, will increasingly be available through a national online health and care portal.

37 The National Personal Budget Survey (June 2011) (POET Survey) Chris Hatton and John Waters (Lancaster University and In Control)

38 Independent Living Strategy: Support planning and brokerage – final report from the support planning and brokerage demonstrator project, ODI (May 2011)

39 See *Right Care: Shared Decision-Making* [www.rightcare.nhs.uk/index.php/shared-decision-making/](http://www.rightcare.nhs.uk/index.php/shared-decision-making/)

40 See <http://www.nhs.uk/Planners/Yourhealth/Pages/Information.aspx>



## Case study: Patient Decision Aids

Patient Decision Aids (PDAs) are designed to help patients make difficult decisions about their treatments and medical tests. Research shows that decision aids can be very effective in supporting shared decision-making, enabling patients to make informed choices about their own healthcare and increasing patients' awareness of expected risks, benefits and outcomes. NHS Direct has developed a set of PDAs on topics covering treatment options for conditions including breast cancer, arthritis and prostate disease. Each decision aid allows patients to create a personal record of their healthcare journey, building into a summary of information visited and the answers to questions asked. This summary is also available to health professionals and can be used when discussing treatment preferences with them.

Beginning in 2012, the Right Care Shared Decision Making Programme is addressing the challenge of embedding access to a group of 36 PDAs developed by the Programme, in primary and secondary provider information systems. These PDAs will be available on a web platform and provided in various formats: long form for patient use; short form for consultation-based discussion, plus mobile apps for ease of access. This will require primary and secondary care provider information systems developments to support integration. Integration should prompt the clinician's awareness of a clinically relevant PDA. Systems should also support the feedback of partially or fully patient-completed PDA content to the provider info system for inclusion in the patient's medical record and to inform further consultation discussions if required. This will provide a truly mutual, transactional process resulting in a recorded shared decision.

<http://www.nhsdirect.nhs.uk/DecisionAids>

<http://www.rightcare.nhs.uk/>

## Case study: Information Prescriptions

The Information Prescription Service (IPS) allows users, both professional and public, to create information prescriptions for long-term health needs. Patients and carers have told us they want to know how to find information they can trust and rely on. Information prescriptions bring together the best quality assured information from NHS Choices and voluntary sector partners to make it easier to find the information patients need. Information includes leaflets from voluntary sector partners, NICE guidance, directory information and packages of specially developed information from cancer patient organisations. To date, there are 90 partners involved and an increasing number of local organisations submitting content to the system.

<http://www.nhs.uk/Planners/Yourhealth/Pages/Information.aspx>

## The journey – transparency

- 4.24 This Government is setting out a clear roadmap for making all of our data open – for the health and care sector, this is set out in more detail in **Annex B**.
- 4.25 At the heart of the Government's modernisation programme is an ambition to deliver outcomes that are amongst the best in the world. This ambition applies equally to healthcare outcomes, public health outcomes and social care outcomes. To support the creation of an outcomes-based health and social care system, where success is measured in terms of the actual results achieved for patients, service users and whole populations, the Government is developing three strategic outcomes frameworks – the NHS Outcomes Framework, the Public Health Outcomes Framework and the Adult Social Care Outcomes Framework.
- 4.26 Beginning with publishing national clinical audit data by clinical team from April 2012, all clinical outcomes data will be put into the public domain by 2015. Building on the successful approach taken in relation to some specific services – notably heart surgery<sup>41</sup> – for areas which are not already planning to release data earlier, the initial stage to April 2013 will enable time for local action to be taken on data quality. This will allow ongoing opportunities for professionals to check their own data for accuracy prior to wider release. The intention will be for data by clinical teams (relating to activity since April 2013) to be available from April 2014 – alongside earlier data for areas where it will be available sooner. (It is important to recognise that for some conditions, a successful outcome will depend upon well-integrated care across a number of different teams.)
- 4.27 The Health and Social Care Information Centre will quality assure and then publish the information it collects, combined and made anonymous, as the default position. This includes a move towards the publication of existing datasets by clinical team. Indeed, this kind of data (e.g. by lead consultant) is already collected – but currently uses a complex process of extraction and coding from paper notes with limited clinical validation, and further work is needed to improve the quality and usefulness of that data.
- 4.28 Information that puts the data in context will be vital to make the best use of it. This is true whether patients are using the information to exercise choice, or whether professionals are using it to improve the care they provide. Collaborative work with professional organisations such as Royal Colleges will help produce guidance, tools and explanations to help people understand the data and support service improvements. The more complete picture of health and care and how it is managed will mean providers become truly accountable to their local areas.

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41 <http://heartsurgery.cqc.org.uk/>

Health and Wellbeing Boards will publish local health and wellbeing strategies and provide a forum for dialogue. The Care Quality Commission will continue to provide information on how providers are meeting essential levels of safety and quality.

- 4.29 Simpler performance measures, metrics or indicators that combine existing information available about organisations (patient reported outcome measures (PROMs) information, MRSA rates, patient feedback etc.) into a small number of indicators would be easier to understand and easier to share with other information providers. This would make comparable information more accessible and meaningful to us – and would also feed into the outcome metrics and indicators used and published through national outcomes frameworks. For social care, the forthcoming care and support White Paper will set out more detail.
- 4.30 We need information about service providers to drive quality improvements and in order to make choice meaningful for us as users of care and support services, whether publicly funded or self-funded. The forthcoming care and support White Paper will set out proposals for ensuring people have access to clear and easy to compare information about the quality of all providers (care homes; domiciliary care providers and potentially personal assistants).
- 4.31 Local organisations will provide information on the quality of care they provide for us through Quality Accounts. Quality Accounts (currently published on the NHS Choices website) enable all providers of NHS services to give us a clear picture of the quality of their services and their future priorities, tailored to local need. This means that we, as well as local commissioners of NHS services, can hold them to account for improving their care. Planned changes from 2012/13 will see NHS trusts and foundation trusts also include in their Quality Accounts a set of indicators about the quality of their care, including patient reported outcomes following surgery, responsiveness to patients' needs and patient safety. This will allow trusts to benchmark their performance and make it easier for commissioners, patients and the public to compare quality locally and around the country.
- 4.32 As an example of this transparency, and as set out in Annex B, comparative information on GP practices is already becoming available, enabling practices – and also us as patients – to compare different practices' health outcomes.
- 4.33 As part of the 'Sector Led Improvement Initiative', led by the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS), Local Accounts will mean councils providing information and undertaking ongoing self-assessment and assurance, enabling comparisons on priorities and progress between and within councils.

- 4.34 Simpler metrics and indicators to help us understand and compare the performance of health and social care providers will be provided centrally on the national online portal (alongside more detailed performance information). This will start with primary care services this year (working with professional bodies). A wider range of simplified metrics will be available by 2015.
- 4.35 The Health and Social Care Information Centre, the Department of Health and the Association of Directors of Adult Social Care are undertaking a 'zero-based review'<sup>42</sup> of social care data. The overall objective of the review is to build an agreed minimum data set of management information which is of direct use and benefit to local authorities and their local strategic partners, to the Department of Health and other Government departments, to regulators and to the general public. Its publication should therefore promote transparency, local accountability and public scrutiny.
- 4.36 Public Health England will report progress against the indicators in the Public Health Outcomes Framework<sup>43</sup>. However, local authorities will wish to consider publishing additional data on the performance of local services, to aid transparency.

## The journey – access to information

- 4.37 In future there will be just three main ways for patients and service users to access help and information at the national level across healthcare, public health and care and support:
- **999** as the telephone service for emergencies;
  - **111** as the telephone service for health and care advice and services; and
  - **a comprehensive online 'portal'** – bringing together the best of the relevant information and online services currently provided by the existing national web services: NHS Choices, NHS Direct online, NHS 111 online content and Healthspace. This will act as a 'front door' to the best information on health and care available on the internet.
- 4.38 Central Government or other national bodies will retain responsibility across some core areas where public accountability, clinical safety or simple pragmatic reasons mean a single set of authoritative or trusted information is required nationally, for example:
- public health emergencies, health protection and the evidence base to guide public health practice;

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42 <http://www.ic.nhs.uk/services/social-care/zero-based-review-of-social-care-data>

43 <http://healthandcare.dh.gov.uk/public-health-outcomes-framework/>

- high quality evidence and guidance information to support high quality standards of care – such as that provided by NICE;
- managing symptoms, common everyday conditions and treatment choices;
- national public health campaigns and guidelines on health improvement – for instance Change4Life;
- directories of services;
- health and social care rights and entitlements – including areas where there is a statutory requirement to inform people of how to claim;
- consistent core information on the safety and quality of services and providers;
- information enabling regulators to support their functions – for example the Care Quality Commission uses user-experience information in its Quality and Risk profiles.

- 4.39 While Government should provide a core set of this information, it cannot try to provide everything to everyone. Within specific areas, there are already organisations, often in the voluntary sector, which can provide better-targeted information. The Government will be clear about what will need to be provided centrally, giving others space to innovate.
- 4.40 Much of the data that is technically available is often hard for us to find, and difficult for us to understand and use with confidence. The Department of Health will work with the Health and Social Care Information Centre and other organisations that collect and hold health and social care data to identify data sources, and will bring these bodies together with information intermediaries, to encourage the development of more accessible ways for people to use this data to inform choices about their care and wellbeing.
- 4.41 A partnership approach will build on the current role of the Department of Health's Health and Social Care Transparency panel to bring together data suppliers, information intermediaries and the end-users of data and information (patients, carers and other service users and service providers and commissioners) to support wider and more innovative use of available data. The development of an inventory of data collected and held by different parts of the health and social care system by April 2013 will form part of this work.
- 4.42 Open information availability and greater transparency will enable people to make these better choices and drive up quality and outcomes. Central bodies such as the Health and Social Care Information Centre are increasingly making anonymised, linked data available for re-use by information intermediaries (organisations that present information in innovative and useful ways), who can then add value by

presenting it in ways that are most useful for specific audiences – for example, using data to produce personal, interactive information products and apps.

- 4.43 In addition, with the growing popularity and use of smartphones and tablets, the health and care system of the future will direct us, as patients and the public, towards accredited health apps to help us keep ourselves healthy and, as appropriate, manage our conditions.
- 4.44 At the same time as exploiting simple services like SMS text used by large numbers of people, there will be considerable opportunities to exploit the cutting-edge innovation which can come through mobile technologies. Mobiles tend to be highly personal devices, always on and always with us. They work in real time and linked to a highly specific location. The mobile industry is vibrant, creative and highly competitive. These factors create a particular climate for innovative applications by imaginative developers. The most appropriate role for Government is not to create apps of its own, but instead to open up public data and content freely for re-use by independent information intermediaries to add value.

### Case study: WellNote by Dr Darzi

Information intermediaries are taking NHS information opened up through simple syndication feeds and adding value as innovative tools and apps. A good example is the 'Wellnote by Dr Darzi' app. Wellnote takes directories of services from NHS Choices and uses GPS technology to help find hospitals, GPs, dentists, pharmacies, walk-in centres and sexual health services. Users can also see user ratings of services. Wellnote also has the functionality for people to store their own personal health details, including medication drawn from a database of over 2,000 commonly used medicines. Personal details can be emailed to self or health professional, and reminders set for appointments.

<http://wellnote.co.uk/>

- 4.45 Beyond the core information provided nationally by Government and creating the right environment to support the development of an information market, the state will not intervene in the information market unless it is necessary to prevent a significant negative impact on outcomes, equalities or efficiency. For example, the state has a responsibility to ensure that public health surveillance systems can identify new and emerging threats to health such as pandemic flu, and monitor the response.
- 4.46 The Government will take the lead in ensuring the environment and conditions are right for a vibrant range of information providers to succeed. If outcomes, equalities or efficiency are being adversely affected the first step will be to focus on better signposting to existing or new information, and removing potential barriers which are preventing organisations from entering the market. If this is not sufficient, the



Government will consider providing organisations with support, guidance or analytical tools to better equip them to innovate or support them to enter the market.

- 4.47 The default position for stimulating the market will be through encouraging internet traffic to third party sites via linking through the single portal or from the endorsement which comes from association with the NHS, rather than directly commissioning or providing the services.

### Case study: online patient communities – HealthUnlocked

HealthUnlocked provides web-based tools to enable online communities of people with specific diseases. The tools help gather the knowledge and experience of patients and share it with a wider patient audience. The information and sense of support can reduce the isolation and fear of people facing chronic conditions. HealthUnlocked works with trusted patient groups and charities to provide a high degree of moderation. Use of web widgets and applications that are distributed across websites encourages patients to access communities. NHS Choices is now stepping back from managing its own online communities and working with HealthUnlocked as an independent information intermediary instead.

<http://www.healthunlocked.com/nhschoices/>

- 4.48 Where there is a need to commission information as a service, this should reflect the approach to commissioning other services – with services being delivered from a mixed economy of providers in a manner which is consistent with promoting economy, efficiency and effectiveness, in order to deliver the maximum value for the system.
- 4.49 Responses to the Information Revolution consultation confirmed the view that we want to be reassured about the quality of content (written and visual information on health and care topics). The national online portal described in this chapter will signpost organisations that provide more detailed, specialised information. The portal will not provide links to organisations that do not comply with requirements for accuracy and quality of information. The endorsement of a link from the national portal, and the volumes of our user visits that this will create, will provide a powerful incentive for maintaining standards.
- 4.50 During 2012/13, Government will continue to support 'The Information Standard'<sup>44</sup>, an independent voluntary scheme that accredits providers of information on treatments, conditions, symptoms and disability.

<sup>44</sup> see <http://www.theinformationstandard.org/about>



- 4.51 Local HealthWatch organisations<sup>45</sup> will have a signposting function and should connect to and involve local groups and organisations that work with and are part of communities of interest, geography, demographic and characteristic. This will mean that, locally, we can have access in different ways to the information we need.

## The journey – support for those who need it

- 4.52 Commissioners of health and care services need to recognise the benefits of ensuring appropriate information and communication support for those of us who particularly need it. Supported by guidance, commissioners should be able to commission the local provision of information, and the support to use it, at stages in the development of our care journeys so that information comes to be seen as an integral and necessary part of every service.
- 4.53 A partnership bringing together representatives from the voluntary sector, health and care professions and industry will consider how to make the most effective use of its combined skills, experience and resources to engage directly with us as patients and the public, increase our health literacy and support information producers to communicate effectively in ways that are meaningful to us.
- 4.54 The NHS Commissioning Board will wish to consider publishing commissioning guidance on support, advocacy and information services. This could effectively be commissioning guidance on meeting the outcomes of domain 4 of the NHS outcomes framework. The forthcoming care and support White Paper sets out how the care and support system will work together to improve access to information and advice to citizens and the additional funding available to local authorities to do this.

### Case study: Continuing Healthcare (CHC) in Stockport

The process for provision of continuing healthcare has been reviewed, made quicker and more person centred. A key aspect of this is the routine offer of independent information and advice through Age UK to support and individual's understanding of alternative care choices available. The assessments are now paper free and use e-forms to input to CHC panel and receive panel decisions electronically and allow for sharing information with the service user and their independent advisor.

[www.mycaremychoice.org.uk](http://www.mycaremychoice.org.uk)

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<sup>45</sup> A Local HealthWatch will be an independent organisation, able to employ its own staff and volunteers, so it can become the influential and effective voice of the public. The aim of Local HealthWatch will be to give citizens and communities a stronger voice to influence and challenge how health and social care services are provided within their locality.

- 4.55 For those of us who need support in accessing information, health and care professionals as 'information givers' have a vital role. Professionals need excellent communication skills for sharing information and for communicating with us in ways that the person receiving care can understand. This includes thinking about language and interpretation support and ensuring that all communications are in formats that each of us – as the individual recipient of the care – can understand.

### Case study: good communication – SignTranslate

SignTranslate provides instant help for clinical staff who need to communicate with a deaf patient. The online interpreting service uses a simple webcam to link to qualified British Sign Language (BSL) interpreters. The service is provided by SignHealth, a registered charity, and interpreters are provided by partner interpreting organisations around the country. SignTranslate is being used for GP visits, hospital A&E departments, maternity units – in fact, any situation where it can be difficult to organise a face-to-face interpreter at short notice.

<http://www.signtranslate.com/>

- 4.56 Improving the health of those of us who are most at risk or with the worst health outcomes will be crucial to reducing the impact on future demand of changing demographics and disease burdens. We need to take a more considered approach to information support for vulnerable and excluded groups, to reduce health inequalities.
- 4.57 For those of us that need extra support, more systematic recording of our particular information and support needs and preferences, and sharing of this crucial information with the other professionals who we encounter along our care pathways would not only have benefits for us, but would also go a long way towards helping care provider organisations to demonstrate compliance with the Public Sector Equality Duty, with the NHS Constitution and with proposed updated obligations on local authorities to provide information and advice services in their area.
- 4.58 Many community organisations exist to meet the needs of people who are vulnerable or disadvantaged or, because of cultural issues, face barriers when accessing state or publicly run services and do not receive the support they need. Services can work with community-led and user-owned organisations to reach people in ways that help ensure they are fully engaged with their own care. Commissioners of health and care services and provider organisations have a particular responsibility to work with and build on the expertise in these, often very small, groups and organisations as information 'intermediaries'. One good example is the Go On<sup>46</sup> partnership, working

<sup>46</sup> see <http://www.go-on-uk.org/>

to increase access and support, including the interpretation of health and care information into more accessible formats and mechanisms, to those who suffer the greatest inequalities.

## The journey – user feedback

- 4.59 This Government believes that every encounter with health and care services should be an opportunity to collect systematically our views and feedback on our experience of those services. Organisations need to take better account of feedback and our other comments as users of services, and of complaints as another valuable source of feedback. They should also consider reporting back how our feedback has been used to improve services and care pathways.
- 4.60 In January 2012, the Prime Minister announced a 'Friends and Family Test' – a step change in local improvement and transparency by obtaining feedback from both service users and staff – frequently and at a granular level – through an easy-to-understand question about the care provided, and then using that feedback to improve services. During 2012-13, in line with expectations in the NHS Operating Framework, the NHS will work towards implementing the 'Friends and Family Test' with SHA clusters, including Midlands and East who are implementing a coordinated scheme, to share tools and know-how.
- 4.61 The Government is now working with the NHS Institute for Innovation and Improvement (NHSI) to identify, promote, and spread examples of practice in local measurement and improvement in patient experience. The Patient Feedback Challenge<sup>47</sup> was launched in March 2012, backed by a £1m fund which will support the development of ambitious demonstration sites that develop a fully integrated patient experience measurement system, create wholly patient-focussed organisations, encourage spread and adoption of positive patient experience practice within and across organisations and develop sustainable approaches that live beyond the initial programme.
- 4.62 We need a way to feed back on experiences, based on our journey of care across a range of services, and for clinical services encountered within an organisation. This is a complex issue to get right and the Government has therefore commissioned research to develop new models for capturing our experience in this way, which will be available by the end of 2013.
- 4.63 To achieve significant and meaningful volumes of feedback we will need to have a range of opportunities to make our views known. This will include using different technologies and channels (online, SMS, bedside TV, etc.) but also giving us choice

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<sup>47</sup> see <http://www.institute.nhs.uk/patientfeedback>

about how we provide our feedback. Some of us will want to make our views known directly via a central website; others will want our comments to go to an independent organisation.

- 4.64 A number of organisations already enable us to provide online feedback about our care, and others are coming into the market<sup>48</sup>. Central Government will not seek to duplicate this specific function but will look to pool the comments made on external sites on the national portal (for example, on provider scorecards). In return, this will help to stimulate new traffic to those sites to help them become sustainable<sup>49</sup>.
- 4.65 In future, we can expect to see further commenting services developing in the information marketplace. It is, entirely appropriately, a local commissioning decision to ensure the right mix of feedback services for effective insight into user experience.
- 4.66 In the long term, our electronic health and care records may prove to be a main vehicle for providing information on health and care outcomes and status, rating our experience of care, and leaving feedback and comment. Innovations linked to our online records could enable us to record and share health comments and also prompt better conversations between us as patients or users of services and the professionals providing our care.

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<sup>48</sup> Including amongst others [www.patientopinion.org.uk](http://www.patientopinion.org.uk), [www.iwantgreatcare.org.uk](http://www.iwantgreatcare.org.uk), [www.goodcareguide.org.uk](http://www.goodcareguide.org.uk)

<sup>49</sup> Publishing Patient Opinion comments on the NHS Choices website has significantly increased site visitors to Patient Opinion's website hence raising its profile.

## Case study: new approaches to patient comment

An increasing range of opportunities are available for patients to provide comment and ratings on health and care services. In addition to commenting via NHS Choices, services such as Patient Opinion and iWantGreatCare give patients the opportunity to comment via independent routes. Further work is being undertaken to expand this facility across the providers of social care services. New initiatives are being developed including the new Action on Hearing Loss locate-and-rate initiative for hearing services. NHS Choices publishes comments from Patient Opinion alongside NHS Choices' own comments, and will increasingly publish comments from other good quality commenting services, increasing volumes of comments and providing choice.

New approaches are also under way to provide more routes for patients to provide comments. Princess Alexandra Hospital NHS Trust, Harlow has piloted patient comment via SMS text messages while Broomfield Hospital in Essex has trialled capturing real-time patient feedback at ward level through bedside television. This is a partnership between the centre (NHS Choices), independent information intermediary (Patient Opinion) and technology provider (Hospedia). These approaches offer a choice of channels which may reach an audience who are unlikely to use online feedback routes.

[www.nhs.uk](http://www.nhs.uk)

[www.patientopinion.org.uk](http://www.patientopinion.org.uk)

[www.iwantgreatcare.org](http://www.iwantgreatcare.org)

[www.actiononhearingloss.org.uk/locateandrate](http://www.actiononhearingloss.org.uk/locateandrate)

- 4.67 The NHS Operating Framework 2012/13 already exhorts NHS organisations to actively seek out, respond positively and improve services in line with patient feedback. This includes acting on complaints, users' comments, local and national surveys and results from real-time data. Increasingly techniques such as sentiment analysis<sup>50</sup> or social media aggregation<sup>51</sup> have the potential to provide rapid indicators and early warnings of some areas of performance. The extent to which patients, service users and carers feel that services are integrated and coordinated should be analysed and form part of the range of issues covered.
- 4.68 Our comments as patients and service users, and our feedback through social media will become of increasing importance as tools and technology evolve to convert that feedback into actionable intelligence. Increasingly, these approaches could be used to understand what existing users think of existing services, what the public think about

<sup>50</sup> Techniques to determine whether feedback is broadly positive or negative – see: [http://en.wikipedia.org/wiki/Sentiment\\_analysis](http://en.wikipedia.org/wiki/Sentiment_analysis)

<sup>51</sup> see [http://en.wikipedia.org/wiki/Social\\_network\\_aggregation](http://en.wikipedia.org/wiki/Social_network_aggregation)

future plans, and to inform other service users about what other people think about services they may use. Technology companies and providers of NHS services will need to consider how best to develop this important area, and how to use emerging technologies such as sentiment analysis.

- 4.69 The NHS Commissioning Board, Public Health England and the Department of Health will work together to encourage and support organisations to allow us to provide instant feedback and ratings at every encounter with health and care services. In the short term, this will supplement national surveys currently undertaken for commissioning and accountability purposes.
- 4.70 The NHS Future Forum Working Group on the NHS Constitution is currently exploring how the NHS Constitution could be strengthened. In particular, it is looking at whether the following could be reflected in the NHS Constitution: ensuring all of us are provided with opportunities, including online, to leave feedback or make complaints about our experiences of health and care services and to help ensure that organisations act on, and make known how they have acted on, that feedback.
- 4.71 To strengthen the responsibility of providers to show they are listening to and acting on our feedback and comment, the national portal will provide aggregated user feedback data for the local area, to enable local Healthwatch to take further action if necessary, including making reports and recommendations to providers or using its Enter and View power. In addition, local Healthwatch would be able to use its signposting function to promote providing comment and feedback on providers. Provider organisations can choose to use their Quality Account to explain how they are responding to themes from our feedback.
- 4.72 The Health and Social Care Information Centre and the Care Quality Commission will continue to strengthen the relevance of feedback data (such as the potential for analysis techniques or tools to provide rapid indicators and early warnings of some areas of performance) to professional teams and highlight good and innovative practice.
- 4.73 As more sophisticated mechanisms develop to capture our views and feedback, these could also be drawn into the portfolio of evidence that, together with clinical information and clinical audit, contribute to doctors' or other professionals' appraisal and revalidation.

## Case study: mental health service user involvement tool: Puzzled Out

Puzzledout.com is a groundbreaking tool that gives children and young people across the UK an easy way to influence how their local mental health services are delivered, designed and commissioned. It is effective at producing evidence of young people's experience of services, and empowering because people see the difference their contribution makes. It works by enabling service user groups and children's mental health services and commissioners to create online surveys, polls and consultations to gather the views of ex, current and potential service users. Using a unique code feature and Google maps, access to surveys can be targeted at specific groups of children and young people in specific areas.

<http://www.chimat.org.uk/resource/item.aspx?RID=102584>



# 5. A quality-driven information system

**Summary:** This chapter covers the elements needed to underpin the information strategy.

## Key ambitions

- *An information-led culture where all health and care professionals – and local bodies whose policies influence our health, such as local councils – take responsibility for recording, sharing and using information to improve our care.*
- *The widespread use of modern technology to make health and care services more convenient, accessible and efficient;*
- *An information system built on innovative and integrated solutions and local decision-making, within a framework of national standards that will ensure that better quality information can move freely and safely around the system.*

Information must be seen as being core to the business of health and care. Sustained investment in information systems is a core part of delivering high quality, cost-effective health and care services. The Government will not expect every organisation to use the same system, but it will expect different systems to connect. The NHS Commissioning Board, Public Health England and the Department of Health will work with partners to ensure standards promote safe data sharing.

Every organisation should identify a clinician or care professional responsible for organising information in support of better care. Investment in equipment cannot be effective without a corresponding investment in staff training, development and support – both for informatics professionals and for everyone working in health and care. Health and care services need to use and share appropriately the information collected about each of us – for our care, to understand and improve quality of services and outcomes, for research and to improve health at a population level.

At present, too much of the data collected is about activity and too little is on the care quality and outcomes that really helps professionals – and us – to make good decisions. Chapter 3 outlined the vision of our electronic care records becoming a core source of all professional information. These records are a rich source of information on quality and outcomes. When combined and made available in anonymised form, this will support a shift to measure and reward quality and clinically meaningful outcomes for care and health.

The Health and Social Care Information Centre will become the focal point for nationally collected NHS, public health and social care information in England; a multitude of organisations and systems will be able to use this data in a variety of different ways to improve experiences of care, choice and outcomes.

## What 'the information system' means for me:

**As a patient or service user, as a carer, as a citizen and member of the community –** I will be increasingly confident that, through transparency, increasing amounts of high-quality data on health and care are becoming available. This will include information built from data recorded once in my care records and shared securely. I will be able to see this leading to improvements in both my own and everybody else's health and care, and that care services are becoming more efficient, more effective and contributing to better outcomes and helping to reduce inequalities.

**As a health and care professional, as a commissioner of care services, as a service provider –** I will have an increasing appreciation of how recording high quality data in care records not only benefits the individuals concerned, but also contributes to improvements in the care I provide or commission, to population-level health and to research. I will increasingly be drawing on data held and made available by the Health and Social Care Information Centre to benchmark the care I provide or commission against others and to improve that care. I will also be able to see how that information is driving more efficient care and reducing burdens across the health and care system. I will be able to compare my practice against Quality Standards that define key elements of a high quality service.

I will know who my local board level information champion is, and will have an appreciation of the contribution my local information and IT specialists play in helping to improve care.

**As an information or IT specialist –** I will feel increasingly valued for the contribution I can make, and I will be recognised for my expertise and professionalism and I will see its impact in an improving health and care system.

**As a system supplier, as an information provider –** I will be able to make an increasing contribution to improving care, and to how my services and innovations can be taken up by the sector, with fewer barriers to take-up for ideas and services that patients, service users and care professionals think can help them.

**As a researcher or academic –** I will have access to a greater wealth of linked data – through the Clinical Practice Research Datalink service and supported by the Health and Social Care Information Centre – to help inform my work, e.g. research to develop new understanding of health and care issues, to improve the efficiency or effectiveness of services, to develop new treatments, etc.

## What we want

- 5.1 Clear messages from responses to the Department of Health's consultation on *Liberating the NHS: An Information Revolution*, from the NHS Future Forum listening exercise and the *Caring for our future* engagement were that:
- professional and managerial staff need to embrace a culture change, improve leadership and promote staff education to maximise the potential of information and informatics to transform the way we deliver services.
  - clinical and professional staff should be supported to develop the necessary skills and capability to support this informatics agenda, including encouraging accreditation of informatics professionals.
  - there should be a move away from centralised management of IT programmes to allow for innovation and services offered by those best placed to provide them.
  - there is huge potential for health and care and support to make better use of modern technology in delivering high quality services that are both convenient for the people using them and efficient for those providing them.

## Where are we now?

- 5.2 We remain a long way from exploiting the full potential of information and new technologies to transform care and support better outcomes. Developments such as cloud computing and smartphones are making information more flexible, portable and cheaper – quite literally enabling us to carry the most sophisticated information in our pockets. The pace of technological change has outstripped the old approach of centrally and regionally commissioned systems, and points to a new approach that is more adaptable and local.

### Case study: paperless at King's

King's College Hospital has set a target of 2013 to be a paperless hospital. E-prescribing has been rolled out across all the hospital's adult wards. Continuation notes are already made electronically, with staff having made more than 3 million notes using mobile computing. This initiative has assured legibility and accessibility of medical records. King's are also collaborating in the development of a new electronic system for monitoring patients' vital signs. Nurses use iPod Touch devices to record vital signs at the patient's bedside. The data are then sent via the trust's wireless network and loaded into a web-based application, which clinicians will access via the core Electronic Patient Record.

<http://www.ehi.co.uk/insight/analysis/791/ehi-focus-on:-paperless-at-king%E2%80%99s>

- 5.3 Information is not always valued as a key tool to support decision-making – and this has a knock-on effect in terms of cultures and behaviour. Informatics is often seen as the preserve of IT specialists and systems analysts, rather than as an enabler to providing better, more efficient and more convenient care. Too often the way care is delivered is constrained by the capabilities of information systems, rather than those systems being designed to support the way we want to deliver or receive our care.
- 5.4 The NHS Future Forum highlighted the cultural challenge around information sharing, which will need to be addressed to realise the potential of joined-up information for joined-up care:
- " ... information technology is only part of the story about data sharing, and not the main part. Time and again it was put to us that the effectiveness with which information is shared is primarily a matter of culture and behaviour"*
- " ... many health professionals do not always display behaviours, skills and attitudes that are conducive to good communication, information sharing and shared decision-making. Poor communication can be harmful to physical and mental health and is sometimes a killer".*
- 5.5 The current use of information and IT, though excellent in parts, is too variable and disjointed to enable the integrated, high quality care we all want to see. There have been significant improvements in the last decade in the information infrastructure – for instance the whole health system is now able to share images securely such as X-rays through the Picture Archiving and Communication system.
- 5.6 However, many professionals working in care and in health struggle with the information systems they need to use, perhaps because of lack of training and support, because these systems are not the most intuitive and user-friendly, because they seem bureaucratic and are not seen as an integral part of delivering excellent care, or because professional staff do not see the links between the data they record and the uses that data can be put to improve their work and the care that they provide.

## The vision

- 5.7 Wider global investment in hardware, software and 'cloud' internet technology offers new opportunities. Hospitals no longer need to buy and maintain expensive servers on site, with systems suppliers offering cheaper web-based storage and software solutions. The explosion in use of hand-held devices represents an under-exploited area, where care professionals and clinicians can use their computers, smartphones and other technologies securely to input data and access records at the point of care.

- 5.8 Web-based tools (such as Gmail, Facebook, Dropbox, online banking) are a normal part of the public experience, and we might well see health and care records shared relatively inexpensively on web-based platforms in the future.
- 5.9 Government is committed to moving away from an approach where it expects every organisation to use the same system, to one where it helps connect and join up systems. The Department of Health and NHS Commissioning Board will only act where systems need to be coordinated centrally – e.g. to ensure effective and secure movement of information across the system, such as key infrastructure, standards and procurement frameworks to help ensure best use of collective buying power.
- 5.10 Health and social care services will make better use of the information they have, and move towards collecting and using information based on outcomes and quality, rather than merely activity and finance. Over time more clinically relevant data will become available for a wide variety of uses because the source data derives from people's care records (with their personal data protected). We also expect information about us to be shared with our consent appropriately for our care purposes, and to be used in anonymised form to improve services and care.
- 5.11 Background data about us which can be used to improve our own care – and which, when held securely and with appropriate confidentiality safeguards in place, can also be used to understand and tackle health inequalities – will, wherever possible, be recorded once within our care records and shared across our care.
- 5.12 Better use of information will enable better care, professionals to compare their own performance and use richer sources of evidence for research, developing new services and innovations which will improve the range and quality of services available to the public. The benefits will not just be quality and relevance of data, but the ability over time to do away with the need for further burdensome additional data collections – which may be based on poor quality information, or may not be focussed on outcomes or other priorities.
- 5.13 Addressing the cultural and behavioural change needed to make best use of information and IT and to support new ways of working will take time and strong leadership. No strategy in itself can address the issues of cultural and behavioural change but education (in the broadest sense), training and development coupled with effective leadership are crucial to make this happen.
- 5.14 To take full advantage of new technology and new information, staff need support and training. Greater recognition of informatics as a profession and of the importance of information and informatics skills for all those working in health and care will be critical within and across organisations. Clear leadership and focus to grasp the opportunities afforded by modern technology will be required.

- 5.15 There is scope for the UK to become a world-class player in the fast-developing multi-billion pound global industry in health and care IT and informatics. Achieving this requires new market opportunities for UK firms, leadership on global standards and the nurturing of professional clinical and care services informatics capability and capacity in the UK.

## The journey – a new approach to IT

- 5.16 Information and IT need to ‘work’ for clinicians and care professionals; suppliers of information systems are encouraged to work with care professionals in developing information solutions that are safe and offer benefits to professionals as well as helping to improve outcomes for us as patients and service users.
- 5.17 Mobile devices can revolutionise the ways in which health and social care staff work. In the past community-based health staff, in particular, have had poor access to information technology and systems. Increasingly cheap, readily available mobile technology is enabling staff to access and update information and communicate on the go, irrespective of time and place. Clinicians can have easy access to real-time resources at the point of care, enabling them to review and update patient records, make bookings and referrals, issue prescriptions, contact specialist sources of expertise, and access guidance and knowledge bases. The Department of Health Mobile Working Knowledge Centre will continue to identify good practice, experience and benefits, and the Information Sharing Challenge Fund to support and promote innovation.
- 5.18 The Department of Health will also support a number of NHS trailblazer trusts with improved adoption of new technologies in maternity services, including the development and use of necessary standards. This builds on successful initiatives such as midwives using digital pens, which cut administration and improve care as shown below.



## Case study – midwives use digital pens to cut administration and improve care

Portsmouth midwives now use low-cost Blackberry digital pens to write up case notes, which has halved their paperwork. The pen works just like normal on the paper record, which the mum-to-be keeps, but the pen also reads and uploads the data on the form onto the hospital patient record system automatically. The hospital system gets accurate, real-time information for clinical care as well as for payment systems, clinical audits and to support internal performance management. The midwife's linked Blackberry smartphone also has GPS features including an emergency alarm to the exact location, supporting safety, and allows automatic mileage expenses by tracking travel. For each midwife it has given back hours of clinical time and improved quality of care. It has also saved the trust over £220,000 per year and has won a number of national awards, including a 2011 E-Health Insider Award.

<http://www.computerweekly.com/news/1280092704/Case-study-Blackberry-app-saves-Portsmouth-NHS-Trust-220000>

- 5.19 The system needs to incentivise and encourage innovation in health and social care delivery. Assistive technologies like telehealth and telemedicine can offer many benefits in terms of improving our health and care outcomes and our experience of services. Yet funding mechanisms can be seen as barriers to adopting these kinds of services. Innovation, Health and Wealth<sup>52</sup>, published in December 2011, set a delivery agenda for spreading innovation at pace and scale throughout the NHS. In this there are a number of commitments which include the exploration and development of tariffs and further funding mechanisms to incentivise and remove the existing blocks to innovative technologies such as telehealth and telemedicine.
- 5.20 To accelerate development and use of innovative information-based services – including mobile 'apps' – for the benefit of people, professionals and organisations, a partnership with industry and with health and care providers will now step up active work towards the introduction, publication and adoption, by no later than 2015, of interface standards. Information will be published on which applications are compliant to which standards. This will enable software applications in use within health and social care services to access, use and exchange data between themselves in a repeatable and standardised manner, so helping to reduce barriers for innovation.

<sup>52</sup> see [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_131784.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131784.pdf)



## The journey – using information well and focusing on quality

- 5.21 Currently, professionals spend too much time on processing administrative data which does not help them do their job better. Often the data collected is on activity and too little information is collected on outcomes or on quality, which can really help professionals, us as services users and also the public more generally to make good decisions. Chapter 3 outlined the vision of electronic care records becoming a key resource for all professional information. Care record data is a rich source of information on quality and outcomes. When anonymised and combined, this will support a shift to measure and reward quality and clinically meaningful outcomes for care and health.
- 5.22 In social care, the long-term ambition is to develop an information landscape where meaningful information and evidence is routinely captured, exchanged and exploited by professionals and by us as service users. Sharable electronic care records, driving truly integrated care, are fundamental to this vision. Those records would also capture meaningful data through routine professional and self-assessments, to understand our needs and outcomes at an individual, provider and national level. Though different in scale and operation to England, New Zealand uses international evidence-based assessment and IT systems to support this approach, supporting better care planning and producing a wealth of ‘business intelligence’. Standardised assessments also support consistent and portable assessments across District Health Board boundaries.
- 5.23 Standardised assessments also support consistent and portable assessments across District Health Board boundaries. In England, aggregate electronic social care record data can drive system improvement, information for choice, build a rich research base for care and support, supporting growth and provide national outcomes data. Over time, care assessments and records should become a core source of the quality and outcomes information used for system improvement, transparency, research and for national data needs.
- 5.24 From April 2013, the Health and Social Care Information Centre will take on its new status and functions – collecting, linking securely and publishing a wealth of core data – enabling it to become the national focal point and key resource for health and care information. Provisions in the Health and Social Care Act 2012 are designed to strengthen and clarify the role of the Health and Social Care Information Centre so that information can be collected, held securely and made readily available to those who need it in safe, de-identified formats, with crucial safeguards in place to protect the confidential data it holds.
- 5.25 The Health and Social Care Information Centre will publish (subject to certain exceptions) the information it collects. It will have a role in quality assuring that

information. Whilst the Health and Social Care Information Centre will be able to hold and link confidential data drawn from our own health and care records, the information based upon that data which is made publicly available will be aggregated and anonymised so that we, as individuals, cannot be identified.

- 5.26 Currently, management information often has to be manually re-entered from the records kept by our clinicians and other care professionals into administrative systems; this is labour-intensive and increases the opportunity for errors. In the future, data that is gathered solely for the purpose of providing us best evidence based care, based on national standards will provide the data for a rapidly growing range of outcome and quality of care information.
  
- 5.27 Deriving management information directly from our own records has the potential to radically reduce the burden of parallel data collection and broaden the range of useful data available. The process whereby clinical and other data is collected from care settings, coded, validated and sent to the Information Centre needs to be modernised. The vision is to use structured, standardised data – wherever possible recorded in electronic form at the point of care, and validated by the professionals who use it to manage care – as a core, direct source of data for uses such as central returns and hospital episode statistics.
  
- 5.28 To move towards extracting key data directly from clinical or other existing records, the commissioning data set (the main data collection from secondary care) will have an option to return data in an agreed standardised clinical coding language format from April 2014 – allowing hospitals using standardised discharge summaries to extract commissioning data-set data directly from their records systems and benefit from the efficiency savings this brings.
  
- 5.29 Our GP records contain a wealth of information about our care, the prevalence of diseases and about our treatments. The General Practice Extraction Service (GPES)<sup>53</sup> is designed to provide data extractions that are comparable across the system, to be used for specific and approved purposes whilst ensuring confidentiality and privacy, enabling improvements to our care, reductions in health inequalities and increased system efficiencies, by providing access to this information on a national scale for the first time.
  
- 5.30 The Department of Health and the Health and Social Care Information Centre will work with key social care stakeholders including ADASS, provider representative bodies and system suppliers in 2012-13 to develop options for streamlining the administrative burden of gathering information for national use from local authorities and providers, including uploading data from local systems without the need

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<sup>53</sup> see <http://www.ic.nhs.uk/gpes>

for manual returns. Subject to a feasibility appraisal, the Health and Social Care Information Centre will look to trial this.

- 5.31 In commissioning the core data that the Health and Social Care Information Centre will collect on behalf of the overall system, a key role for central bodies including the NHS Commissioning Board, the Care Quality Commission, NICE and Monitor as well as the Department of Health will be to learn from the Fundamental Review of Data Returns and the zero-based review of social care data to minimise the burdens of data collections and ensure that the data collected across the system is the information that is actually needed to improve health and care outcomes.
- 5.32 With the wealth of data collected linked and made available in anonymised form by the Health and Social Care Information Centre, it will become an increasingly attractive option for those collecting separate external collections to draw on data already held, and to share their own collections with the Health and Social Care Information Centre. Where there is a strong clinical case, specialised data collections will still exist in other organisations – for example the rich and widely respected cancer registries and national clinical audits.

### Case study: Health and Social Care Information Centre portal for primary care data

The Health and Social Care Information Centre has launched a new portal to make primary care data easily available. The indicator portal brings together in one place clinical service and outcomes data, which can be linked and analysed in different ways. This will allow patients, academics and information intermediaries to use the data, including adding value by publishing in innovative ways. The first set of primary care data was made available via the portal in December 2011. During 2012, the portal will be developed to widen the data available and to include a set of tools to make it easy for information intermediaries and commissioners of primary care to make the most of the data.

<https://indicators.ic.nhs.uk/webview/>

- 5.33 In addition – drawing on data held by the Health and Social Care Information Centre and from other sources – a complementary new secure data service, the Clinical Practice Research Datalink (CPRD), has been established within the Medicines and Healthcare products Regulatory Agency (MHRA) to service the specialised needs of the research and life sciences communities.
- 5.34 The Nation Adult Social Care Intelligence Service (NASCIS) provided by the Health and Social Care Information Centre allows access to timely, up-to-date information from national social care data collections. NASCIS provides initial, early access for authorities to data that has not been validated, together with a range of analytical

tools to support service planning. As the data is validated and published it becomes open access and available for anyone to use.

- 5.35 The Department of Health has made tackling inequalities and promoting equality a key principle in designing the NHS Outcomes Framework<sup>54</sup>. It is using equalities and inequalities breakdowns to assess data availability in order to monitor this commitment. The process of selecting outcomes and determining how to measure them included active consideration as to how the indicators can be analysed by equalities and inequalities dimensions to support action on reducing health inequalities. In addition to the legally protected characteristics (age, race, religion and belief, gender, disability, sexual orientation, pregnancy and maternity, gender reassignment, marriage and civil partnership), particular consideration has been given to socio-economic groups and area deprivation, as these are key drivers of poor health outcomes. Improved information collection and flows are vital to understanding and improving health and care outcomes for the whole population.
- 5.36 Throughout this transformation, locally and nationally we need to realise the contribution of information in reducing future health needs and dependencies. Upper tier and unitary local authorities will take on a new duty to take appropriate steps to improve the health of their populations from April 2013, funded by a ring-fenced grant. Directors of Public Health will act as champions for health across all of the local authority's business, and will take on day to day responsibility for the use of the new grant, commissioning a range of public health services, such as smoking cessation, drugs and alcohol treatment and weight management.
- 5.37 There will be specific informatics requirements to support the new public health system. These include helping local authorities to collect data that was previously collected by the NHS, for example child height and weight surveillance data to track child obesity and data to monitor delivery of the NHS Health Check programme. There is also an opportunity to improve the effectiveness and efficiency of national screening programmes by enhancing the informatics systems that drive them. Finally, the health of our children is of paramount importance to the future health of our nation. An expansion in the Health Visitor service and a series of other public health policies rely on the Child Health Information System to be effective. This system needs to be developed further to provide the best possible support for national and local child health priorities such as vaccination, commissioning care for disabled children and child safeguarding.

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<sup>54</sup> See [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_131700](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131700)

## The journey – information governance

- 5.38 As well as recognising the importance of providing safeguards around access to our records online, the NHS Future Forum received a clear message that **not** sharing information has the potential to do more harm than sharing it. There is a need for greater clarity over the circumstances when it is in our interest for our personal health and care information to be shared. Typically this means allowing clinicians and other professionals involved in our care to access our records, to ensure that we get care and treatment that is safe and appropriate to our needs. In practice, most of us would want and expect this to happen routinely, but we need to be assured that only those involved in our care will be able to access our records unless we give our consent for our personal information to be used for other purposes not related to our personal care, such as surveillance or research.
- 5.39 The data held in our health and care records is a valuable source of information, which can be used for the benefit of wider society, as well as in our personal care. So, we should move towards allowing our data to be more readily used for the wider benefit of society. The NHS Future Forum proposes a 'deal' or 'contract' along the lines below:
- *"You have a right to access your data and a right to withhold consent to its being shared. You have a corresponding responsibility to let us use your data in the interests of your own care and of improving the service for others.*
  - *We have a right to use your data, and a corresponding responsibility to tell you exactly what we plan to do with it and, when sharing it, to take all reasonable steps to protect your confidentiality."*
- 5.40 Bringing these themes together, the Government has commissioned a review of the current information governance rules and their application, to ensure that there is an appropriate balance between the protection of confidential and identifiable information within our health and care records and the use and sharing of information to improve the quality and safety of our own care and for the benefit of wider society. This independent review will be led by Dame Fiona Caldicott and will report later in the year.
- 5.41 The Government has also committed to consulting on an amendment to the NHS Constitution<sup>55</sup>. Following on from the independent review of information governance, this will make more explicit proposals for the 'consent deal' – and will ensure that all interested parties have a chance to express their views on how they would like consent for the sharing of personal information to be sought and recorded.

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<sup>55</sup> see <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution>

## The journey – supporting information and informatics skills

- 5.42 We expect all clinical and care professionals to be effective in their use of information<sup>56</sup> and IT systems and to keep up-to-date in these areas as well. Professional and other support staff can and must have a central role in driving positive change, so that systems ‘work’ for them and staff ‘buy into’ the use of information and IT to improve care. Employers are encouraged to ensure that these skills – as well as communication skills – are properly factored into professional appraisal processes. Similarly, professional and regulatory bodies are encouraged to consider how these skills are factored into revalidation and education and training.
- 5.43 There is a need for informatics development to be woven into education and training activity (planning, commissioning and delivery) for health and care staff, recognising that information and IT are at the heart of new ways of working. The Department of Health and Health Education England will want to consider building informatics standards into education outcomes.
- 5.44 A clinician, care professional or other relevant lead responsible for organising information in support of better care should be identified in every organisation. We are starting to see action in this area. Some organisations are creating new posts of Chief Clinical Information Officers (CCIO) on their Boards and a CCIO Leaders Network has recently been launched. Other organisations are not creating new posts – for example most general practices already have a clinical lead with responsibility for their information and systems. The responsibility could be explicitly taken by the Medical Director, in the same way that they often take on the Caldicott Guardian role.
- 5.45 Confirmation at board level of the importance of clinical and professional leadership in informatics will help ensure that organisations deliver safe, effective, evidence-based and accessible services and systems to meet the health and care knowledge and information needs of patients and services users, as well as clinicians and other health and care professionals. A nominated lead at board level will also improve accountability and strengthen governance around the quality of an organisation’s data. All providers are encouraged to make explicit where that responsibility sits for their own organisations.
- 5.46 Strengthening the status of the informatics profession is needed across health, public health, care and support to ensure we recruit and then retain the very best information and IT specialists. One way to do this would be to encourage the development of career pathways and professional accreditation as well as leadership

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<sup>56</sup> The Audit Commission's 2008 paper *In The Know: using information to make better decisions* discusses the skills and approaches required to using information to improve public services; see [www.audit-commission.gov.uk/nationalstudies/localgov/Pages/intheknow.aspx](http://www.audit-commission.gov.uk/nationalstudies/localgov/Pages/intheknow.aspx)



development and other opportunities for informatics specialists to realise their full potential as top leaders.

- 5.47 Professional development of clinical staff (both pre-and post-registration) and other professional staff should support new ways of working, collaborating, communicating and sharing information in secure and efficient ways between care professionals and with us as service users, patients and carers. Great leadership is paramount and needs to embrace and bring together the contributions of all workforce elements – clinical, general and informatics, as they all play distinct and interlinked roles in the successful flow and exchange and application of information across the health and care sectors. Equally, organisations outside of the health and care system are increasingly providing information and other support services to patients and service users. Close collaboration, sharing of knowledge and joint learning will deliver better outcomes faster.
- 5.48 Specific action will include exploring:
- work with Health Education England (building on existing tools and resources) to:
    - develop and implement strategy in the area of clinical and care professional education, development and workforce planning
    - encourage the building of informatics capability development strategies at local levels and in all organisations
  - work with the national Leadership Academy to make sure our leaders of today and leaders of tomorrow can make best use of informatics as a tool to develop excellence in both care delivery and business performance
  - provision of professional leadership for informatics, including support for accreditation and leadership development
  - agreement in principle to building informatics across health and social care as a recognised profession.
- 5.49 Other stakeholders in this partnership work should include Royal Colleges and other professional bodies, industry representatives, educators, commissioners and providers of health and care services.

## The journey – growth

- 5.50 With greater access to health and care data, the UK can become a centre of excellence for health and care IT and informatics, playing a prominent part in a global industry which will deliver economic growth. The NHS in England already has internationally acclaimed infrastructure and workforce development products that could be used for economic advantage.



- 5.51 By September 2012 the Health and Social Care Information Centre, as part of its secure data linkage service, will deliver data extracts using linked data from primary and secondary care and other sources on a routine basis, made available at an unidentifiable, aggregate level. The service will be available to all users of health and care information in order to drive improvements in care, enterprise and innovation, and will operate on a self-financing basis where users would pay the cost of the linking process.
- 5.52 Government will work with industry and academia, identifying specified data sets for open publication and linkage as well as championing emerging data-based innovations in health and life sciences. Over the longer term, further consideration will need to be given as to how information can be linked to wider services. For example, an underlying factor of an asthmatic's poor health could be poor housing. An improvement in their accommodation could have a far greater impact in terms of improving their health than simply treating their symptoms. Or links across to the criminal justice system could reveal underlying patterns of behaviour that could support an individual trying to tackle their drug dependence.
- 5.53 The Health and Social Care Information Centre's secure data linkage service and the complementary new secure data service, the Clinical Practice Research Datalink (CPRD), will be available to health and care organisations, managers, commissioners, public health specialists, researchers and industry and others. The ability to draw upon a wealth of linked, then anonymised, data from these invaluable services to improve health and care – when coupled with other resources such as the UK Biobank<sup>57</sup> – will serve to reinforce this country's reputation as a global centre for health and care data and research.

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<sup>57</sup> See <http://www.ukbiobank.ac.uk/>

## 6. Making it happen

- 6.1 This strategy sets a shared, coherent vision for information across healthcare, public health and care and support, along with some initial steps. This is a collective strategy rather than a centrally driven programme.
- 6.2 The ambition is bold, and it will take time. As with any large service or industry, investment in modern information technology and systems is central to success, proving cost effective over the medium term. To achieve real benefits across the system for people using services, and for taxpayers, we need a fresh approach to the direct and flexible use of information and IT to address real business needs.
- 6.3 This strategy deliberately avoids prescription in all but a few essential areas. This is because central organisations cannot hope to keep pace with the potential multitude of options that technological innovation will make available, nor is it appropriate to set out centrally imposed solutions that meet the needs of each and every local population.
- 6.4 A small number of actions will need to be led nationally, such as setting common standards to allow information to flow effectively around the system. More detailed implementation planning will be led by organisations including the NHS Commissioning Board, the Health and Social Care Information Centre, and Public Health England.
- 6.5 Central Government, or other organisations working at the national level, can take a range of actions, from:
- *Doing what can only be done centrally* – meeting core responsibilities well, providing essential information on services, being transparent with all data and providing the infrastructure and national standards that only the centre can provide; to
  - *Catalysing action where needed* – through working with suppliers and professionals, removing barriers and building the case for change; to
  - *Providing space where it makes sense* – for local and market-based innovative solutions, by not ‘doing’ where others can do it better.
- 6.6 As an example of central action, the Department of Health has asked the NHS Future Forum working group to consider whether the NHS Constitution could be strengthened – in particular whether the following could be reflected in the NHS Constitution: use of our data to improve health, care and services for others;

providing feedback in ways which are convenient to us; accessing services and our own care records online; and the provision of information support services for those of us who may need them.

- 6.7 Central Government is no longer signing big national contracts for local IT in the health and care sector. Instead, this strategy signals the move towards a localist approach – encouraging diversity and innovation at a local level. From 2016, when nationally held contracts wind down, the balance of funding and responsibility for IT will increasingly become local.
- 6.8 Significant savings have been made on the existing contracts – ensuring that the Government can continue to protect funding for providing high quality care, making as much funding as possible available locally to invest in NHS services (including investing in information and informatics).
- 6.9 Many trusts have or will have patient administration systems from the national programme. For those that have not been able to secure patient administration systems from the national programme capital funds will be available in the usual way for investment in IT from the Department of Health.
- 6.10 In moving to a more locally driven model for delivering informatics, the Department of Health recognises the need for central funding to be made available to the local NHS. A capital fund is being developed that will initially cover 2013-14 and 2014-15 to achieve this. The detail of how this can be best made to work will be developed over the summer/autumn of 2012.
- 6.11 There is a continuing role for a national IT infrastructure – ensuring effective and secure information flows across the health and social care system. Central organisations – the Department of Health and the NHS Commissioning Board – will continue to secure national infrastructure (such as the ‘spine’ allowing secure connections between organisations), doing only what needs to be done centrally.
- 6.12 But many more actions will require local decisions, local leadership and local drive. Implementation will be driven at the local level, responding to local priorities and needs across health, social care and public health. Indeed, the case studies within this document – and in the linked case study bank available online – demonstrate local actions already being implemented to deliver parts of this broader vision.
- 6.13 To achieve this collective vision across a complex health and care system will involve many different kinds of action, taken by many different organisations.

- 6.14 **Annex A** summarises the actions set out in this strategy within the following four categories:
- **commitment** (for example, access to GP records by 2015);
  - **planned central action** (for example, developing and implementing national standards);
  - **necessary local action** (for example, the need to conform to national standards); and
  - **encouraged local action** (for example, where there is a clear benefit for local action, with case studies or evidence to support that action, but this is for local determination).
- 6.15 **Annex B** summarises how transparency and open data will also help drive implementation of this strategy.
- 6.16 **Annex C** sets out how particular organisations – both locally and centrally – can help deliver this shared ambition. At the national level, the NHS Commissioning Board, Public Health England and other bodies, together with the Department of Health, will wish to consider more detailed implementation plans to achieve this vision within specific parts of the health and care sector – and will need to continue to work together to ensure this remains a unified vision which delivers real improvements and integrated services.
- 6.17 Other specific early action which all relevant central members of the health and social care system will consider will include exploring levers, including financial levers, to incentivise better access to information – for example, building on the experience of local areas that are already incentivising the use of telehealth and telecare, video conference consultations, etc. for the benefit of patients and service users.
- 6.18 Indeed, many of the local actions required to deliver the vision set out in this strategy are already being implemented somewhere, by someone. In the context of the current financial climate, the need to encourage local action and to demonstrate what is already being done, this strategy is available as an interactive online version<sup>58</sup>, supported by an extensive case study bank, Impact Assessment and Equality Analysis.

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<sup>58</sup> see <http://informationstrategy.dh.gov.uk/>

# Annex A: Summary of actions

Action in the strategy	NHS Future Forum Recommendation
Commitment	
<p>All <b>NHS Patients</b> will have secure online access, where they wish it, to their personal GP records by 2015 (by the end of this Parliament)</p> <p>By 2015, <b>all general practices</b> will be expected to make available electronic booking and cancelling of appointments, ordering of repeat prescriptions, communication with the practice and access to records to anyone registered with the practice that requests these services.</p>	3
<p>All <b>Patient</b> data* (in publicly funded health and social care) should be identified by the NHS number as the primary identifier at the point of care by 2015. Local authorities are committed to working towards much better integration of our health and care information and the consistent use of NHS numbers.</p> <p>*some exceptions apply, for example small voluntary organisations and for specific public health services</p>	10
Central action	
<b>Patients</b> will be able to view online which GP Practices offer online access to records by 2013.	3
The Government has asked the <b>Royal College of General Practitioners</b> , working in partnership with patient groups and other professional organisations, to lead development of a plan, policy and procedures to support patient access and engagement with their GP records.	3, 4, 5

Action in the strategy	NHS Future Forum Recommendation
<p>The <b>Department of Health, NHS Commissioning Board and Public Health England</b> will work with national stakeholders to lead and coordinate plans to facilitate and enable establishment of the infrastructure for patients and service users to have secure online access to all their health and care records. This will include:</p> <ul style="list-style-type: none"> <li>• identification and authentication of patients and service users, in conjunction with other public services;</li> <li>• capability to enable patients and professionals to locate accessible electronic records held by all the services they have used; and</li> <li>• ways of sharing electronic copies of their records with people and organisations of their choice who can help in understanding and managing their health and care.</li> </ul>	6, 11
<p><b>Intellect</b> has agreed to work with the <b>Department of Health, NHS Commissioning Board and Public Health England</b> to develop the evidence case for a 'portal' approach to patient and professional secure viewing of appropriate health and care records and information online.</p>	
<p>The <b>NHS Commissioning Board</b> will consider publishing commissioning guidance for support to assist patients to make the best use of the information provided.</p>	

Action in the strategy	NHS Future Forum Recommendation
<p>The <b>Department of Health, NHS Commissioning Board and Public Health England</b> will work with national stakeholders, in particular including Monitor, Care Quality Commission and Royal Colleges, to publish a roadmap setting out a programme of work and ensuring implementation of standards for national and local networking of systems and to enable effective sharing of direct care information including:</p> <ul style="list-style-type: none"> <li>• unique identifier – NHS number;</li> <li>• professional record keeping (for instance the Academy of Medical Royal Colleges records standards and social care assessment);</li> <li>• terminology (including pathology and diagnostic imaging, medicines and devices, and clinical coding language); and</li> <li>• best-practice information governance and management.</li> </ul>	
<p>All <b>Providers of NHS-funded care</b> (including social enterprises and AQPs), as part of their commissioning contracts with the NHS, will be given access to a limited number of NHSmail accounts to facilitate secure email communication where this is cost effective.</p>	6
<p>The <b>Department of Health</b> has already announced an independent review of information governance, led by Dame Fiona Caldicott.</p>	11
<p>The <b>Department of Health</b> will sponsor the provision of a comprehensive online 'portal' – to bring together the best of the relevant information on health, public health and care and support</p>	
<p>The <b>Department of Health</b> and other central bodies will, over time, stop providing certain information where this is better done by the market. For instance, we will no longer provide patient comment – instead we will show patient comment from a number of routes.</p>	
<p>The <b>Department of Health</b> and the <b>NHS Commissioning Board</b> will bring together representatives from the voluntary sector, health and care professions and industry, to consider how to increase health literacy and support information producers to communicate effectively in ways that are meaningful to us as citizens, patients and service users.</p>	5



Action in the strategy	NHS Future Forum Recommendation
<p><b>The Department of Health, NHS Commissioning Board and Public Health England</b> will work with national stakeholders in line with the roadmap for the health and care sector, to make all data open, and to continue to improve the information available to better support transparency and patient choice. This will include:</p> <ul style="list-style-type: none"> <li>• simpler health and care performance metrics on the online portal;</li> <li>• the Health and Social Care Information Centre publishing all nationally held clinical data by April 2014, where possible by clinical team; and</li> <li>• the Health and Social Care Information Centre publishing assessments of the quality of data it makes available.</li> </ul>	14
The <b>NHS Commissioning Board</b> will lead and coordinate work on developing commissioning data sets (the main data collection from secondary care) to allow data returns in SNOMED CT from April 2014.	
The <b>Department of Health</b> and the <b>Health and Social Care Information Centre</b> will work with stakeholders to investigate reducing the administrative burden of gathering social care information for national use.	
The <b>Health and Social Care Information Centre</b> will provide a secure data linkage service, complemented by the research data linkage service. This will be in place by September 2012.	
<b>The Department of Health</b> and <b>NHS Commissioning Board</b> will work to pilot new ways to incentivise the use of integrated barcode medication administration systems in care homes by September 2014, including the use of Social Impact Bonds, with the results informing future plans for implementation across England.	
<b>The Department of Health</b> will support a number of NHS trailblazer trusts in 2012 with improved adoption of new technologies in maternity services, including the development and use of necessary standards.	

Action in the strategy	NHS Future Forum Recommendation
Necessary Local Action	
A senior <b>Clinician or Care Professional</b> responsible for taking the lead in ensuring that information is organised and utilised effectively in support of better patient care should be identified in every organisation.	13
<b>Commissioners and Regulators</b> should, through regulatory and contract frameworks, ensure that information system procurement decisions are underpinned by robust business cases which ensure effective value for money and benefits realisation and that are in line with published information standards.	
<b>Providers</b> should ensure they assess the capability and meet the training needs of their clinical and care professionals in the best-practice use of information as part of their routine development planning.	
<p><b>NHS organisations</b> should actively seek out, respond positively and improve services in line with patient feedback. This includes acting on complaints, users' comments, local and national surveys and results from 'real-time' data techniques.</p> <p>During 2012-13, in line with expectations in the NHS Operating Framework, the NHS will work towards implementing the 'Friends and Family Test' – a simple test where patients will be asked an easy-to-understand question about the care provided – with SHA clusters, including Midlands and East who are implementing a coordinated scheme, to share tools and know-how.</p>	16
<b>Providers and Commissioners</b> should communicate electronically rather than using the post where possible – minimising the delay in treatment pathways and reducing manual processes.	9
<b>Providers and Commissioners</b> are encouraged to implement personal and professional access to view records across specialties and settings through 'portals' or other solutions.	

Action in the strategy	NHS Future Forum Recommendation
Encouraged Local Action	
<b>Patients and Service Users</b> are encouraged to help their services by knowing and sharing their NHS number with professionals.	10
<b>GP practices</b> that can already provide their patients with online access to their records are encouraged to do so as soon as possible.	
<p><b>GPs</b> are encouraged to extend the range of transactions that people can deal with online, for example:</p> <ul style="list-style-type: none"> <li>• electronic booking (and cancelation) of GP/nurse consultations;</li> <li>• repeat prescriptions and patient nomination of pharmacy (for online prescription services);</li> <li>• access to test results; and</li> <li>• online secure communications between GPs and patients.</li> </ul>	6
<b>Pharmacies</b> are encouraged to provide electronic transmission of prescriptions using printed labels featuring barcode scanning for medicines.	6
<p><b>Providers</b> are encouraged to improve medicines management for safer, more effective care by:</p> <ul style="list-style-type: none"> <li>• building on the roll-out of NHS Electronic Prescription Service, delivery of ePrescribing outside GP practices (for example, hospitals), including the electronic exchange of medication information inside and outside organisations; and</li> <li>• using Automatic Identification and Data Capture (AIDC – barcodes/scanning) for hospital medication, including hospital manufactured medicines.</li> </ul>	
<b>Providers</b> are encouraged to ensure test results, X-rays and scans are exchanged safely between all settings by building on national information standards (such as the National Laboratory Medicines Catalogue), and ensure test orders and results are communicated in a standard, interoperable, electronic format.	

Action in the strategy	NHS Future Forum Recommendation
<b>Providers</b> are encouraged to ensure safer, quicker, more efficient care by transferring electronically all correspondence about patients and service users, including referrals, discharge summaries, medication details, assessments (including CAF), outcomes and letters, between professionals and services. These data transfers should be coded and structured as far as possible, in particular in respect of discharge diagnoses. This will enable increasingly automated derivation of national data sets, national statistics (such as Hospital Episode Statistics) and national outcome metrics.	
<b>Providers and Commissioners</b> are encouraged to contribute to the ongoing development of the informatics profession across health and care and support by developing and implementing clear plans and strategies as part of their mainstream business planning, drawing on available best practice and support.	13
<b>Providers</b> are encouraged to use secure electronic links to transfer information from providers <b>to service users</b> .	
<b>Providers</b> are encouraged to make wider use of innovative alternatives to face-to-face in health and care consultations where this improves value for money and patient experience.	
<b>Providers</b> are encouraged to increase the use of mobile technologies for professional viewing and recording of information.	
<b>Providers</b> are encouraged to be innovative in using technology to allow <b>patients</b> and <b>service users</b> to participate in their health and care. Examples include enabling service users to enter information into their care records, including self-assessed test results, feedback on treatment progress, updating demographic information and general comment. Suppliers are encouraged to develop their systems to allow this functionality in partnership with the services.	
<b>Providers</b> are encouraged to make existing shared and patient-held records, such as maternity records and parents' Red Book information, electronic and accessible to <b>patients</b> online.	
All <b>Local Authorities</b> are encouraged to <b>provide clients</b> the choice of accessing their assessment and care plan information online as soon as IT systems allow.	

# Annex B: transparency and open data – our open data strategy

Transparency and open data are a key part of the Government's efficiency and reform agenda. They are essential to our ability to make informed choices about the care we need and the services we use. It empowers us as patients and users of services to hold public services to account for the money they spend and the services they provide and can encourage greater public participation in decision-making. It underpins getting better value for money in public spending. It can deliver economic benefits by enabling businesses and not for profit organisations to use public data to develop innovative applications and tools that in turn also support the public, patients and carers, service providers and commissioners to make better, more evidence based decisions.

## Department of Health Open Data strategy 2012-14

The starting point is that Government will make the data it holds routinely available unless it would not be appropriate to do so, for example because it would not be possible to ensure patient confidentiality if the data were released. The Department of Health and the health and care sectors have already demonstrated a strong and ongoing commitment to the transparency, growth and open data agenda, with a number of commitments announced last year.

However the Department of Health is clear that the delivery of a strategy to support reform and improvement through transparency and citizen participation requires a systemic – rather than piecemeal – approach, with making data available as the default position. The Department of Health's information strategy, 'The Power of Information – Putting all of us in control of the health and care information we need' reflects this system wide approach. It sets out its strategy for:

- the release of **Big Data**: making large routine public service data sets available;
- the capture and release of **My Data**: provision of access for service users to their own identifiable data;
- the gathering and use of **Satisfaction and Experience Data** to support customer insight and user feedback on services;
- the **creation of dynamic Information Markets**: how we will engage with data users to drive social and economic growth; and
- **continuously improving the quality** of data published.

The way in which 'The Power of Information' addresses these areas is summarised below.

## Big Data

In addition to the commitments made last year (2011) the Department has set out further plans to release specific data sets. Details on these existing and new commitments, and dates for delivery, are set out in table 1.

In addition to these, Chapter 4 of 'the Power of Information' sets out the Department's proposals to make data more available to support public accountability and patient and service user choice. This includes putting all clinical outcomes data in the public domain by April 2015, and the development of better and easier to understand measures and indicators across the health and social care system.

We have established a Health and Social Care Sector Transparency Panel, with external membership drawn from key groups with an interest in the delivery of the transparency agenda, to advise us on the priorities for open data. They have helped to develop our plans for the next two years.

The Health and Social Care Act 2012 includes provisions marking a step-change in the health and care sector's approach to transparency, growth and open data. It requires the Health and Social Care Information Centre to publish (in safe, 'de-identifiable' format) virtually all of the data it is required to collect across the health and care sector. The Information Centre has already started routinely releasing the data that underpins their statistical publications. As part of this a further 83 datasets were released for the first time in 2011-12, completing the roll-out of this approach.

The Information Centre has a pivotal role in improving the quality of health and social care data by assuring the quality of nationally collected data. The Information Centre has already delivered a Data Quality Assurance Strategy which outlines its role and how it will support other national bodies such as the Commissioning Board and the Care Quality Commission to deliver their responsibilities. It is developing a Data Quality Assurance Framework. This will harness its current data quality assurance activities to establish a more consistent and comprehensive approach to data quality assurance for all health and social care data collected by the Information Centre. Data quality will be measured against a series of key indicators and provide much greater reporting and visibility of performance across health and social care organisations and for those that use the data.

The Department understands that knowing which information is available is one of industry's biggest 'asks' of it. To this end, the Act requires the Information Centre to maintain and publish a register ('catalogue') of the data it has collected. In addition the Department will ask the Information Centre to undertake work to develop an inventory of the wealth of data collected by other parts of the health and social care system so that over time it can provide a single source of information on the data that is collected and where it can be accessed.



Most of the data collected nationally for Social Care is also made available from the Information Centre. The Department is currently undertaking a zero based review (ZBR) of adult social care data collections which aims to ensure that the information collected from local authorities is outcome-focused, and based on the results councils achieve for local people, rather than counting activities and processes. A consultation on the proposals will be launched shortly. Subject to the outcome of this consultation, the Department will continue to work with the Information Centre and local government to deliver changes to collections from 2013-14 onwards.

Data is collected and held by a number of different parts of the health and social care system and the principle of data transparency is well established in a number of areas. In public health, the Health Protection Agency (HPA) already makes available most of the data it collects at an appropriately aggregated level through its health protection profiles and regular disease specific topic reports. This information is fully accessible through the HPA website. Public Health Observatories (PHOs) produce information, data and intelligence on people's health and health care, for practitioners, commissioners, policy makers and the wider community. Much of this information is also already published. The PHOs will become part of Public Health England (PHE) and as part of the transition process they are undertaking a review of how they manage and use data. When this is complete the Department will work with PHE and the PHOs to see whether there is scope to make more of the information and data they produce available.

In health there are major benefits from linking data – to industry, to research, to providers and commissioners of care services as well as to patients, service users and the broader public – so that we understand more about the whole patient journey, not just isolated episodes of care. We are again addressing this issue at the systemic level by offering a specifically tailored service to meet the needs of research as well as a more generic service able to securely link and make available data held by the Information Centre.

## My Data

The most important source of data is the information held within our own health and care records. It is key to ensuring that the health and care services we use can join up efficiently and effectively, with us at their centre, and can support improved outcomes and informed patient choice. Being able to access, add to and share our own health and care records electronically can help us share decision-making in partnership with the professionals supporting us. Chapter two of 'the Power of Information' highlights steps to make our own records readily available and accessible to us as patients and service users. The first step will be to give us electronic access to our own GP records by 2015 and to our social care records as soon as IT systems allow.



## Satisfaction and Experience Data

Feedback and complaints data is a valuable way to influence the development and improvement of services and supports public accountability and service user choice. Chapter four of 'the Power of Information' sets out how the Department will encourage the collection of more feedback, in real-time wherever possible, and use it to improve services – making each experience count. The NHS Future Forum Working Group on the NHS Constitution is also currently exploring how the NHS Constitution could be strengthened to ensure all of us are provided with opportunities to leave feedback or make complaints about our experiences of health and care services. This will include how to help ensure that organisations act on, and make known how they have acted on, that feedback.

## Creation of dynamic Information Markets

The Department has established a partnership with Intellect Health – an industry body representing 280 information service and technology firms of all sizes – to provide crucial insights into the requirements for industry to play a full part in supporting widespread innovation and development to help achieve the Department's information strategy. This includes work to develop the evidence base for simple patient and professional 'portals'.

There is an expectation that the act of making data more readily available will in itself help to encourage the development of an information market in health and care data. In addition specific proposals in 'the Power of Information' will support the development of a more vibrant and diverse market in information providers. This includes the Information Centre's data linkage service and the open publication of specific datasets (chapter five) and the development of a catalogue and inventory of health and social care data (above). In the longer term (by 2018) we expect to establish minimum information standards across the health and social care system to enable data to be shared safely and in a consistent way that will also allow the market to develop further (chapter three).

## Continuously improving the quality of data

Connected information can support safer, more integrated care for us and for the professionals providing our care – for example, through online access to GP records in hospitals, electronic prescriptions, barcode-scanning in care homes and hospitals to reduce medication errors, and electronic access to results, X-rays and scans. Many benefits and efficiencies can be achieved through information being recorded once, at first contact, and shared securely between those providing our care – supported by consistent use of information standards that enable data to flow whilst keeping our confidential information safe and secure. This can support improved outcomes, informed choice and greater productivity.

Chapter three of 'the Power of Information' sets out how the Department will support and encourage better integration and improved quality. This includes setting information standards, using the NHS number as the default patient identifier and encouraging local action to make greater use of technological solutions to improve care and facilitate information sharing, both between professionals and with the people they provide care for. Chapter five also considers how the rules around information governance support the appropriate use and sharing of data.

## Protecting your confidentiality

The Department recognises that for data held in the health and care sector there are also risks in releasing data. It needs to balance the significant benefits from being able to link up data across health and care services with the need to ensure that it protects patient confidentiality. So while it is right and proper that Government should assume that it will make data available to support public accountability it must have in place a systematic approach to ensuring that it has considered any risks to individual confidentiality, and taken appropriate measures to address these. The Health and Social Care Transparency panel will have a key role in supporting and advising the Department on these issues.

Although publicly available datasets will always be anonymised there can be a risk of 'jigsaw' identification. For example if data at hospital episode level were to be released – if someone knows the hospital, admission date and approximate age of a patient, they may well be able to deduce which record relates to that person. The risks are low and there are ways of mitigating it (eg. removing low numbers or aggregating data sets) but these can also reduce the value of the data. Our view is therefore that the level of granularity of data to be released needs to be reviewed carefully on a case-by-case basis for each dataset.

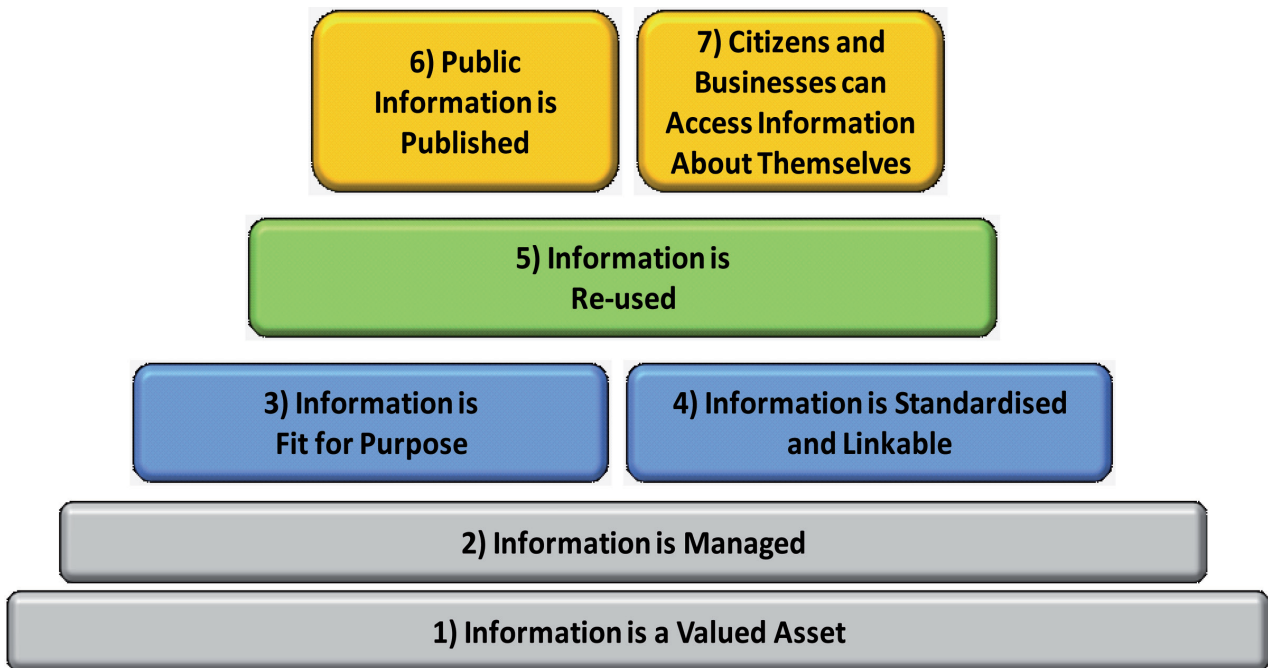
For every release of data we will consider:

- the purpose and benefits of the data;
- data protection and related issues, consulting with the Information Commissioner where necessary;
- confidentiality and the potential for 'jigsaw' identification from data;
- the format and specific level of data that should be released;
- the costs of collecting, releasing or linking the data and who should pay;
- any commercial implications or impacts on current information providers; and
- the impact on the broader transparency agenda, for example will the data promote a marketplace of intermediaries to present the data for specific audience?

Wherever possible we will make data available under the Open Government Licence and at no cost to the user.

## Information Principles

'The Power of Information' is underpinned by the seven key principles set out in the recent Government publication 'Information Principles' (December 2011).



The Department expects that local health and social care organisations will ensure they have appropriate systems in place that take account of these so that their use and management of information is underpinned by a common set of key principles and best practice. In doing so organisations will want to make use of the Information Governance toolkit developed by the Department to support NHS and partner organisations in assessing themselves against its information governance policies and standards.

The NHS Information Governance toolkit can be found at <https://nww.igt.connectingforhealth.nhs.uk/>

**Table 1. 'Big Data'**

**Our open data commitments** this includes existing commitments and our plans for the next two years. More general commitments to support the availability of data are referred to above and covered in detail in the main text of the Information Strategy

Dataset or Information released	Description	Date of release	Frequency of publication	Open Government Licence?
<p>Health and Social Care Information Centre to set up a secure data linkage service as part of its core delivery service to health and social care, and by September 2012 will:</p> <ul style="list-style-type: none"> <li>• deliver data extracts using linked data from primary and secondary care and other sources on a routine basis at an unidentifiable, individual level</li> <li>• be used and commissioned by the specialist research service (CPRD – see below) for their specific research purposes</li> </ul>	<p>The service will be available to all users of health and care information in order to drive improvements in care, enterprise and innovation. It will operate on a self-financing basis where users pay the costs of the linking process.</p>	<p>Service available from September 2012</p>	<p>n/a</p>	<p>n/a</p>
<p>Complementary to HSCIC data linkage service a new secure data service, the Clinical Practice Research Datalink (CPRD), will be established within MHRA to service the specialised needs of the research and life sciences communities.</p>	<p>Service launched March 2012.</p>	<p>Service available from 31 March 2012</p>	<p>n/a</p>	<p>n/a</p>

Dataset or Information released	Description	Date of release	Frequency of publication	Open Government Licence?
Data on comparative clinical outcomes of GP practices in England to be published by December 2011	Data under 5 key headings: Demographics, Patient Experience, Quality Outcomes, Infrastructure and Impact on NHS Resources. Also available in accessible format for public through NHS Choices.	Data 7 December 2011	Each individual data source will be refreshed when it becomes available	yes
<b>NEW</b> Additional GP practice data and indicators	17 additional indicators including a Patient Experience Composite indicator covering 5 domains: accessing care, waiting to be seen, opening hours, consultations with a doctor and consultations with a nurse. This is a new approach, the aim of which is to better measure performance and raise standards.	7 June 2012	As above	yes

Dataset or Information released	Description	Date of release	Frequency of publication	Open Government Licence?
Comparative GP Data Tool	The Comparative GP Data Tool will enable GPs (and other stakeholders e.g. emerging CCGs or HWBs) to compare practice performance, allowing them to see where they could perform better, leading to fresh, innovative ideas. The tool will also allow practices, emerging CCGs, current PCT clusters and (in future) the NHS Commissioning Board to link the data to wider information on healthcare need, activity and outcomes.	7 June 2012	n/a	n/a
GP reference data (eg locations of practices, their list sizes and demographics), as part of comparative data tool	As above	Data 7 December 2011	Updated monthly	yes
Choose and Book usage at GP practice level, as part of comparative data tool	As above	Data 7 December 2011	Updated monthly	yes

Dataset or Information released	Description	Date of release	Frequency of publication	Open Government Licence?
<b>NEW</b> GP Practice Profiles for Cancer	GP Practice Profiles bring together a range of outcomes and process information relevant to cancer in primary care. They provide comparative information for benchmarking and reviewing variations at a general practice level. This initiative supports the National Awareness and Early Diagnosis Initiative to improve early diagnosis of cancer and outcomes for cancer patients.	31 July 2012	annually	tbc
Prescribing data by GP practice to be published by December 2011, at 'chemical' level	Initial release at chemical level, flat file (.csv) format so users can undertake analysis and data intermediaries can develop innovative approaches to presentation.	Pre-release of format 29 November 2011.  Data 14 December 2011	Updated monthly	Released under terms of OGL



Dataset or Information released	Description	Date of release	Frequency of publication	Open Government Licence?
Practice level prescribing data at presentation level, giving quantity prescribed, by September 2012 – subject to further analysis of costs, benefits and affordability issues	Greater level of detail to provide information desired on quantity prescribed.  Further analysis on costs and affordability, currently in hand, will be a precursor to delivery	September 2012	tbc	tbc
<b>NEW PROMS</b>	First regular annual release of final PROMS data at patient record level (for 2010/11)	August 2012	annually	yes
Complaints data by NHS hospital so that patients can see what issues have affected others and take better decisions about which hospital suits them.	Data available nationally in report form at NHS Trust level. As first step in making data more readily available breakdown of complaints by PCT and FT now available on IC website. DH and IC are working to makes data easier to access and understand, subject to affordability. Also working with information intermediaries eg NHS Choices to use this data more widely	August 2011	annually	yes

Dataset or Information released	Description	Date of release	Frequency of publication	Open Government Licence?
Clinical Audit data, detailing the performance of publicly funded clinical teams in treating key healthcare conditions, will be published from April 2012. The service will be piloted in December 2011 using data from the latest National Lung Cancer Audit.	Initially data published at the same level as information in relevant last annual report.  Some data to be published at various dates in 2012-13 except new audits where data not available until 2014. Work to develop release of data at more granular level, and at clinical team level where appropriate, between 2012-14. Publishing dates dependent on availability of data.	Lung cancer December 2011  Rest various dates in 2012-13	annually	tbc
Data on staff satisfaction and engagement by NHS provider (eg by hospital and mental health trust) will be published from December 2011	Organisation level data is published annually in a report. A flat file of 2010 data will be made available by December 2011 at NHS Trust level. 2011 data will become available, in report and .csv file form by April 2012.	Underpinning 2010 data December 2011.  Thereafter April	annually	no
<b>NEW</b> previous years annual data on staff satisfaction and engagement by NHS provider for 2003-2009 to be made available	as above – the release of earlier years data will allow others to analyse data to compare performance between years and identify trends	July 2012	n/a	no

Dataset or Information released	Description	Date of release	Frequency of publication	Open Government Licence?
The Care Quality Commission's Provider Profile Reports – CQC will also consider the scope for making available information that routinely feeds into these provider profiles.	CQC has agreed to consider how to make more of the information that supports provider profiles routinely available. Quality and Risk Profiles (QRPs) bring together a wide range of information about a provider to monitor compliance with essential safety and quality requirements, assess where risks lie and inform commissioning of services.	September 2013	tbc	tbc
Data on the quality of post-graduate medical education by provider will be published from April 2012	(data is not owned by DH). First element of this commitment, GMC annual survey of junior doctors, was published on 31 October (annual report, tables by provider and data in .csv file format). Further data released through GMC in April (deanery reports and Royal Colleges specialty reports) will provide further context and add to richness of qualitative data available.	Data 31 October 2011	annually	n/a

Dataset or Information released	Description	Date of release	Frequency of publication	Open Government Licence?
DH will work with Local Authorities to further develop Local Accounts in adult social care with the aim of ensuring the accounts provide citizens with relevant information in a way that allows comparison between councils. DH will also continue to support the development of wide, comparable social care metrics (in accordance with the Zero Based Review of social care data, Information Strategy, Social Care White Paper and Future Forum work) by September 2013.	Local accounts, although not mandatory, have been widely adopted by local authorities as a way of providing meaningful, comparable information about their performance to local people. Many councils have already published accounts. During 2012-13 the Local Government Association and the Association of Directors of Adult Social Services will continue to support those councils that are still developing their first account. An evaluation programme is planned to support further improvement in accounts' content.	September 2013	annually	tbc

Dataset or Information released	Description	Date of release	Frequency of publication	Open Government Licence?
<b>NEW</b> Data that passes through the NHS 'Spine'	We will undertake a review of the data and messages that pass through the NHS information 'spine' and assess the potential to make more effective use of this information, including to provide more open data. This work will take into account the benefits and costs and how this fits with the Spine extension programme and the migration to future national messaging and reporting systems. This initial phase will identify an agreed programme of open data initiatives with a roadmap for delivery and will be completed by October 2012.	Review completed October 2012	tbc	tbc
All patients in the NHS will have online access – where they wish it – to their personal GP records by the end of this Parliament. GP practices that can already provide online access are encouraged to do so as soon as possible.  NHS Choices will publish an interactive map at the earliest opportunity.	See Chapter 2 of 'The Power of Information – Putting all of us in control of our health care information.'	2015	n/a	n/a

# Annex C: Organisational roles and responsibilities

<b>Department of Health</b>	<ul style="list-style-type: none"> <li>• setting strategic vision and direction, and ongoing oversight for the agenda across health, public health and social care</li> <li>• setting the forthcoming care and support White Paper, with more detailed implementation plans to achieve this vision for social care</li> <li>• setting information standards and commissioning the Health and Social Care Information Centre to collect information for social care</li> <li>• taking forward legislation and also commissioning some of the central systems required to underpin this strategy</li> </ul>
<b>NHS Commissioning Board</b>	<ul style="list-style-type: none"> <li>• setting more detailed implementation plans, including informatics planning, to achieve this vision across the NHS</li> <li>• setting information standards and commissioning the Health and Social Care Information Centre to collect information for NHS care</li> </ul>
<b>Public Health England</b>	<ul style="list-style-type: none"> <li>• setting more detailed implementation plans to achieve this vision across public health</li> <li>• setting information standards and commissioning the Health and Social Care Information Centre to collect information for public health, working with registries and public health observatories</li> <li>• overseeing and implementing an approach to surveillance of new and changing threats to health</li> </ul>

<b>Health and Social Care Information Centre</b>	<ul style="list-style-type: none"> <li>• the focal point for information across the health and care sector</li> <li>• collecting, holding securely, linking and making readily available the data it holds in safe, de-identified formats</li> <li>• publishing a register of the information that is collected by the HSCIC and that is held by other organisations</li> <li>• managing safeguards to protect confidential data</li> <li>• providing assurance of the quality of the data received</li> <li>• helping reduce the burden of data collection across the sector</li> </ul>
<b>National Information Governance Board</b>	<ul style="list-style-type: none"> <li>• lead on information governance issues until 2013</li> </ul>
<b>Care Quality Commission NICE &amp; Monitor</b>	<ul style="list-style-type: none"> <li>• commissioning the Health and Social Care Information Centre to collect information and with specific supporting existing regulatory and other roles</li> </ul>
<b>Royal Colleges and professional regulators</b>	<ul style="list-style-type: none"> <li>• providing professional leadership in use of information</li> <li>• Royal College of General Practitioners, working in partnership with other professional organisations and patient groups, to develop proposals to support the roll-out of access to patient records by 2015</li> </ul>
<b>Health Research Agency</b>	<ul style="list-style-type: none"> <li>• leadership for use of information to support research</li> </ul>
<b>MHRA</b>	<ul style="list-style-type: none"> <li>• a specific data linking service to support the research and life sciences community</li> </ul>
<b>Health Education England</b>	<ul style="list-style-type: none"> <li>• ensuring that the education, training and workforce development support is in place to deliver this vision</li> </ul>
<b>clinical commissioning groups</b>	<ul style="list-style-type: none"> <li>• driving local delivery of this strategy, with local information champions</li> <li>• commissioning specific support for those who need it to understand and use information as an integral part of care</li> </ul>
<b>local authorities</b>	<ul style="list-style-type: none"> <li>• setting more detailed implementation plans, including informatics planning, to achieve this vision across the NHS</li> <li>• commissioning specific support for those who need it to understand and use information as an integral part of care</li> </ul>



<b>health and social care provider organisations</b>	<ul style="list-style-type: none"> <li>• driving local delivery of this strategy, with local information champions</li> </ul>
<b>health and wellbeing boards</b>	<ul style="list-style-type: none"> <li>• understanding the health and wellbeing needs of local communities through the Joint Strategic Needs Assessment (JSNAs), agreeing shared priorities and setting the joint health and wellbeing strategy to address these as the foundation for NHS and Local Government commissioning</li> <li>• influencing how information, and support for people using services to understand and access information, can help reduce the burden on local services.</li> </ul>
<b>local and national HealthWatch</b>	<ul style="list-style-type: none"> <li>• advising health and wellbeing boards on information needs</li> </ul>



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2900056 May 2012

Produced by Williams Lea for the Department of Health