Preparing the NHS for an information revolution

BCS report on the NHS Information Revolution consultation on proposals

Enabling the information society

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Foreword

This report by BCS, The Chartered Institute for IT, came out of our response to the government’s information strategy consultation ‘Liberating the NHS: An Information Revolution’.

It has been one of the largest engagement exercises that BCS has ever undertaken. We have undertaken a widespread internal consultation involving many hundreds of our members, either in person or online. We have also provided the environment and opportunity to convene the wider informatics community to openly debate the Information Revolution proposals in order to encourage their own responses.

BCS welcomes the opportunity to actively engage in shaping the information strategy for health and care, and to practically assist the decisions that need to be made by leveraging its considerable pooled membership expertise and its role as the professional body for IT.

Acknowledgements

We would like to thank our members for rising to the challenge, our specialist and member groups for their response contributions, our Strategy & Policy Committee and Health Executive for their oversight and leadership, Clever Together for the provision of innovative crowd sourcing services, KPMG for their sponsorship and helping to facilitate our open debates and Mott Macdonald for their research contribution.

We would also like to thank our strategy and policy leads, who expertly gathered together our report content from diverse experts/ input materials, for their hard work shaping it into the chapters of the report: Roberta Carter; Kevin Dean; Brian Derry; Christopher Exeter; Ian Herbert; Jane Juniper; Stephen Kay; Jem Rashbass; Mike Sinclair; Roger Taylor; Alasdair Liddell; Paul Altmann; and Robin Vickers.

Prof Matthew Swindells
Chair, BCS Health

Dr Justin Whatling
Vice-Chair, Strategy & Policy, BCS Health
The health and care sector requires fundamental transformation to deliver the required productivity and efficiency targets, whilst setting itself up to be able to respond to the ever-increasing demand pressures from chronic disease burden in an ageing population.

Health is one of the last major information-intensive sectors awaiting a fundamental transformation, and like other sectors before it, this can not be accomplished without using information and technology to reinvent both its internal operational functions and its outward facing business model. An information revolution can support and help drive the changes that are required in the processes and methods of care provision at the start of the 21st century.

Health informatics is key to the success of the envisaged Information Revolution. Our members were keen to bring their expertise to bear on a holistic approach to the challenges that face informatics in the health industry to support this initiative. The report focuses on nine different areas that will, and need to be, affected and taken into consideration by any information strategy in the health and care sector. The report contains almost 100 recommendations, but a number of themes are regularly occurring throughout. These themes are presented below.

**The scale and pace of the productivity challenge faced by the NHS over the next five years cannot be met without much greater and more effective use of information and IT.**

The NHS is seeking to deliver 20 per cent productivity improvement over the next five years through better commissioning and more effective provision. This would be a hugely challenging task for a single organisation, but for the NHS this is above and beyond anything that it has ever achieved before. Failure will result in a reduction in the services offered to patients.

As a rule, any established industry that has achieved this scale of improvement has used one of two techniques: moving a large proportion of its workforce to a country with much lower employment costs – not a route that is available to the NHS; or the adoption of information and IT to radically redesign business processes and often the business model.

We believe that the NHS must seize the opportunity offered by information and IT.

Our key recommendations include the following:

- We recommend that Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs) should encourage shared services, managed either by NHS or by commercial organisations, to evolve in the marketplace between provider networks and across local health economies as part of their exit strategy.
We recommend that the NHS develops with the main software vendors standard implementation of best practice processes and places these in the public domain, so that new implementations do not begin with a blank piece of paper but start with, for example, ‘the three best ways to run emergency admissions are built into the system, which one will this hospital adopt?’ This will need to be carried out in a way that does not stifle innovation.

A risk-based approach should be adopted to allow prototyping of new patient-centred technologies and consumer information. It does not have to be right the first time so long as risks are understood and mitigated. Creating the culture of ‘change at pace’ is vital for a world-class health service.

The implementation of information services and IT needs to be viewed as a necessary supporting infrastructure to the redesign of service, not as an end in itself.

Successful implementation of the Information Revolution will involve very substantial behaviour change on the part of clinicians, patients, managers and others. Simply providing information and IT will not of itself guarantee that information will actually be used – or even collected, analysed and understood in the first place.

Evidence also shows that you can only extract the full benefit from information and IT if you apply it to the whole process of care. International evidence, supported by UK experience, shows that, if you implement modern technology into old processes, you end up with more expensive old processes.

To meet the massive productivity challenge, the Information Revolution must start with the design of working practices and cover the whole operating model of care to determine how processes are adapted and how resources are used, prioritised, planned and mobilised as a consequence of better information. The opportunity is to completely rethink the way a service is delivered.

Our key recommendations include the following:

- We recommend that the information strategy commissions an academic institution to develop and maintain a library of successful IT-enabled service redesign in health care around the world and the return on investment delivered in order to support boards in making investment decisions and enable organisations to confront redesign programmes at the appropriate scale.

- We recommend that the information strategy focuses on the operational changes that are needed to extract the value from information technology and not simply on the technologies themselves.

- We recommend that all organisations providing care to the NHS should be given notice that they will be expected to use an electronic patient record (EPR) in a meaningful way within five years. Following review of the US criteria for meaningful use, the NHS should create a set that is appropriate to the UK.

The rigorous enforcement of standards is not an example of heavy-handed government interference, but a necessary condition to allow a flourishing market of interoperable solutions.

Critical to its success, the Information Revolution requires the creation and nurturing of a viable market for information services, software and transactions to deliver high-quality information services to patients, clinicians and organisations.

The Information Revolution correctly identifies the need for an information market to flourish without solutions being provided centrally. However, for this to happen and for IT suppliers to invest most effectively,
the centre\(^1\) should give very clear signals as to what it will be doing and what it will be leaving to others to do. Without this, there will be confusion for both care organisations and suppliers.

Our key recommendations include the following:

- We recommend a single overarching approvals and/or assurance body for informatics standards, directed by the Secretary of State for Health, covering health, social care and population health. The role should include rapidly setting stable standards with a road map for information management, enabling ICT suppliers to rapidly innovate solutions for health and care.

- We strongly support the NHS CIO’s (Chief Information Officer’s) commitment to the NHS number and urge that it be mandated in health. Commissioning, regulation and financial penalties for non-use by all care providers should be applied.

- We recommend that ICT supplier accreditation schemes need to keep standards high, but also keep barriers to entry low.

- We recommend that central funding should continue to support the Interoperability ToolKit (ITK) and efforts should be made to leverage industry funding where there is market demand for integration profiles against specific use cases. The Integrating the Healthcare Enterprise (IHE) integration profile ‘standards’ should be exploited as a powerful lever for interoperability.

The NHS needs to build on the infrastructure of the National Programme for IT, but take rapid steps to reintroduce competition into the NHS supplier market.

Whilst the benefits of the national programme are frequently down-played by people who forget the chaos and lack of progress that preceded it, we are now at a point where the NHS’s move to multiple independent care providers, the focus on care pathways rather than institutions and the pressing need for every NHS organisation to be making progress simultaneously mean that a more dynamic and entrepreneurial supplier market is required.

In an environment of monopoly suppliers, every new innovation that the NHS wants needs to be specified, priced and paid for. We require a competitive environment where suppliers will build in the functionality that the market wants to enable them to win the next contract. Additionally, the centre will want to maximise the use of legacy investments in information collection, transfer, storage and reporting – vital if the execution of the information strategy is to be affordable. This cannot be left solely to the open market where reinvention could predominate.

Our key recommendations include the following:

- We recommend that existing NHS procurement frameworks such as ASCC (Additional Supply Capability and Capacity) are enhanced so that new vendors can be added to the framework if they demonstrate that a product meets the national minimum requirements for information governance, functionality, data standards and interoperability, or removed if they are subsequently seen to fall below those standards.

- We recommend the commercial structure of the National Programme for IT to be reviewed to allow any purchasing organisation in any cluster to choose solutions from any local service provider (LSP) so that the NHS can benefit from competition between LSP suppliers.

\(^1\) We have used this term to mean central functions of the public sector including NHS, social care and Department of Health.
• We recommend government support for the development of the UK health ICT supplier market by ensuring that frameworks are sufficiently flexible to allow small companies to bid for contracts.

The NHS and the informatics community need to win back public and care professional trust through better explanation of the benefits of the Information Revolution and more care in ensuring that the individual patient is engaged and activated in their health and wellbeing.

The Information Revolution offers the potential for an improved relationship between care system and the individual; indeed the transformation of care services will rely on it. This will require a combination of information, education and support, delivered through trusted relationships.

The consultation has not distinguished between the different purposes of the Information Revolution and must now do so. Creating care services that are accountable to the public through information transparency cannot happen unless data is shared and those in leadership are prepared to explain what the information means and what an appropriate reaction is. Transparency and trust in the quality of the information are key and wholly dependent on getting the basic standards in place to ensure data is recorded accurately, is shareable and that people can access the information they require to enhance care and wellness.

Evidence tells us that information alone will not suffice. Trusted relationships are key and we now require new ‘health intermediary’ and ‘navigator’ roles to be fulfilled by patient groups, commercial and third-sector organisations and others. However, in order to take this on, they require help in overcoming concerns around liability, skill sets and ability to scale to the market needs. Technology also has strong potential to engage people in the care system, often through disruptive disintermediation. Individuals will more readily engage when there is clear value or utility for them.

Our key recommendations include the following:

• We recommend that the information strategy is clear on the purposes of the Information Revolution and that they are individually approached with patients (and their care professionals) in the right way to achieve the desired outcomes:
 ○ enabling patients to become equal partners in their health care and take control of managing their own health;
 ○ enabling patients to make choices about where, who and what health services to use, liberating the patients and incentivising providers to improve;
 ○ creating transparency so that the public can hold the NHS to account.

• We recommend that, where sharing is appropriate, there should be a statutory obligation on health care providers to release information as a minimum standard if contracting with the NHS. The NHS Commissioning Board should require all providers of services to publish meaningful, comparative performance data at the level at which patients are being offered choice and that the public will understand and value.

• We recommend that the NHS Commissioning Board contracts with NHS providers, the third sector, commercial organisations and others to develop, carry out and be recognised for performing roles as health ‘intermediaries’ and ‘navigators’ for patients and the public.

• To mitigate the risk that, in the early stages of data release, organisations, clinical teams and individuals will be unfairly judged by inappropriate interpretation of data that is not fully explained, we recommend that ministers, the Department of Health and commissioners take a mature attitude in responding to data release and be at the forefront of explaining to the public and the media why overreaction is inappropriate.
Finally, the NHS is failing to provide the support that it could to the research community, to the detriment of research and development, the UK economy and patients.

England has three of the world’s leading university research establishments in Imperial, Oxford and Cambridge, as well as world-class pharmaceutical companies such as GSK. This places us at the forefront of Europe.

Our integrated health system offers us the opportunity to provide a world-leading environment for clinical research and trials, creating jobs and getting patients early access to ground-breaking treatments. However, the NHS has failed to support this opportunity to its fullest extent, as unproductive debates and ignorance around information governance have held back the sharing of data.

Our key recommendations include the following:

• We recommend that work is commissioned to develop effective linking systems for medical data and the informatics tools already in use in research institutions, to enable medical data to be used in conjunction with scientific data from pharmaceutical companies and other researchers.

• We recommend that opportunities are sought following any permissive regulation changes and appropriate patient consent processes to improve communications of clinical trial eligibility to patients through the use of EPR systems.

• We recommend that opportunities are sought to enable interfaces between the case report form (CRF) used in clinical trials and the patient’s medical records in order to increase efficiency in information capture and use through reduced duplication of data capture and improved search for information needed by individual studies.

These core themes, the Information Revolution and the awaited information strategy will all falter if we fail to invest in our health informatics workforce capacity and capability. A sustainable health informatics workforce infrastructure is required to be put in place, spanning health, public health and adult social care, and the public, private and third sectors. Such an approach should be encouraged by commissioners and regulators as a means of improving the quality and professionalism of the health informatics workforce and thereby the quality of data and the management of patient- and organisation-critical IT and information systems.
2. Preparing the BCS response

BCS organised a number of activities to engage the informatics community in helping it prepare its response to the NHS Information Revolution consultation on proposals. Our response was guided and assisted by our BCS Health Strategy and Policy Committee and overseen by the BCS Policy and Public Affairs Board. The scope of our response was for England. We would like to recognise and thank KPMG for sponsoring our crowd source activity and facilitating our open debates.

*Information Revolution BCS open debates held in Leeds and London*

The debates were opened with a set of presentations from senior figures in the Department of Health’s Informatics Directorate, followed by breakout discussion sessions and open debate on four key themes: setting the direction for information strategy; informatics professionalism; privacy, security and risk management; and informatics standards and interoperability.

The events offered an opportunity to raise issues and feedback directly to those managing the consultation process for the Department of Health. The output was captured and shared amongst the attendees for use in any response they wished to make to the Information Revolution consultation, and shared with the Department of Health.

There were over 100 participants in Leeds and over 60 in London, with a good mixture of informaticians, managers, clinicians, academics, industry, policy and think-tank organisations. The events were open to both BCS and non-BCS members.

*Information Revolution BCS crowd source*

BCS undertook an online crowd source activity to inform our response. Online anonymous discussion with the ability to add new ideas and promote/demote others brought together leaders from the NHS, clinical bodies, academia and the private sector, with the membership of BCS to catalyse open debate in the informatics community.

The crowd source debates themed on ‘making the revolution happen’, ‘the future role of the centre’, ‘the future of informatics as a profession’, ‘gaps in the DH consultation’ and ‘standards and interoperability’. Of the 200 people invited, 46 per cent were active contributors with 269 value-adding contributions. Contributions were provided anonymously from central agencies, GPs, provider trusts, Primary Care Trusts (PCTs), vendors, consultancies, independent health informatics specialists, BCS members, academia, local authorities, patient groups and private health providers. Attendees to our open debates were invited to join the crowd source to continue the debate.

Quotations from anonymous individuals are included throughout our response and the material from the crowd source contributed to our response content. The crowd source tool and methodology were expertly provided and facilitated by Clever Together (clevertogether.com) and sponsored by KPMG.
**Information Revolution BCS membership consultation**

BCS sought views across all of its health members through newsletter and email invitations.

**Information Revolution BCS specialist and member group inputs**

BCS specialist and member groups have contributed their own responses to the consultation, which were provided as separate files to our main response, and where these have been made available in good time have been reviewed as input to our main response. Response contributions have been put forward by BCS ASSIST, BCS Primary Healthcare Specialist Group (PHCSG) and BCS Nursing Specialist Group. Each had their own methodology for gathering input across their communities.

**BCS health strategy and policy activities**

BCS holds regular strategy and policy debates against its core themes for this year: ‘Preparing for information being mission-critical to the NHS’, ‘Driving integration and interoperability through opening up systems’ and ‘Patient engagement and self service’. Further information on core themes can be found on our website www.bcs.org/health under Strategy and Policy.

Open debates that contributed towards our Information Revolution response were:

- patient engagement and self-services (patient groups were invited to discuss with health informatics specialists the requirements they have of an information revolution);
- workshop on the future for the health informatics profession;
- challenges of sharing information for multiple purposes across local health economies;
- the Information Revolution and business transformation.

In addition, BCS has commissioned research being carried out by Mott McDonald into our first theme on ‘Preparing for information being mission-critical to the NHS’. They have reviewed the evidence base, conducted a survey completed by over 220 people from a variety of backgrounds and interviewed thought leaders. Mott McDonald attended our BCS open debates and received the inputs listed above. Their full report is awaited, but their interim report was used as an input into our Information Revolution response and quotations from thought leaders have been used throughout.

**Information Revolution report drafting**

Report section leads were identified from our BCS Health Strategy and Policy Committee who had expertise in the subject areas of our report sections. Our committee and report section leads are leaders in the health informatics market across the NHS, academia, research, think tanks and industry, as well as a mixture of BCS members and non-members.

Report section leads took outputs from the activities above and others and worked with a team of experts from within and outside of BCS to pull together drafts for each chapter. A central editing team compiled the chapters into a draft report.

The draft report was circulated to our Strategy and Policy Committee for feedback and ten members of the group met to discuss all the recommendations put forward in our response. The draft report was updated and then approved by the BCS Health Executive and the BCS Government Relationships Group.

Full reports from our open debates can be found on our website www.bcs.org/health under Past Events.
3. Patient, service users, carers and the public

One of the most significant impacts of technology on society in recent years has been the way in which the consumer has been put in control of traditional ways of performing tasks and familiar distribution channels have become increasingly redundant. Whether booking travel arrangements, banking, ordering goods or communicating with friends, the way we perform these basic activities has been disrupted. As a consequence our expectations as individuals – in terms of transaction speed and breadth of choice – have become much greater. This is known to economists as ‘disintermediation’ or, in other words, cutting out the ‘middleman’.

The technology-empowered consumer has challenged both public and private sectors, and in some cases there has been resistance. The entertainment industry, for example, has been slow to react to how people are accessing games, music, films and TV with consequent damage to the financial standing of some once-great companies. Health has also been a slow sector to respond. Yet how change will come about is less clear – disintermediation in health is unlikely to come about in the same way as it has in other sectors.

A common misconception is that information equals power and knowledge; this is not necessarily true. It requires context and support to activate people for behaviour change and thus to be of any use. The degree to which this guidance is required will vary: some people may prefer to have little or no interaction with anyone, whilst others will prefer to interact with the health care system as they always have. The health care system, especially an entirely tax-funded one, needs to be flexible enough to accommodate a variety of consumer needs and wishes.

The Information Revolution cannot be a ‘one size fits all’ approach. Similarly, it cannot be a ‘many flowers bloom’ approach, which characterised the information strategy in the NHS prior to the National Programme for IT. Instead, we now require a mature relationship based on trust between the health care service and the individual.

The informatics community has a key role to play in empowering patients, carers and the public in the Information Revolution. It is often a critical link between suppliers, clinicians and increasingly patients and carers when information systems are designed, implemented and evaluated.

In summary, the Information Revolution offers the potential for an altered state between the health care system and the individual. However, to ensure this can happen a number of issues need to be addressed, not least of which is to acknowledge that patients will only be activated through a combination of information, education and support, delivered through trusted relationships.
3.1 Issues

**Information Revolution purposes**

Our open debate with patient groups discussed whether the Information Revolution was focused on fixing problems in the system or activating patients in their health and wellbeing or both. The consultation has not distinguished between the purposes of the Information Revolution and the behaviour or process change that is desirable for each purpose.

Exposing information on quality of providers and their services as a mechanism to drive choice and create a marketplace or to allow the public to assess the quality of local services are fundamentally ways of trying to fix an imperfect system. This is a very different purpose to sharing information to enable people to make choices and change behaviour to improve their health and wellbeing.

Clarifying the different purposes of the Information Revolution is important to avoid confusing patients and the public and to support the wider aims of the Information Revolution. Each purpose is valid and important and needs to be argued individually.

**Behaviour change**

The role of information and technology to support individuals in having a healthy lifestyle, reducing their health risk or managing their long-term condition is a topic that needs to be addressed. The government is pursuing a policy of behaviour change and transferring responsibility to individuals, based on the idea that subtle shifts can influence the public without the need for a ‘nanny state’ approach. The evidence for what works in changing health behaviour is in its infancy. However, the experience in 2009 of the National Flu Pandemic Service, though born of a crisis, showed that it is possible to transfer limited diagnostic and prescribing responsibility to the public.

Technology has the potential for giving people choices and responsibilities. At one level, this could involve giving patients access to their medical record to empower them to take control of their health care, in the same way that online banking has empowered people to manage their finances. At another, it may be that online expert advice, the use of social networking or home-based devices will allow patients to manage their condition without needing to see a doctor in person.

There are financial implications of an information revolution that may not be immediately obvious. We argue that, overall, the use of information and technology improves productivity and raises quality, but in some circumstances additional costs may arise. For example, information will drive better predictive analysis, which may uncover unmet need. Another example will be information communication services that NHS organisations will need to put in place to deal with the request for sharing information and dealing with public enquiries.

"Exposure of information is wholly beneficial. My practice has given patients full access to their records for the past five years without any problems. Patient access has improved the accuracy and completeness of records and has helped the patients to become more actively involved in their care and able to self-help: a "partnership of trust"."

*Senior clinician (GP)*
Health literacy and the role of intermediaries

How can the system provide support and education to the ill, those living with long-term conditions and the well? The role of health ‘intermediaries’ and ‘navigators’ will come to the fore here, but who will fill these roles?

- GPs, through their role with patients and commissioning responsibilities under the coalition government’s reforms, will have an important navigation role with specific patients, but may not have the time and resources to meet this role in its entirety.

- Nurses are the health care professionals that generally have the most contact with patients, and have traditionally taken on an advocacy role. Given robust training and development, this role should be developed further.

- Expert patients have shown themselves to be able to play an important role in helping fellow sufferers navigate the health system and manage their illness. Yet, again, they cannot be the whole solution.

- The third sector may well have an important role to play. They are likely to be trusted by patients and already provide many services directly to patients and the vulnerable. However, they are unlikely to be the whole solution as their focus frequently tends to be on condition-specific rather than generic support.

To be effective, the health navigator role will need to be adopted by a number of different groups and tools: ICT tools to help well individuals understand how to move around the system (cf. online ‘ask me’ consumer tools); the third sector for people with long-term conditions and some acute conditions; the GP for those that prefer them. Consideration could also be given to commercial organisations offering services to act as the navigator, through the NHS, either for specific questions or as a long-term guide.

Informaticians should support these new health intermediary and navigator roles. Traditionally, they have not had patient-facing roles, but as more ICT systems become patient-facing, this could change.

Focused work is required to create a network of intermediaries to ensure that all patients benefit from the Information Revolution. Getting this right will have a profound effect on addressing the ‘digital divide’ and lessening the burden on health and social care systems for developing and providing these roles.

We should look at patient advocate roles that have developed in other countries, such as US hospitals, where intermediaries help patients and families navigate the system.

Shared decision-making aids

A recent Salzburg Global Seminar referenced a Cochrane review of 55 randomised controlled trials, which found the use of decision aids leads to greater knowledge, more accurate risk perceptions, greater comfort with decisions, greater participation in decision-making, fewer people remaining undecided and fewer patients choosing major surgery.

We believe that technology and information systems have an important role to play in shared decision-making and supporting the introduction of suitable decision aids into patient pathways. However, we believe that there are issues to think through, such as the liability in the provision of such decision aids. Standards might be required, but overuse of standards could kill the market as business models are hard anyway. If

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no standards are put in place or considered, then the market could fill this vacuum, but with the risk that some standards may be inadequately designed, insufficiently evidence-based or even dangerous.

There will be a tension between the need to stimulate the market and the need to protect patients and the public. This could be achieved through appropriate accreditation mechanisms. We believe that the proliferation of shared decision-making aids, which is likely to occur, could generate a potentially serious issue around patient safety and that a careful balance is required in terms of stimulating the market versus protecting patients and the public.

**Utility and patient engagement**

Individuals will more readily engage when there is clear value or utility for them. In banking, people use online services to make payments and transfer money more easily. In a similar way, health and care could provision simple tools that deliver quick value and utility to patients, such as online booking, ordering repeat prescriptions and secure email communication with their care professionals in order to transform the patient experience and stimulate further engagement. The information strategy must not just focus on better engagement and coproduction\(^3\) of health through access to information in medical notes – both tools and information access are important, together.

This is also an opportunity to utilise new technology such as smart phone apps to tap into the explosion of consumer interest in this technology – for example, imagine the interest in an NHS iPhone app to enable people to order their repeat prescriptions.

> ‘Patients who are enabled to self-help, e.g. request prescriptions, view clinical letters, get test results – only need to speak to the doctor if results are not normal, and this contact can often be by phone rather than requiring a visit.’

**Patient representative**

Utility services could also offer efficiency savings by reducing administrative burdens of the health care system.

> ‘Coproducting health care: Most industries over the last decade (travel, banking, ecommerce) have engaged their consumers to coproduce their products. This achieves two things: personalisation for consumers and reduced operating costs for companies.’

**Individual’s perspective from BCS crowd source**

> ‘More coproduction of health care between patients and clinicians will better meet the needs of patients and also reduce the cost of the service – beware of the “choice paradox” leaving people feeling disempowered and less satisfied with the choices they’ve made.’

**Individual’s perspective from BCS crowd source**

\(^3\) Coproduction is a process that involves people in the design and, crucially, in the delivery of the services they enjoy.
**Information assurance**

How can people be assured that the information they are accessing is credible and trustworthy? There could be a single provider of information, such as NHS Choices. However, that implies that information can be ‘controlled’, which it cannot. Not everyone sees information provided by the NHS as truly independent. Disintermediation is already a major characteristic of health information – people access information from international health providers’ websites; social media sites; a range of patient information groups including very small specialist ones; the third sector; and the private health care market.

There are existing patient information standards, such as The Information Standard, that should be encouraged, and brands and organisations that want to build credibility for the quality of their information provision should increasingly adopt these standards. Respected accreditation mechanisms will be helpful and important in allowing a wide range of high-quality information sources to arrive without government direction.

**Patient record access**

The consultation proposal suggests that people will have access to their own records and be able to store them where they choose, even in relatively insecure environments. They can then choose to give their data to others such as third-party suppliers, patient support groups, researchers or family members. This raises several issues, including the difficulty of withdrawing data already given and protection from misuse by others.

Patients need to be aware of the potential dangers of sharing an out-of-date copy of their record with other clinicians caring for them. For this reason, real-time access is preferable where available. Guidance is required for patients and care professionals on the safe handling of their data. The guidance could advise on procedures and technology to minimise the risk of coercive access; best practice for systems design for comprehensive and clear audit trails; the technological implications of various models of patient-limited record sharing, in conjunction with clinicians and patients to determine what is feasible technologically and in various care settings.

The Information Commissioner is very clear that, once extracted by a patient, the confidentiality of the extracted records becomes the responsibility of that patient. However, there may be a duty of care to inform patients or otherwise protect them in these circumstances. At a minimum, clear and simple guidance is needed for patients on how to store their data securely and how to give others access to it safely and effectively. Appropriate accreditation mechanisms will prove invaluable.

Patient groups representing vulnerable people have raised the issue of coercive access by partners, parents, employers and so on. Warnings and protections will need to be put in place to enable those at risk of coercion to take steps to prevent access to their records being used as a weapon against them (see Chapter 11). Patient information is of potential high value to those marketing health products and services, so organisations may provide significant incentives for giving access to records, and the government must maintain a watchful eye on such practices.

‘The biggest hurdle remains that of confidence. They [patients] do need information and are frustrated by the lack of it but have been scared by all of the disclosure stories. Let the patient define how they want their information whilst we concentrate on making it safe so that we can respond. No more second guessing and making it so complicated.’

*Individual’s perspective from BCS crowd source*
**Patient ‘control’ of medical records**

Open debates held by BCS highlighted that it is unclear what is meant by ‘control of medical records’ and that the word ‘control’ may mean something very different to a health informatician, a patient, a politician or others.

Control, as described in the Information Revolution consultation, comprises the patient’s ability to access the record [2.3] and to download a copy [2.7, bullet 3]. These things have been guaranteed to patients since 1990, although having a copy may be charged for and facilities to download a copy are rare compared to the availability of print-outs.

The concept of ‘control’ implies that a patient record has ‘ownership’ – these terms are confusing. However, medical notes will often reference multiple parties and document various happenings (‘Mrs Smith complained that her knee pain prevented her driving and that she was relying on her sister to drive her daughter to school’ – who owns or should control which part of this statement?). The record describes the interaction of patient and clinician, and the clinician also has rights and obligations associated with it. Other, more helpful terms, such as ‘responsibilities’ or ‘obligations’, should be considered.

If patient control means choosing who can see their record and who cannot, the question is to what level people should be able to specify (that is, individuals, teams, organisations) and whether they should be able to restrict sharing parts of their record as well as the whole record and to what level of granularity. Having access to data held by the clinician and being able to have a copy of it does not put the patient in control in the usual sense of the word or as understood in the Data Protection Act (1998).

Patients may well be content with full audit trails being available in medical record systems that enable them to see who has accessed their record and when. However, many systems are not yet able to produce a robust audit trail that is easy to understand.

Patient data will be collected once and used for secondary purposes such as management and research as well as direct care. Patient control should include the ability for people to say that they do not want their data used for specific secondary purposes. People are now much more conscious of their privacy and the management of their personal data. Through natural altruism, people are often willing for their data to be used to help benefit others, providing there are effective management controls.

**Using patient-entered data in the care process**

Currently, any patient/carer observations and views present in the clinician’s record are filtered and summarised by the clinician before entry into the record. Patient data entry is very different. Besides observations, patients could, for example, provide their history of presenting complaints or views on their quality of life with a chronic illness since their last annual review before attending the consultation with the clinician.

However, any move towards incorporating patient-entered data into the care process is the thin end of a major cultural change in the care process, which, whilst desirable, will be found threatening by many clinicians, will take time to achieve and will initially only suit a small (but growing) percentage of patients. Clinicians would therefore have to be prepared to support more than one paradigm of care for some time to come and be convinced of the benefits for all of doing so.

Using patient-entered data raises questions, such as:

- Should patients enter data into their clinicians’ records, their own record, which they may then make accessible to clinicians in whole or part, or a mixture of the two?
• If patient data is entered into clinicians’ record, who is responsible for its governance?

• Should patient-entered data be shared with others involved in the care process, for example when making referrals?

• Does patient-entered data have the same credence as that entered by clinicians? Should it be used for automated decision support?

• What should other users of the record do if confronted with material entered by the patient and the clinician that conflicts?

• How should relationships between material entered by clinicians and patients be persisted and shown?

This raises the need for the creation of a ‘personal health record’ distinct from the electronic health record, the latter owned by the provider and containing data for which the provider is legally responsible, the former pulling data from the electronic health record and being supplemented by data added by the patient or others at the patient’s discretion. This creates the opportunity for multiple vendors such as Microsoft and Google to find their appropriate place in the national strategy. There is a risk with a separate personal record that it is only used by the individual patient as an aide memoire when a powerful use is when this is used by professionals in the care of that patient. Professional use is unlikely in most cases.

Marketing the benefits

The NHS needs to make it clear to individuals what is in it for them to engage with the Information Revolution. However, the NHS lags behind other sectors (e.g. online shopping, banking, travel and social networking) for a multitude of historical reasons. One reason why the NHS is so far behind other sectors is that the NHS does not sufficiently ‘market’ these services to patients and the public. No consumer asked for ATMs or online banking; few would now ever enter a bank. The banks had a commercial interest in these new services and marketed them to create consumer demand, and now compete with each other to respond to that demand as it increases and develops. As the fall in TV revenues show, traditional ‘national’ marketing is beginning to have limited effects. The NHS does, however, need to improve the ways it tells people of the basic services now being offered electronically – through seeing and feeling of these functions. However, the bigger issue is how the NHS – both nationally and locally – can both counter cynicism and create a fresh vision of the future digital NHS.

Decision aids to engage

The question of ‘what is in it for me?’ will also manifest as an individual decides whether they want to engage in health through any particular information or communication technology. People do not have stable preferences about what is important to them when choosing services. For example, when choosing a hospital people find it difficult to make trade-offs between quality, safety, patient experience and location. Similarly, when deciding on whether to share information, people struggle to make trade-offs between privacy and the public good for medicines research or epidemiology. There is no real honest voice or wise head for the public to trust. Such an approach would have been invaluable for the roll-out of the NHS Summary Care Record service.

Inclusion

Whenever ehealth programmes are discussed, there is a justified concern that they will become another tool for improving access for the affluent and educated whilst further excluding those parts of society who need the NHS the most. The information strategy needs to address this issue, whilst recognising that society is moving on. In 2010, 60 per cent of adults in the UK accessed the internet every day or almost every day, nearly
double the estimate in 2006. However, internet use is linked to various socio-economic and demographic indicators, such as age, location, marital status and education. For example, a survey showed that the majority of those aged 65 and over (60 per cent) had never accessed the internet, compared with just one per cent of those aged 16 to 24. Whilst 97 per cent of adults educated to degree level had accessed the internet, only 45 per cent without any formal qualifications had done so.

The use of technology, particularly communication technology, offers a huge opportunity to reach out to one of the NHS’s most hard-to-reach groups – young people from any background – but may be less effective with older, poorer people. Programmes will need to be designed to support those groups particularly, but also to recognise that many people will want to continue to use the NHS in the ‘old-fashioned way’. This need not be a problem. For instance, a significant number of people choose to access their GP through an econsultation, taking half the time; this will leave more time available for those people who need face-to-face contact.

Much that is written about exclusion and the digital divide focuses on age and social background. It is important for the information strategy to also address the challenges faced by people with physical and mental disabilities. These groups do not need to be excluded by increasing the role of information and technology, indeed they may be some of the people who have the most to gain, but the strategy must deliberately include them and build on the huge expertise that already exists in the voluntary sector, for example, the RNIB (Royal National Institute of Blind People) has a website and accredits other websites as being accessible to people with impaired vision.

3.2 Recommendations

Information Revolution purposes

(1) We recommend that the information strategy is clear on the purposes of the Information Revolution and that they are individually approached with patients (and their care professionals) in the right way to achieve the desired outcomes.

(2) We recommend separation of the following purposes:
• enabling patients to become equal partners in their health care and take control of managing their own health;
• enabling patients to make choices about where, who and what health services to use, liberating the patients and incentivising providers to improve;
• creating transparency so that the public can hold the NHS to account.

Utility and patient engagement

(3) We recommend that the information strategy should encourage care providers to use technology and media as a tool to engage patients and the public in taking responsibility for their own health and wellbeing. The NHS should utilise existing technologies that people use on a daily basis and harness fresh and exciting technology, including web 2.0 approaches, to leverage social capital and to meet patients’ desire for better interactions with health and care systems.

(4) We recommend the development and use of decision aids that help patients weigh up their benefits and concerns in order to decide on how to engage in their health and care through the use of information and communication services and that existing patient information standards, such as The Information Standard, are more widely publicised and adoption encouraged.

(5) We recommend that the NHS Commissioning Board contracts with NHS providers, the third sector, commercial organisations and others to develop, carry out and be recognised for performing roles as health ‘intermediaries’ and ‘navigators’ for patients and the public.

**Patient access to medical records**

(6) We recommend that care provider organisations should have an electronic patient record in place within five years. This should include the ability for patient remote access and work towards enabling record extracts for patient-held electronic personal health records.

(7) We recommend that work is carried out with patient and carer groups, and others, to simplify and make consistent a consent model (for information to be accessible to others) across England and liaise with other countries on the essential elements of a universal consent model.

(8) We recommend that further work is carried out to understand what patients want and expect in terms of ‘access’ and ‘control’ of their medical records and to use this as a basis for determining requirements. Robust and easily comprehensible audit trails of who has been accessing patients’ medical records are an essential, cost-effective tool for helping patients manage risk associated with sharing their medical data and should be implemented.

(9) We recommend that guidance is put in place on the safe handling of patient data for patients who are storing and sharing their personal medical data, including sample sharing agreements.

**Inclusion**

(10) We recommend that procurement contracts specifically address the needs of people for whom new ways of delivering the NHS through technology and information may not be naturally inclusive and that service redesign addresses the needs of those people.

(11) We recommend that the NHS partners with voluntary sector organisations to ensure that best practice in engaging harder-to-reach patient groups is firmly embedded in the information strategy implementation.
4. Clinical engagement and enablement

The BCS clinical community recognises the need for high-quality information centred on patients rather than disease, interventions or service. It endorses the partnership with patients and welcomes the sharing mechanisms to give patients access to and, where appropriate, control of their records. It supports the development of structured records (particularly required in secondary care) as a method to underpin routine data collection, acknowledging that this is essential if data is to be collected at the point of care and if those entering data are to contribute to the accuracy and completeness of the records.

This will require standardised methods for recording (and possibly coding) data, which means that there needs to be agreement on the core data items that should be collected on each patient with a particular illness. This should form part of a long-term vision to develop electronic records.

At the same time there needs to be an acknowledgement that health care is not an exact science and many decisions have to be made on the basis of judgement rather than knowledge or exact data. Also, clinical knowledge and practice is context-dependent and can vary in subtle ways to suit individual patients at different locations, cultures and clinical networks; one size may not fit all.

4.1 Issues

Behaviour change

Successful implementation of the Information Revolution will involve very substantial ‘behaviour change’ on the part of clinicians, patients, managers and others. Simply providing the information and IT will not of itself guarantee that the information will actually be used – or even collected, analysed and understood in the first place. This key topic is raised in more detail in Chapter 5.

Clinical leadership

The concept of ‘clinical engagement’ runs the risk of implying that clinicians are passive participants in information programmes run by other people. We believe that clinical engagement requires clinicians to be in leadership positions in these programmes, sharing the credit and responsibility for the difficult challenges. Only in this way will accountability and true engagement be achieved.

In many countries, the concept of a chief clinical or medical information officer is common, generally reporting to the medical director, though sometimes to the CIO, giving a senior, credible clinician responsibility for the success in the use of information and IT. The business of health care must come to value the requirement for this role.
**Education**

Clinicians require much more support, training and education on the use and value of data and information, and education on how to use information and tools with patients. Education should create confidence and a desire to engage.

Much of this can be achieved by rapid feedback of raw data to the clinical teams that generated it, thereby creating a ‘spiral of quality’. Medical, nursing and allied health professional training should encompass the collection, analysis and use of data within their curricula.

‘Improve data quality and uptake of standardised terminology in records. Clinicians need educating in how to use information more effectively. Once they appreciate the benefits this could motivate them to be better at entering good quality data.’

*Health professional body*

**Marketing the benefits**

The benefit of clinical engagement and enablement to clinicians and patients is pivotal and must be understood by all to gain trust and participation in information sharing.

‘Information needs to be fit for purpose and not seen as a threat – danger of defensiveness/gaming if there is increased fear of challenge/litigation/punitive action.’

*Independent consultant*

‘There is a risk that greater exposure of patient level data will cause some clinicians to adopt defensive practice in data recording to avoid the risk of challenge.’

*NHS information professional*

**Clinical record structure and standards**

Increasingly, as care is provided in multidisciplinary teams, the art of clinical history-taking involves meshing several models of the world, including of course the patient’s. This gives rise to a major challenge around record and data standards, language and record usage expectation when designing and configuring clinical information systems appropriate to a multidisciplinary world.

There is a need to understand better the different terminologies and cultures of different care professionals and how they can be accommodated, whilst achieving a common degree of standardisation. There will need to be intercollegiate standardisation on clinical content and noting to ensure that information is comparable and terminology consistent. There needs to be a recognition that the quantity and quality of the information collected for clinical decision depends on the context, including such factors as time available, state of patient and the experience and seniority of the professional.
Professional groups should participate through the Royal Colleges and professional societies to agree a range of professional standards for data recording and sharing. This might not necessarily need a drawn-out timetable as, in the first instance, the data does not need to be comprehensive.

**Establish a data standard for sharing information with patients**

We want patients to have access to medical records to engage them in their health care, so we need to make efforts to make this as easy as possible. Implementation of new technologies to deliver health care will be helped by these plans to share health data with patients. This will be of greatest benefit, if data can be structured in standard ways facilitated by establishing a data standard for sharing of structured data with patients. This should greatly increase the speed with which ways can be found to engage patients in shared decision-making and greater self-care.

The balance of argument between use of plain English and medical jargon (professional terminology and shorthand) should be tilted more in favour of the former, without taking this to absurd limits. Whatever we say, some clinicians will automatically tilt towards the latter (just as managers do), so we would like to encourage more of a pressure wave for plain English. Failure to do this may lead to clinical time being taken up in responding to patients seeking interpretation/translation and inaccessible language will create a barrier to patient participation and engagement.

‘Clinicians need to ensure that records are concise, understandable and not using unnecessary medical terminology – not “dumbed down”, but relevant, accessible and to the point – helps all parties, not just the patient.’

*Acute hospital consultant clinician*

**Improving data quality**

In common to other sections, a key theme necessary for the Information Revolution to work is the need to define the data standards, make sure they are put in place to record data accurately, and to ensure that people can access the information they require. Without such an approach, nothing will happen. The health system has to focus on the fundamentals; we need clinicians and other care professionals to trust the data and we need to incentivise them to use this information to change the way they work and the processes of care.

Sharing data makes it all the more important that source data is accurate, up-to-date and comprehensive enough for the intended purpose and for its correct interpretation without the additional contextual (that is, tacit) knowledge that the original authors possess. Sharing data that does not fit these criteria may lead to the provision of unsafe and/or inappropriate care, or may harm patients in other ways. Not sharing data for personal care embodies even greater risks, unless patients can make their clinician aware of what they need to know by other means.

Every time data is entered, there is a possibility for error. Single data entry that is accurate and transferable leads to improved effectiveness in care and reduced costs in terms of administration and time.

We must start by addressing the weakness in data quality, such as inconsistencies in recording of routine data, incompleteness of care data and incompleteness of clinical audit data. It is not easy to enforce data quality retrospectively – we need quality control for data entry. There is a minimum set of things to record
and to get right. This minimum set of information must be agreed by the clinical profession and must be of value to them and their care of patients.

Data quality needs to be enforced at point of collection through data standards, validation and enforcement. This can only be achieved through a multipronged approach such as through:

• greater clinical engagement and professional responsibility around data recording;
• greater external scrutiny and audit of data quality and professional monitoring;
• data quality facilitation, such as that provided by PRIMIS+ in primary care, in all care settings;
• clearer legal obligations around data quality;
• creation and use of clinical standards/guidelines for record-keeping and clinician training in them;
• the deployment of standard information structures and good system design that properly reflects business processes;
• use of contracts under commissioning to impose national data standards.

‘Feedback to the originators is a key to improving data quality and completeness. Clinicians and other professionals need feedback from the data they collect if they are to take an interest/get value from the information they record and provide. Too much currently disappears into ‘black hole’ systems that give nothing back to the originators.’

NHS information professional

Data audit

An important component of ensuring information quality is the audit of data. This will require that processes for interpretation and analysis of data to generate information are also transparent and subject to audit – this will help to ensure that information can be trusted.

Some disease registries with a verification process of source data have good information; others do not. Patient access to medical records is an important mechanism as it allows the individual with most interest to inspect and audit their own data held in medical records and should help to drive up quality.

Despite the risks, exposing poor-quality data to others can be a powerful force for its improvement, but only if appropriate and timely feedback loops to the original data sources are in place. Responsibility for ensuring the quality of patient health care data ultimately lies with those who generate and record it.

5 PRIMIS+ is a free service to primary care organisations to help them improve patient care through the effective use of their clinical computer systems, http://www.primis.nhs.uk/.
4.2 Recommendations

**Clinical leadership**

(12) We recommend that the chief clinical/medical information officer role be created in NHS organisations to ensure that clinicians lead the demand and use of better information and tools; and that Monitor\(^6\) looks for this as a senior role when evaluating the governance of foundation trusts.

(13) We recommend that education curricula for doctors, nurses and other care professionals be adapted to educate on the use and value of data and information and the use of information and tools with patients. For those that are already practising, education should be provided as part of the continuing professional education.

**Improving data quality**

(14) The information strategy must, as a priority, address the weakness in data quality at the point of collection through data standards, validation and enforcement. We recommend a multipronged approach through:

- determining a minimum set of information agreed with the health and care professions that has value to the care process, ready for NHS Commissioning Board and GP commissioning consortia launch;
- clarifying the professional obligations and professional monitoring for data quality and completion of minimum data requirements;
- clarifying the legal obligations of organisations around data quality and completion of minimum data requirements;
- greater external scrutiny and audit of data and information quality;
- creation and enforcement of clinical standards/guidelines for record-keeping, data recording and sharing, with intercollegiate standardisation across Royal Colleges and professional societies to ensure that information is comparable and terminology consistent;
- imposing national data standards inside contracts with health and care providers, with penalties for non-conformance.

(15) The information strategy must reinforce data quality through both professional and public data and information audit. We recommend a multipronged approach through:

- transparency of provider and commissioner information to enable the public to hold their local health system to account;
- encouraging patients to access their medical records and feedback on data inconsistencies;
- encouraging a market for data quality facilitation tools, such as medical record audit tools, training services and peer comparison;
- inspection enforced through commissioners contracts with health care providers.

(16) We recommend that the annual financial audit of health care providers should include a check that the data held on their core data systems matches the data submitted to the Care Quality Commission (CQC), Monitor, the commissioners and other statutory returns.

\(^6\) Monitor is the current independent regulator of Foundation Trusts, and is being setup now as the economic regulator for all providers of NHS care.
Standardisation and interoperability

(17) We recommend that the information strategy should require and prioritise work on the standardisation of terminology used in its specific areas, such as defining disease, symptoms, treatments and outcomes.

(18) We recommend that data standards/guidelines for sharing structured medical record data with patients should be put in place and that these should strongly encourage the move to use of plain English in medical notation.
5. Business change, management and governance enablement

We believe that the reforms proposed will help improve the information available to those involved in business change, management and governance, including regulators, local authorities (overview and scrutiny committees, Primary Care Trusts (PCTs), GP commissioning consortia and managers of health care services, such as hospitals, primary care, community care and so on).

The direction that has been laid out is welcome – in particular we welcome:

• a move away from top-down direction and a greater focus on local accountability, transparency and patient engagement;

• the shift of emphasis from data being used to administer the system to data being used to measure the outcomes and cost-effectiveness of treatment;

• the recognition that the highly complex issues of making information useful to managers (as well as patients and clinicians) will require an industry of competing approaches;

• the encouragement of greater independent and public scrutiny and commentary on quality of health services.

The management information challenge will shift from meeting centrally dictated targets within budget to identifying the quality of services (and, with the introduction of revalidation, doctors) and delivering the best possible quality of services within budgets. In particular, management will focus on identifying those areas where quality is below par and resources are being wasted. This is essential if the NHS is to meet the current financial challenge. Management (both commissioners and managers of providers) will be held accountable.

However, we believe very strongly that information transparency and the adoption of information technology are essential tools in the transformation of the NHS. If the NHS opens up its data and implements new IT without fundamental changes in service design and a shift in the priority that the NHS places on data, the public will be confused and alarmed by the poor quality of the information and the service will not extract the huge benefits that are to be gained.

In the past, patient decision-making, commissioner strategies and information publication have had a much weaker influence on the NHS than central direction. It is important that each of these levers is reinforced by the centre every time they intervene in the NHS and not ignored every time there is a new initiative.
5.1 Issues

Behaviour change

Successful implementation of the Information Revolution will involve very substantial behaviour change on the part of clinicians, patients, managers and others. Simply providing the information and IT will not of itself guarantee that the information will actually be used – or even collected, analysed and understood in the first place.

One of the flaws in the National Programme for IT was the failure to recognise it as a major change programme requiring substantial changes in working practice and behaviour, and to build this in as a major (if not the major) part of the programme. There is good evidence in published studies on the implementation of IT in health services around the world that shows, firstly, that computerising poor process can actually make the process worse and more expensive; and secondly, that quality and cost benefits come only from comprehensive IT implementation – if you only computerise part of the process, you cannot extract the benefit of a complete redesign.

In the NHS we need everyone to respond to new information flows and this will require locally driven change management plans. These need to be led and promoted by top management, including clinical leaders, and not left to informatics experts.

Success for the Information Revolution requires a culture change. But culture change itself is not a useful goal – it cannot be touched or felt, and therefore focus needs to be applied to behavioural change and routine change. Measuring what people do and creating the right incentives or disincentives are critical.

‘After a 10 year career trying to underpin clinical change enabled by IT systems, I am certain that the cultural/behavioural and process changes required to deliver the value of the Information Revolution (underpinned by standards) will only come through the application of direct incentives for individual and organisations.’

Individual perspective from BCS crowd source

As we have seen in areas such as telehealth, there is a danger that the Information Revolution proposal will just generate many tiny projects that do not get broadly adopted. A strategy is required by the NHS to avoid this situation and this is currently lacking. There needs to be incentives for individuals, teams or organisations to copy best practice and not just to share best practice.

Process change

The Information Revolution needs to cover the whole operating model of health and care services to determine how processes are adapted and how resources are used, prioritised, planned and mobilised as a consequence of better information.

The real response to the huge changes facing the NHS is a change in the processes and who carries them out. Only when the processes are understood can we really know what information is required, when, by whom – and therefore what governance, collection and reporting is necessary. Mechanisation of existing processes is not a revolution, but merely papering over the cracks.

However, we should not wait for a huge process redesign centrally. Rather, what is required is a rapidly established set of standards for information collection, production, storage and use by the different actors
Setting expectations

The consultation document gives a strong sense of direction, but little idea of expectations in terms of the speed with which it hopes to see change occur. The proposals will require a rapid and significant shift in culture and working practice. This process would be helped by the centre setting the standard to which organisations are expected to work and what it hopes to see occur in terms of the quality of information available to managers, patients, clinicians and the public.

For example, ‘high quality care for all’ includes a useful definition of the level for information on quality that services should hope to achieve. It proposes that managers should be able to produce timely data on the clinical effectiveness, safety and quality of experience for each service line offered. This is a good definition for secondary care, community care, possibly mental health and, with some adaptation, also primary care. The same approach should be taken to understanding the quality of services across organisational boundaries and cost information.

In common with other sections a key theme for the Information Revolution is the need to define data standards, make sure they are put in place to record data accurately and ensure that people can access the information they require. Without such an approach nothing will happen. The health system has to focus on the fundamentals; we need clinicians and other care professionals to trust the data and we need to incentivise them to use this information to change the way they work and the processes of care.

Improving data quality, gaps and access

The main blockages to management having the information it requires are data quality, data gaps and data access. Key to successfully addressing these areas is the necessity for providers to have in place electronic patient record (EPR) systems – this is not a diversion, but a core activity.

Improving data quality

The systems in place to collect routine data from primary, mental health, secondary and social care provide a good starting point. However, this could be greatly strengthened by addressing data quality issues. This topic has been covered in more detail in Chapter 4.

Improving data gaps

There are a number of areas where no current data collection systems produce adequate information. In particular, data on functional outcomes is missing, as well as regular feedback from patients. This is particularly important for people with long-term conditions. Also, data on the activity of individual doctors will need to be improved to meet the requirements of revalidation.

We believe that the first priority should be to make existing data systems fit for purpose, and that a clear road map should be set out for addressing these data gaps. Ultimately, the only way that a comprehensive data set will be available for monitoring quality and measuring outcomes is through completing the roll-out of EPRs.
Improving data access

The main issues with regard to access to data are:

• access by commissioners to routine primary care data, social care data and clinical audit data;

• creation of anonymous linked data sets to understand the whole health system;

• access to national data sets to allow benchmarking;

• making appropriately available key clinical registers such as cancer, stroke and sentinel audits, whose
data capture is undertaken by third parties on behalf of the NHS.

Improving data sharing

Greater clarity is needed in the area of information sharing. In particular, the consultation document
recognises the difference between sharing data for the purposes of treating an individual patient and sharing
data to create anonymous aggregate data for the purposes of business change, management and
governance. The creation of data sets for the latter purposes cannot be done without the following issues
arising:

• Creating anonymised data sets. To effectively manage local health services, it is essential to understand
the process of care across organisational boundaries. This requires linking of data from different
organisations (including across health and social care organisations) using patient identifiers in order to
create anonymous data.

• Rules on using data sets with small numbers. The anonymous data sets needed to manage and monitor
health systems will include data about small numbers of unusual cases. There is some risk of patient
identification through combining this data with other knowledge. Clarity is required around the minimum
data set size that can be put into the public domain and the uses to which it can be put.

• Legal uncertainties about data sharing for management purposes. Such uncertainties should be addressed
in a way that leaves local NHS organisations able to collate the information they need to manage the local
health economy and benchmark their performance nationally with minimum reliance on the centre (see
also Chapter 11).

Uncertainty about how to handle these issues will result in limited availability of information needed to
manage and monitor quality of health systems. Guidance is required to make it possible for local
commissioners and health economies to create the data they need to manage health systems and report
to the public and organisations with governance and oversight responsibilities.

Obligations to release data

Managers may be reluctant to release information where there are concerns over its quality, its interpretation
or over its release in an increasingly competitive provider market. Clinicians are appropriately conservative
over the protection of patient confidentiality. Legitimate concerns to sharing data need to be addressed, but
where sharing is appropriate there should be an obligation on health care providers that are contracting with
the NHS to release data to minimum standards of detail and quality.
‘Exposure of service data would drive improved quality, but published data must be adequately analysed, presented and qualified to avoid false interpretation.’

*Acute hospital consultant clinician*

The clinical community is broadly supportive of the fact that exposing data to wider scrutiny results in an improvement in quality, but also recognises that clinical data can be difficult to interpret due to differences in case mix and context. There is therefore a risk that, in the early stages of data release, organisations, clinical teams and individuals will be unfairly judged by inappropriate interpretation of data that is not fully explained.

‘At the moment, much of this information is not suitable for exposure to the public as it is not fit for purpose, i.e. not suitable for guiding real patient choice either because of reliability issues or lack of appropriate analysis and presentation – or because patients often don’t have a real choice anyway about where they go for treatment.’

*Information professional*

**Support local investment in informatics**

The move to commissioning for outcomes will shift responsibility and risk closer to provision of service with implications for information management – for example, the need to measure outcomes, agree metrics, share information in provider networks and connect their outcomes.

Providers could make information available in different ways, but there needs to be convergence and standardisation for commissioning and payment information – indeed there is no choice. Health providers will need to supply certain basic information in order to play at all.

These changes will create local incentives for investments in information analysis. Private sector organisations and suppliers may be able to fund some of this investment on a risk-share basis with their returns linked to future savings. Some public sector organisations may be limited in their ability to access capital on a similar basis to fund internal work. Consideration should be given to arrangements to support financing for these purposes. This is particularly important with regard to GP commissioning consortia who will have most to gain from investment in better provision of systems to manage long-term conditions and support self-care and home care.

**The role of the centre**

The Information Revolution correctly identifies the need for local NHS organisations and non-government organisations to develop solutions rather than central government. For these organisations to invest most effectively, the centre should give very clear signals to what it will be doing and what it will be leaving to others to do.

With the accelerated move from centralism to localism, there are dangers that the market will fragment into confusion. It is critically important that the market understands the role of the centre and local organisations in terms of information management. There needs to be an integrated view of the health market and the supply chain that will come together to deliver information services. Without this, there will be confusion for both local organisations and suppliers.
We believe that there are certain core functions that must be performed by central bodies:

• setting data standards;
• setting standards for recording of information;
• auditing and assuring the quality of data recording (arguably);
• establishing and making clear the legality of data usage;
• collecting and processing data for their own purposes, including accountability (such as answering parliamentary questions and publishing official statistics), policy development and monitoring. Central bodies need their own data dissemination systems, including making data available to the private sector on an efficient and equitable basis.

The centre should focus on the core functions that it must perform. It will be particularly important for the centre to signal its future plans to address data gaps and introduce new data standards. This will enable local organisations, companies and other non-government organisations to invest appropriately.

The informatics market needs to be built to deliver systems (clinical, operational, transactional and analytical) for the frontline and to supply the centre with tools and expertise.

5.2 Recommendations

Clinical leadership

(19) We recommend that the chief clinical/medical information officer role be created in NHS organisations to ensure that clinicians lead the demand and use of better information and tools; and that Monitor looks for this as a senior role when evaluating the governance of foundation trusts.

(20) We recommend that education curricula for doctors, nurses and other care professionals be adapted to educate on the use and value of data and information and the use of information and tools with patients. For those that are already practising, education should be provided as part of the continuing professional education.

The role of the centre

(21) We recommend that the information strategy sets out clear roles for the centre and the marketplace in terms of information management. This must offer an integrated view of the health market and the supply chain that will come together to deliver information services. This is critically important to help shape a vibrant market through leadership and signalling of how everyone can appropriately engage. Core functions of the centre would include setting data and indicator standards, deciding and controlling national data requirements, ensuring data quality and publishing official statistics and data.

(22) The centre needs to ensure better informatics impact assessment at the earliest stages of Department of Health policy development. Data quality, data standards, public trust,
informatics efficiency and clinical systems are jeopardised by poorly considered, last-minute demands for information for monitoring national policies.

(23) To mitigate the risk that, in the early stages of data release, organisations, clinical teams and individuals will be unfairly judged by inappropriate interpretation of data that is not fully explained, we recommend that ministers, the Department of Health and commissioners take a mature attitude in responding to data release and be at the forefront of explaining to the public and the media why overreaction is inappropriate.

Behaviour change

(24) We recommend that commissioners incentivise the sharing and rapid adoption of best practice in process redesign and the use of IT without stifling innovation in the market.

(25) We recommend that the information strategy focuses on the operational changes that are needed to extract value from information technology and not simply on the technologies themselves.

(26) We recommend that the information strategy commissions an academic institution to develop and maintain a library of successful IT-enabled service redesign in health care around the world and the return on investment delivered in order to support boards in making investment decisions and enable organisations to confront redesign programmes at the appropriate scale.

Adoption and use of information systems

(27) As an early priority, NHS organisations should map out their information requirements, identify gaps and put in place a clear road map to address these gaps through making their existing data systems fit for purpose to capture this information.

(28) All organisations providing care to the NHS should be given notice that they will be expected to use EPRs in a meaningful way within five years (see Chapter 8). This should include the ability to meet commissioner and CQC quality assurance requirements from routinely collected data, and to send and receive an electronic care summary at handoff points between care provider organisations along the care pathway for a patient.

(29) We recommend that the establishment of GP commissioning consortia should be done in a way that supports their ability to internally invest in high-quality information analysis and cost-saving technology, particularly with regard to management of long-term conditions and supporting self-care.

Data sharing

(30) We recommend that where sharing is appropriate there should be a statutory obligation on health care providers to release information as a minimum standard if contracting with the NHS. The NHS Commissioning Board should require all providers of services to publish meaningful comparative performance data at the level at which patients are being offered choice and that the public will understand and value.
(31) The information strategy should make it clear that sharing data in order to create anonymous aggregate data sets for the purposes of business change, management and governance is appropriate, but that risks need to be mitigated through security standards and technologies.

(32) We recommend that the information strategy provides clear guidance on data access to address:
• the required access by commissioners to routine primary care data, social care data and clinical audit data;
• the creation of anonymous linked data sets to understand the whole health system;
• the required access to national data sets to allow benchmarking;
• the appropriate availability of key clinical registers.

(33) We recommend that the information strategy enforces a policy that all invoicing transactions should take place through a central clearing house so that the focus on improving data quality is on this shared data set. It should be made clear that providers will not be paid for activity which does not follow this procedure.

(34) Alongside clarity on the data standards that must be followed and a regime of penalties and sanctions on organisations that fail to comply, we recommend that an obligation be placed on any organisation that has the power to set a mandatory standard – such as commissioners, Monitor, CQC – to behave professionally. It is important that providers of care to the NHS and their informatics suppliers are given appropriate notice and reasonable time to prepare for the data standards that are to be imposed.
6. Research enablement

The proposals in the consultation recognise the need for standardisation, quality of data capture and measurement techniques that will underpin better research capability. The UK currently has a competitive edge in the quality of its longitudinal data to underpin medical research, which it has so far failed to exploit fully to the benefit of the UK economy. It is not too late to extract this benefit, but our competitive edge will erode as initiatives elsewhere in the world start to enable data linkage.7

The consultation document only briefly comments on the importance of research and the immense potential value offered by the use of electronic patient records (EPRs). We outline below the broader opportunities and implications of the Information Revolution on research.

6.1 Issues

Clinical/pharmaceutical research

Information on patient experience and concordance with medications

Improving outcomes for patients through effective medicines is the stated goal of the pharmaceutical industry. More effective medications generate the profits that the industry needs to reward its shareholders and reinvest in further research. The recent government policy to move towards value-based pricing has the potential to align ever more closely the industry and the NHS’s desire for better medications.

However, the ambition to create a growing pharmaceutical and research and development industry and move towards a new paradigm for drug pricing will require a step change in the use of health care data. The UK has the leading medical research universities in Europe with institutions like Oxford, Cambridge and Imperial, who can compete with the best in the world. In failing to give them world-class access to data, we fail to support their work. The data that we currently collect on outcomes will not support a sophisticated, value-based pricing model.

Enabling measurement of attaining these goals through accepted outcomes frameworks for health care delivery and aligning outcomes for measuring effectiveness of treatments with data collection are key steps.8

Concordance with pharmaceutical treatment regimes is often a big challenge for patients and incremental innovation is frequently geared towards improving the patient experience to achieve this. Consequently, what should actually be measured in addition to clinical/physiological factors brought about by the treatment regime is the patient experience – patient-reported outcomes measures.

7 See, for example, the Observational Medical Outcomes Partnership in the US (http://omop.fnih.org).
8 See MRC NWHTMR (North West Hub for Trials Methodology Research) COMET initiative (Core Outcome Measures in Effectiveness Trials) http://www.methodologyhubs.mrc.ac.uk/news__events/comet_initiative.aspx.
Standardisation and interoperability

The ability effectively to demonstrate outcomes in health care delivery and enabling better and more complex research to be undertaken using medical records will require improvement on three features of health care delivery and the data collected:

- standardisation of terminology used in defining disease, symptoms, treatments and outcomes measures;
- interoperability of IT systems used in any health care setting to enable linkage of data between systems and to other disparate data sets;
- capture of clinical data as a by-product of clinical care through EPRs in order to gather contextual data and time series data, rather than simply the admission and discharge of information.

The following three areas could be improved through better information management, a well-structured core EPR infrastructure and specialist tools such as integrated clinical trials software modules offered by vendors like Cerner.

Individual perspective from the BCS crowd source

“In the case of pharmaceutical intervention [medication] the following link would be ideal: diagnosis and assessment of condition; prescription; and measure change of condition. Aggregated information of this sort would help sift out ineffective treatments and enable prioritisation of cost and clinically effective treatments.”

Interfaces between informatics tools

Thought needs to be given to how patient medical data will be used in conjunction with the scientific data that pharmaceutical companies and other researchers work with. Effective interoperability between the informatics tools (to organise and analyse, for example, disease pathways, genomic information and molecular structures) already in use in research institutions needs to be developed.

Clinical trials and studies: interventional clinical trials

The following three areas could be improved through better information management, a well-structured core EPR infrastructure and specialist tools such as integrated clinical trials software modules offered by vendors like Cerner.

Protocol optimisation

For any study there will be a protocol describing the eligibility criteria for patients that are needed to conduct the trial. The process for identifying suitable patients, sites and physician investigators to run the trial and adapting the protocol as necessary is currently cumbersome and could be greatly improved if eligibility information customarily sought in each case was built into the EPR and inclusion/exclusion criteria tools overlaid.

Patient recruitment

Currently patients have to be contacted individually to take part in a trial. Clearly, if other ways of communicating the existence of trials are found, together with a cultural acceptance that eligibility criteria
derived from medical records could generate faster communication to patients of the possibilities, then recruitment is likely to improve. However, there are sensitive data privacy issues to consider.9

Furthermore, patients are increasingly aware of the clinical advances that are delivered through research, and one consequence of the Information Revolution may be that they actively choose to select which trials they would like to share their own clinical record with, without involving their clinician.

**Trial execution**
The interface between the case report form (CRF)10 and the patient’s medical record could reduce duplication in data capture. Standardising data entry fields for vital signs recording in the EPR/CRF as well as providing searchable data capture areas for specific information needed by any individual study would increase efficiency in information capture and use.

**Clinical trials and studies: non-interventional studies and outcomes research**

**Expansion of access to data**
The UK has long been considered a leader in outcomes research and epidemiology due to the NHS providing ‘cradle to grave’ health care and the availability of large primary care data sets. A wide range of outcomes studies can be performed with the data, such as assessing the relative effectiveness of treatments; economic studies evaluating the burden of disease or costs of treatment; and pharmaco-epidemiology studies exploring the use and impact of drug treatments. However, currently, most research is conducted using records from only some 5 to 10 per cent of the population11 and expansion of access to primary care databases is essential.12

**Linkage between primary care and secondary care databases**
Linkage between primary care and secondary care databases is also vital. Tools and techniques to link disparate databases will greatly enhance the research richness that NHS data is potentially capable of and there is progress towards this.13 The principles of standardisation of terminology and interoperability of databases are applicable, and well-constructed EPRs incorporating the data that would yield good-quality research results would improve outcomes research.

**Attitudes and awareness amongst GPs and patients about the use of patient data in research**

**Attitudes and awareness to research**
In December 2009 the UK Clinical Research Collaboration (UKCRC) Sub-Group on Public Awareness commissioned market research into the attitudes of patients and GPs to the use of patient data for research purposes.14

The key findings emerging from the GP and patient focus groups provide useful insight into how the use of patient records in research plays out for those participating, and those acting as the conduit for records to

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9 Much work is ongoing in this area and this issue is likely to be central to the Academy of Medical Sciences Report on the Regulation and Governance of Medical Research expected in 2011.
10 The CRF is the electronic patient documentation used in clinical research and is used by sponsors to collect data from enrolled patients at each participating site.
11 From the General Practitioners Research Database, Hospital Episodic Statistics and others.
12 The General Practice Extraction System (GPES) is a proposal to cover 100 per cent of GP practices.
13 See, for example, the UK government’s Research Capability Programme’s ‘Health Research Support Services’ tool to enable linkage between several databases to enable complex research.
14 Attitudes and awareness amongst General Practitioners (GPs) and patients about the use of patient data in research – a study by the UK Clinical Research Collaboration Board Sub-Group on Public Awareness. UK Clinical Research Collaboration (UKCRC) Board Sub-Group on Public Awareness: August 2010 (full report is yet to be published; quotes are from a report summary document). The work will contribute to constructive dialogue with the British Medical Association, the Royal College of General Practitioners and related partners on changing attitudes to the use of patient data for research.
be used. The work has uncovered concerns about the level of ignorance around this issue amongst community GPs and their resistance to having any part in facilitating this vital aspect of health care development.

Many other issues for GPs were uncovered, such as time, costs and distractions from clinical care, impact on relationship with patients and so on, but those of direct informatics interest were:

- Confidentiality: GPs are extremely cautious about allowing third party access to identifiable patient records since there is a risk of them being struck off if anything goes wrong.
- Scepticism: GPs appear to be generally sceptical about the use and abuse of data, particularly electronic data.

The report’s bottom line concern was that GPs will not spend their time gaining consent from patients to use their records unless they are paid for it, and even then, some of them do not feel it is worth the aggravation and risk.

Patients were found to be largely positive about the requirement and the only point of relevance from an informatics perspective was that patients wanted to know that their consent would be specific and time-limited and their information would be properly protected (see also Chapter 11).

6.2 Recommendations

**Clinical/pharmaceutical research**

(35) We recommend that the information strategy addresses how to design and implement the information capture and storage mechanisms for patient-reported outcome measures and medication concordance data.

(36) We recommend that work is commissioned into developing effective linking systems with medical data and the informatics tools already in use in research institutions, to enable medical data to be used in conjunction with scientific data from pharmaceutical companies and other researchers.

Recommendations from other chapters:

- The information strategy should require standardisation of terminology used in specific areas, such as defining disease, symptoms, treatments and outcomes. We recognise that this is difficult to achieve, but prioritised work will help to ensure that maximum benefit is obtained in both clinical care and research through effectively demonstrating outcomes in health care delivery, and to enable better and more complex research to be undertaken using medical records.

- All organisations providing care to the NHS should be given notice that they will be expected to use EPRs in a meaningful way within five years. The comprehensive roll-out of EPRs across health care providers is crucial to the creation of a data set that is complete and accurate enough to support world-class research and development.
Clinical trials and studies: interventional clinical trials

(37) We recommend that patient eligibility criteria for clinical trials and studies are built into the EPR with overlay of inclusion/exclusion criteria tools.

(38) We recommend that opportunities are sought following any permissive regulation changes and appropriate patient consent processes, to improve communications of clinical trial eligibility to patients through the use of EPR systems.

(39) We recommend that a national clinical trial register is created so that GPs, hospital clinicians and patients can see where trials are recruiting and that GPs and hospital clinicians are able to access them for their patients.

(40) We recommend that opportunities are sought to enable interfaces between the CRF used in clinical trials and the patient’s medical records in order to increase efficiency in information capture and use through reduced duplication of data capture, and improved search for information needed by individual studies.

Clinical trials and studies: non-interventional studies and outcomes research

(41) We recommend expansion of access to primary care databases for non-interventional studies and outcomes research with appropriate governance arrangements.

(42) The improved linkage and terminology standardisation between primary and secondary care databases is of importance not only to clinical care provision and commissioning, but also to increase the research richness of NHS data and improve outcomes research.
7. ICT suppliers

Critical to its success, the Information Revolution requires the creation and nurturing of a viable market for information services, software and transactions in order to deliver high-quality information services to patients, clinicians and organisations. ‘Viable’ for ICT suppliers means the creation of profitable returns within reasonable timeframes to generate shareholder value – the information market must take shape in such a way to enable ICT suppliers to flourish. This is a risky new market and barriers need to be lowered.

The real response required to the huge changes facing the NHS is a change in the processes of care and who carries them out (see Chapter 5). The market won’t self-create and it is too risky to leave it to form itself.

In taking steps to build a supplier market that can support the NHS’s challenge to improve productivity and quality, the information strategy must begin by being honest about the positive and negative impacts of the National Programme for IT. On the positive side the chaos that existed in the 1980s and 1990s has been replaced by a robust infrastructure, world leadership in the development of standards, the roll-out of software to previously underdeveloped areas, such as mental health and community trusts, and beginnings of a breakthrough in computerising the hospital sector. On the negative side the local service providers (LSPs) contracts have taken competition out of the software market, resulting in a situation whereby product improvement is driven by specification rather than market innovation, the NHS has reduced its non-government spend on IT to almost nothing and the small, innovative UK health software industry has been squeezed almost into extinction.

The information strategy needs to lay out a road map that builds on the hard-won gains of the National Programme for IT – maintaining the vision of integration and standards, incentivising the NHS to start investing in IT locally and create an environment where the big companies are competing with each other and smaller companies to develop better products. There is space for an indigenous software industry to flourish.

‘Implementing systems that collect information in real time and at source, rather than retrospective transcribing of medical records... would provide more focus on clinical and outcome information rather than the current procedure recording (often aimed at financial and/or target recording).’

*Individual perspective from the BCS crowd source*
7.1 Issues

Role of the centre

The Information Revolution correctly identifies the need for an information market to flourish without solutions being provided centrally. However, for this to happen and for ICT suppliers to invest most effectively, the centre should give very clear signals to what it will be doing and what it will be leaving to others to do. Without this there will be confusion for both local organisations and ICT suppliers (see Chapter 5).

The centre will need to understand what success looks like for ICT suppliers and over what period a viable and sustainable market must evolve. The centre will also want to maximise the use of legacy investments in information collection, transfer, storage and reporting – vital if the execution of the information strategy is to be affordable, and this cannot be left solely to the open market where reinvention could predominate.

Centrally agreed open standards for information processing

A rapid, centrally driven agreement of standards is needed for information collection, production, storage and use by the different actors across health and social care.

If standards are not established openly, then there could be two consequences:

- poor data structures, data quality and integration (returning to the failure of ‘a thousand flowers blooming’ of the previous IT generation); and/or
- the de facto establishment of standards by a few major industry players, enforcing potential monopolies on services, continuing to squeeze out innovative small companies.

Liabilities and risks

Importantly, information governance must be clear in the new strategy to allow ICT suppliers and others investing in the market to understand the risks and liabilities that they and others either bear or share – including the patient as an individual. Further, information governance should be designed to make processes efficient and safe, not simply to protect privacy.

A description of clear governance processes with liabilities and risks for each party is required. For instance, individuals should not be allowed to change or delete information on a health record without governance and traceability, as this would raise industry risk and liability to an unacceptable level. Another example is the need for data quality assurance processes to generate confidence in published data sets to minimise inadvertent risk for the ICT supplier.

Enabling a sustainable market

The enablers for a sustainable market based on health and social care information must be part of the information strategy – currently, the market is unsophisticated, fragmented and extremely complex to enter. The new commissioning arrangements must reflect the information strategy, particularly when supporting the use of information, and thereby create a market that industry can size and assess with some confidence.

As already indicated, efficient processes to create information services that comply with regulation and are designed to deliver benefits not barriers to operation must be rapidly established and published.
Communications for public, patients and clinicians establishing the benefits and risks they will encounter from the Information Revolution must be used to facilitate user acceptance and demand for information services.

Collation of the enablers to be put in place to support individuals, private and third-sector organisations collecting, sharing and acting on information, will be required. This should not just cover the existing data sets and technology, but also the data produced by web 2.0 approaches to leverage social capital.

Accreditation and certification schemes have been set to a very high standard in the National Programme for IT and, as a result, are expensive for ICT suppliers. Setting the bar too high will diminish innovation in the market, will differentially inhibit smaller ICT suppliers and will cost too much to maintain.

**Creating a competitive environment**

To benefit from rapid innovation and adoption of existing ICT solutions to underpin the Information Revolution, the NHS will want to create an open competitive environment. This will also assist the NHS to procure the most effective solutions.

A health competitive environment will require consideration of incubator funds for UK suppliers, facilitated introduction of international ICT suppliers to the UK market, as well as lean and fair access to procurement frameworks.

Procurement and national contractual overheads often undermine pace of delivery and agility. Streamlining these processes is required to allow health commissioners and provider organisations to obtain and utilise new services and products within reasonable timescales to support innovation and adoption of new and more effective working practices.

**Electronic patient record systems**

As noted in other chapters, electronic patient record (EPR) systems are a critical building block for data and information capture, quality, access, and assurance.

No other information-intensive sector has undergone such substantial business transformation without completing the roll-out of electronic systems that enable its core processes. Health urgently requires that EPR systems replace paper records for clinical care and, importantly, that they become the definitive source of data and information. This will require clarity on the scope of the EPR and the priority of functionality in order to support the Information Revolution (see Chapter 8).

**Supporting suppliers with core requirements**

Likewise, there are challenges for ICT suppliers to keep pace with the NHS demand that is going to be placed on them, such as lending support to the NHS to articulate the art of the possible, being flexible in their ability to interface with other systems and to generate standards-based information exports.

In a rapidly changing policy landscape, suppliers feel uncertain about the legitimacy and stability of requirements they need to be addressing with regard to patient-facing IT systems. Such systems will be used jointly by patients and clinicians and will need to enable patients to share their records safely with others of their choice. We need vendors to step up to these challenges and shift from finance-centred recording systems to patient/treatment-centred systems.
7.2 Recommendations

The role of the centre

(43) We recommend that the roles of the centre include:
- rapidly setting stable standards and a standards road map for information, enabling ICT suppliers to rapidly innovate solutions for health and care;
- taking action to open up the health and care software market and bring the benefits of competition;
- encouraging continuous exploitation of existing investments in infrastructure, data and channels for the Information Revolution to be affordable.

(44) The NHS Commissioning Board has an important role to play in encouraging competition and innovation in the marketplace, driving best practice.

Recommendation from other chapters:

- The information strategy sets out clear roles for the centre and the marketplace in terms of information management. This must offer an integrated view of the health market and the supply chain that will come together to deliver information services. This is critically important to help shape a vibrant market through leadership and signalling of how everyone can appropriately engage.

Open standards for information processing

(45) ICT supplier accreditation schemes need to keep standards high, but also to keep barriers to entry low. Interoperability ToolKit (ITK) accreditation is a good recent example that has allowed rapid innovation from ICT suppliers – this accreditation scheme should be maintained and extended as a ‘kite mark’ for interoperability.

(46) We recommend maximising reuse of standards being adopted by global ICT suppliers as this will accelerate importable innovation to the UK market and reduce the costs of implementation.

(47) We recommend adoption of initiatives such as Integrating the Healthcare Enterprise and Continua Health Alliance, which are ICT supplier-driven initiatives to self-select standards for practical interoperability.

Enabling a sustainable and competitive market

(48) The NHS must be prepared to commit resources to marketing information access and tools to patients and clinicians to create consumer demand and interest to engage.

(49) We recommend that existing NHS procurement frameworks such as ASCC (Additional Supply Capability and Capacity) are enhanced so that new vendors can be added to the framework if they demonstrate that a product meets the national minimum requirements for information
governance, functionality, data standards and interoperability, or removed if they are subsequently seen to fall below those standards. This will create a dynamic framework that allows new UK vendors and the best internationally to be available to the NHS.

(50) We recommend the commercial structure of the National Programme for IT be reviewed to allow purchasing organisation in any cluster to choose solutions from any LSP so that the NHS can benefit from competition between LSP suppliers.

(51) We recommend that existing procurement frameworks available for the NHS to purchase IT are extended to allow any organisation providing clinical services to be utilised in order to create a level playing field.

(52) We recommend that the Department of Health should encourage the development of the UK health ICT supplier market as a potential provider of jobs and exports by:
• ensuring that frameworks are sufficiently flexible so that small companies get the opportunity to bid for contracts;
• entering into discussion with the Treasury and Department for Business, Innovation and Skills to explore the potential for incubator investment in the UK informatics industry.
8. Driving efficiency

In the current environment, with the NHS seeking 20 per cent productivity improvement over five years, efficiency must be viewed as a key outcome of any business change alongside equity, clinical effectiveness and patient experience. The harsh reality is that any shortfall in productivity improvement will have to be made up by a reduction in the services offered to patients. As a consequence, the failure to redesign working practices to reduce costs will have a direct impact on patient care.

In most, possibly all, industries that have delivered productivity gains of the scale that the NHS now seeks, there have been one of two key factors: one has been the shifting of production to countries with much lower cost workforces – not an option that is readily available to the NHS; the other has been the use of information, IT and automation to transform working practices. There has never been a more important time to use informatics to challenge the status quo and drive efficiency.

However, the lack of focus on the redesign element of implementing information technology and a lack of internal skill and expertise has meant a perpetuation of the old way of thinking about the use and application of systems at local level. It is an internationally recognised feature of IT implementation in all industries that computerising outdated procedures is likely to make them more expensive rather than less. We have seen this mistake too often in the NHS, both before the National Programme for IT and during it. Implementing new IT must be owned by the organisational executive and be seen as a change programme supported by technology, not simply a project in the IT department.

The centralisation of spend and cost for many elements of IT in the NHS (from the National and Local Care Records Service to Enterprise Wide Agreements for software) has led to many health organisations and communities losing their focus on the value of IT systems and services. Services have consequently become reluctant to make the internal investment needed to really drive the benefits from systems. The NHS leadership needs to step away from the outdated idea that IT is expensive and difficult in the NHS and recognise that transformation of the service cannot happen without it, without investment and without senior leadership.

‘Efficiency should not trump quality of care or patient experience – but it should be one of our objectives, with or without the “Nicholson £20bn Challenge”. Efficiency is an outcome, alongside equity, (clinical) effectiveness, patient experience (including access) etc.’

*Individual perspective from the BCS crowd source*

Health informatics offers massive opportunities for improving productivity, ranging from supporting delivery of direct care and treatment to the management and administration of the health service, as well as in the informatics arena itself. There is, however, a real danger that informatics is merely seen as a ‘back office’
service that can be cut to save money. Many opportunities to utilise leading-edge and transformational informatics will be lost if this approach dominates decision-making.

Realising the productivity opportunity needs a new, more innovative and less risk-averse approach in both organisational boards and the health informatics profession. Investment in informatics should not be decoupled from wider service improvement and clinical change to deliver efficient and effective services – in short, the change programme for driving efficiency is enabled by the Information Revolution.

Key focal points where informatics can deliver efficiencies include:

• Integration, interfacing and collaborative working enabling technologies and development of information management practices that facilitate sharing of, and access to, information about patients, their care and treatment across organisations and sectors. The key to significant efficiency is connected records and integrated workflow; being able to see that end-to-end patient journeys will realise opportunities to build synergies and design more efficient care pathways. It can also save staff time and reduce duplication (both things that can deliver significant savings within and across organisations).

‘... be able to see end-to-end patient journeys, opportunities to build synergies and therefore opportunities to redesign patient pathways to drive huge efficiencies.’

*Individual perspective from the BCS crowd source*

• Central facilitation of learning and the sharing of best practice can enable organisations and health and social care communities to benefit from tools and methods that have resulted in savings and efficiencies being realised in other organisations by:
  - dissemination or availability of examples of good practice delivering efficiencies or increases in productivity on the ground;
  - publicising successful experiences of those adopting innovative/new technology and facilitation of the translation of effective R&D into practice;
  - supporting rapid procurement and implementation of systems and services that have demonstrated efficiencies and productivity gains.

• Developing the understanding, skills, capability and capacity of all staff in the NHS (e.g. clinicians, technicians, managers, administrators and informatics professionals) will reap real benefits. Like all tools, health informatics is most efficiently and effectively used if people understand the core purpose and potential of the tools they have at their disposal.

Clearly, informatics can increase productivity and efficiency and make savings at a number of different levels. As outlined below, the most gains are to be realised when applying technology and information to support the application of innovation and the redesign of service and this should be recognised as the priority area for focused effort – although many benefits are to be realised in the technology itself.

As has already been noted in other chapters (see in particular Chapters 4, 5 and 6), successful implementation will involve very substantial ‘behaviour change’ on the part of clinicians, patients, managers and others. This issue is not re-explored in this chapter.
8.1 Issues

Focus in informatics should shift from cost to value, whilst recognising that ‘value’ can mean different things to different people (e.g. efficiency, enhancement or transformation) so the overall approach needs to be comprehensive and balanced. A coordinated approach to identifying best practice, sharing methods and facilitating a learning approach will enable change and adoption of new ways of working that deliver efficiencies and increased productivity.

Optimisation can be considered at four levels:

- **Level 1**: procurement of systems and services.
- **Level 2**: direct cost reduction on informatics systems and services.
- **Level 3**: increased collaboration and joint working between service/business and informatics.
- **Level 4**: innovation and radical redesign of services.

Level 4 offers the biggest opportunity for an information revolution to truly change the processes of health care and drive efficiency, but changes in levels 1–3 will be required to get there. The levels are listed in order of increasing difficulty, but also of increasing value of the savings that can be realised. Enabling work at all of these levels in a complex environment such as the NHS is challenging, but the following considerations will help support and sustain productivity and efficiency.

**Level 1 – Lean procurement**

Procurement and national contractual overheads often undermine pace of delivery and agility. We recommend streamlining these processes to allow health commissioners and provider organisations to obtain and utilise new services and products within reasonable timescales to support innovation and adoption of new and more effective working practices.

We recommend that the framework agreements that are currently available for the NHS to purchase IT against are maintained, but are adapted.

**Level 2 – Efficiency of informatics services**

There is the opportunity to increase productivity and realise savings in informatics services themselves (e.g. investment in proven technologies using new commercial models, such as benefits-based payment, risk sharing, commissioner/care provider partnerships and shared services).

To deliver economies of scale there is a clear need to drive the efficiency of health informatics services through more shared services and shared solutions, including consortium procurements.

As the regional bodies (Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs)) are wound up, they should see part of their exit strategy as being to encourage shared services to evolve in the marketplace between provider networks and across local health economies. They could also facilitate collaborative working, for example, better roll-out and sharing of good practice (such as effective business cases, shared procurement and commercial models, shared common services such as education, training and development services). One current example of a national initiative to share best practice and develop collaborative working is demonstrated by the Health Informatics Benchmarking Club.
Level 3 – Collaboration and joint working

Both within the health community (acute, primary and community care) and between health, social care, voluntary and private providers, there are huge opportunities to realise economies of scale and to consolidate working practices and smooth the flow of information along patient pathways.

Like any merging organisations that already have existing unique identifiers, we need a robust way of ensuring that people continue to be identified uniquely. In particular this is true across health and social care as some of these organisations are merging and all need to work together collaboratively and share information. The NHS has the NHS number as the key identifier, whereas social care uses case numbers. Consideration needs to be given to how identifiers are linked or shared across health and social care.

Level 4 – Utilisation of new/leading-edge technologies and approaches

Informatics should be universally regarded as the close integration of ICT, information, training and programme delivery in a single entity, not as separate disciplines. This should be integrated with an increased focus on the need to redesign services, using technology as a support tool.

Technological advancement is rapid and new technologies are becoming available at a faster rate and with greater capacity to provide more sophisticated functionality in shorter timescales. There are also some established technologies that health has not engaged in as much as it might have. Examples include web-based tools, use of open source, social networking and so on. If a stronger link between routine health care and the application of leading-edge technologies, research and development and innovation were established, the benefits of new technologies could be realised more swiftly.

8.2 Recommendations

**Efficiency of informatics services**

(53) PCTs and SHAs should encourage shared services, managed either by NHS or commercial organisations, to evolve in the marketplace between provider networks and across local health economies, as part of their exit strategy.

(54) PCTs and SHAs should facilitate collaborative working, for example through encouraging rollout and sharing best practice (such as effective business cases, shared procurement and commercial models, shared common services such as education training and development services), as part of their exit strategy.

(55) We recommend that, in order to maximise the benefits from engagement with the private sector for informatics supply or outsourced services, NHS organisations must retain or develop the expertise to act as an intelligent client.

(56) NHS organisations should develop a commercial ethos in the health service. This will include adopting best practice solutions for ecommerce, customer and market segmentation, workflow and customer management, scheduling, resource management and information use/analysis.
**Collaboration and joint working**

(57) We recommend that key patient identifiers will be linked or shared across health and social care.

(58) We recommend that the NHS develops with the main software vendors standard implementation of best practice processes and places these in the public domain, so that new implementations do not begin with a blank piece of paper, but start with, for example, ‘the three best ways to run emergency admissions are built into the system, which one will this hospital adopt?’ This will need to be carried out in a way that does not stifle innovation.

(59) We recommend that NHS Spine\(^{15}\) should be developed as a common provider of core functionality and the infrastructure for national interoperability. The Spine should be opened up as a platform for innovation through encouraging the market to reuse these Spine services to speed up innovation and reduce costs.

(60) We recommend that the US criteria for meaningful use for electronic patient records are reviewed and that the NHS then creates a set that is appropriate for the UK and reuses, where it is sensible to do so, those criteria set in the US that global ICT vendors have already developed compliance to.

(61) We recommend that the NHS considers ways in which other public sectors have realised increased savings, efficiencies and public engagement through IT and information services, including application of leading-edge and innovative technology.

(62) The information strategy should encourage a stronger commitment to the use of shared technology and information to support cross-sector, whole-care pathway working that can realise efficiencies and productivity on a far greater scale, whilst improving quality.

**New technologies and approaches**

(63) We recommend that the National Institute for Health and Clinical Excellence (NICE) evaluates and recommends, as part of its work programme, technologies to support the extension of self-care in long-term condition management.

(64) A risk-based approach should be adopted to allow prototyping of new patient-centred technologies and consumer information. It does not have to be right the first time so long as risks are understood and mitigated. Creating the culture of ‘change at pace’ is vital for a world-class health service.

Recommendations from other chapters:

- The information strategy states that all organisations providing care to the NHS should be given notice that they will be expected to use an electronic patient record in a meaningful way within five years. This

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\(^{15}\) NHS Spine is a contract let by NHS Connecting for Health that provides the national care record service consisting of a secure database of patient information and a messaging system with central informatics services to support clinical information systems.
should include the ability for patient remote access and work towards enabling record extracts for patient-held, electronic personal health records.

• Where sharing is appropriate, there should be a statutory obligation on health care providers to release information as a minimum standard if contracting with the NHS. The NHS Commissioning Board should require all providers of services to publish meaningful comparative performance data at a level at which patients are being offered choice and that the public will understand and value.

• The information strategy should encourage care providers to use technology and media as a tool to engage patients and the public in taking responsibility for their own health and wellbeing. The NHS should utilise existing technologies that people use on a daily basis, and harness fresh and exciting technology, including web 2.0 approaches to leverage social capital and to meet patients’ desire for better interactions with health and care systems.

• The NHS continues to evaluate adoption of ‘privacy-enhancing’ technologies and techniques. These methods can challenge assumptions and conventions about where and when personal information needs to be stored or processed, enabling solutions that would be impractical or even impossible using conventional methods.
Clinical service quality, informed patient choice, clinician revalidation, productivity and public accountability depend fundamentally on health and social care informatics innovation and expertise, and thus the capability and capacity of the health informatics workforce.

Patient safety and public confidence in the quality of NHS information depend critically on the quality and professionalism of the health informatics workforce, whether managed by the NHS, local government, the private sector or third sector. It also depends on the health informatics knowledge of clinicians, social care professionals and others who record essential information.

A true information revolution takes health informatics from the back office into frontline clinical services, operational management, NHS transformation and patient empowerment. Running safe, effective and productive health informatics services requires in-depth knowledge of health and social care processes, systems and health informatics standards. Specialist technical knowledge and expertise is necessary, but not sufficient.

Structural and other changes to the NHS and local government, the wider economic climate and building an informatics market have significant implications for the composition, distribution and skills of the health informatics workforce. Public sector bodies will need to retain their own health informatics expertise, regardless of the market, at the very least to advise boards on investment and to act as expert customers. Whilst transactional activities and commodity services (e.g. desktop, network support and routine data processing) could generally be considered for contracting out, business-sensitive and context-specific activities (e.g. health informatics strategy and planning, performance analysis and transformation) require full organisational ownership.

Workforce development is no less important in health informatics than in other sectors of the NHS and social care. There are about as many health informatics specialists in the NHS (around 25,000–30,000) as, for example, midwives (26,000) or qualified health care scientists (32,000). The information strategy will need some substantive actions mirroring activities such as those professional regulations in the Public Health White Paper¹⁶ and for the clinical workforce in the consultation on ‘Developing the Healthcare Workforce’.¹⁷

‘Liberating the NHS’ proposes that employers have greater autonomy and accountability for planning and developing the workforce, alongside greater professional ownership of the quality of education and training. The focus is on the clinical workforce, but provision needs to be made for other specialist areas, including finance, HR and health informatics.

BCS has conducted a survey\textsuperscript{18} into the 10 most important factors for achieving a step improvement in the use of information in the NHS (220 respondents from across the NHS, of which 54 per cent were IT and information professionals; draft survey findings are available now and a full report will be published shortly). The second most important factor identified by informatics and other professionals was the need for ‘more health informatics skills’ (the first was ‘more flexibility to share information’).

9.1 Issues

Assurance of health informatics services

The role of the health informatics workforce in providing assurance to commissioners and regulators of information quality and informatics risk management needs to be determined.

Leadership

We require the role of CIOs to include spearheading service transformation through the innovative use of information and IT. Leading private sector organisations see such skills as assets fundamental to business advantage and invest heavily in their development.

Informatics professionals are not taken seriously – largely because they (a) focus on operational issues, (b) have rarely sought to be an agent of change as opposed to “keeping the lights on” and (c) rarely have the true buy-in of their board.’

\textit{Individual perspective from the BCS crowd source}

Professional registration for health informatics

Health informatics stands out from similar services in the NHS and social care in having no formal professional registration or regulation. The most basic financial and HR activities operate under greater professional controls than the management of patient-critical and organisation-critical IT and information systems.

The national focus on IT and information should be augmented by standards for health informatics specialist competences, skills and professional conduct.

Education, training and development

The pace of change in health informatics now is amongst the fastest of any health and social care discipline. Failure to keep up to date with the latest proven technologies and knowledge does not just miss opportunities for service improvement, it brings real safety and organisational risks to clinical and other critical IT and information systems.

Building understanding amongst senior decision-makers and CEOs of the central importance of informatics services and informatics skills is vital to the current policy agenda and transformation of health and social care. Almost everyone working in and for health and social care will need good information handling, presentation and communication skills.

\textsuperscript{18} The survey is part of research by Mott McDonald, commissioned by BCS, into BCS Health’s first theme on ‘Preparing for information being mission-critical to the NHS’. The full report is awaited.
**Health informatics workforce capacity and capability**

Structured health informatics workforce planning and skills development are more necessary now than ever before because of the ever-increasing strategic criticality of informatics to safe, effective, efficient and transparent service delivery.

> ‘Directors of finance own and lead professional development activity at local levels and all contribute to the cost of local and national activity and resources. Why can’t we, as informatics professionals, take and adapt this model for ourselves?’

*Individual perspective from the BCS crowd source*

Action is required on the shortage of key health informatics skills in both health and social care, notably clinical coding, information analysis, information governance, commercial management and change management.

> ‘The health service currently lacks analytical capacity to produce and present meaningful information, e.g. inadequate links between data and information to drive commissioning processes. There are too few people with analytic skills and this resource is likely to be lost/diluted with devolvement of commissioning to GP consortia. Skills resource gap needs to be addressed.’

*Information professional*

### 9.2 Recommendations

#### Assurance of health informatics services

(65) We recommend that standard NHS service contracts should require assurance of data quality, including:

- explicit board-level accountability for the quality of data and information analysis vested in someone with demonstrable skills and training;
- the accreditation of health informatics services through evidenced compliance with standards for health informatics outcomes, processes and specialists. The Health Informatics Benchmarking Club could be commissioned to provide this, drawing on best practice from both public and private sectors;
- designated heads of profession for health informatics in informatics services with formal responsibility for the professional conduct and continuing professional development for health informatics practitioners. This would mirror existing arrangements in the Government Statistical Service, designed explicitly to build public confidence in official statistics.

#### Professional registration for health informatics

(66) We recommend that formal professional registration is required for all health informatics specialists with explicit standards for entry, conduct and continuing professional development. UKCHIP could be the basis for this.
We recommend that all informatics professional associations and bodies, for example, UKCHIP, clinical coders, health records managers and social care, should have stronger links with BCS Health to ensure an integrated, industry-recognised professional and registration model for health informatics and to achieve better alignment of BCS professional development activities.

**Workforce capacity and capability**

The impending proposals from the Department of Health on future arrangement for education, training and development should explicitly address health informatics skills, both for the specialist health informatics workforce and for clinicians, managers and other staff. This requires standards and coordination spanning individual care providers and commissioners in health and social care.

We recommend that a sustainable health informatics workforce capacity and capability infrastructure is put in place, spanning health, public health and adult social care, and the public, private and third sectors. Such an approach should be encouraged by commissioners and regulators as a means of improving the quality and professionalism of the health informatics workforce and thereby the quality of data and the management of patient- and organisation-critical IT and information systems.

We recommend that a national CIO development programme is put in place, mirroring other NHS and local government senior management development schemes. This should focus on producing leaders with skills comparable to CIOs in the commercial sector, who can lead business transformation through the innovative use of information and IT. This will help take health informatics as a function from the server room to the boardroom, reflecting its transition from technical support to organisational transformation.

We recommend the continuation and expansion of the existing health informatics graduate training scheme.

We recommend that joint informatics development activities spanning health and social care are established.

We recommend that the development of a range of clinical coder training is continued and that coder and information analyst development centres are established across the country to provide training and wider professional skills; quality-controlled by the Department of Health, but provided by NHS, academic or commercial bodies.

We recommend that health informatics workforce and succession planning should be established. The starting point should be the collection of data on the current workforce and its constituent parts. This should be undertaken by The Centre for Workforce Intelligence, in line with its role in ‘liberating the NHS’ as a ‘consistent source of information and analysis, informing and informed by all levels of the system’.

We recommend that a health informatics career framework is put in place as a basis for structured career planning and development, so that staff have a blueprint for career progression. This should build on the work already done by UK health departments.19

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19 Health Informatics Career Framework: www.chicf.org.uk.
(76) We recommend that the NHS is careful to retain health informatics investments of Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs) as these regional bodies disappear. We recommend that transition planning for PCTs and SHAs includes informatics skills and practices.
The government policy to release the reins of top-down instruction and encourage devolution, local innovation and public empowerment should not be interpreted centrally or locally as meaning a reduction in the application of informatics standards. Indeed, we contend that central mandation of systems and central mandation of standards are opposite ends of the spectrum. Strong and clear standards create the environment for local innovation, the development of competition in the IT industry, competition in the health care industry and information transparency for the public. Without such standards the alternatives are either setting direction as to the systems that must be used – this is undesirable and, indeed, implausible in a plural health care supply market – or accepting chaotic data interchange, which would increase costs and reduce transparency.

We believe that:

• Informatics standards are necessary, but not sufficient for the success of the Information Revolution. Regardless of any other initiatives in the information strategy succeeding, without quality standards the information strategy will fail.

• Standards are not simplistic panaceas for success. There has been previous commitment to informatics standards and to standardisation by the NHS, but these have not yet resulted in dramatic benefits. It is worth investing resources to determine the impact of previous efforts, limitations and successes in order to show how best to make standards work.

• All those involved in health informatics standards have to find more effective and efficient ways of working together to improve the value of standardisation outcomes and to reduce the high levels of fragmentation that still exist and plague the delivery of quality health care.

Three key parts of any solution will be to:

• focus on the most important areas and select appropriate level standards, where available, to deliver maximum benefit;

• manage the perceived opposition between standardisation and innovation; frameworks need to be put in place that are flexible and accommodate change;

• closely link the development and application of standards to policy, commissioning and regulatory decisions so that the standards support the NHS’s objectives and are enforced through the NHS’s core institutions.
**Breadth of standards**

Our response is concerned with relevant UK standards and standardisation, with the use and impact of deployment on a broader scale than is covered by the current English consultation on the Information Revolution. As with healthcare itself, related informatics standards are often more effective and provide greater benefit if liberated from boundaries' constraints.

The term ‘informatics standards’ will be used as the inclusive term to group all the technical type of standards, including ‘information standards’, ‘safety standards’, ‘data quality’, ‘information governance’, ‘terminology’ and ‘interoperability standards’, and to differentiate such standards from professional and clinical types of standards, which are different in kind.

General and specific requirements for informatics standards are given in the consultation document. These include subject identification, information governance, standard structure and formats for electronic records of various kinds, record-keeping, visualisation, summarisation, presentation, assistive technologies (devices), outcome measures (patient-reported as well as clinical), benchmarking, continuity of care, data warehouses, secondary uses, safe software, improved data quality, internet standards, data sets, aggregate data and anonymisation, management of technology via sustainable frameworks, user interfaces, automatic identification and data capture by clinicians, decision support, information architecture, accreditation and certification, and last but not least, terminologies.

This breadth of standards types will consequently require precision of specification and priority in implementation to ensure maximum benefit. Our response argues for an awareness and coordination that surpasses the current, almost random, approaches to informatics standards.

**10.1 Issues**

**Role of the centre**

As has been noted in other chapters there is a need for the centre to identify the core functions for which it is responsible. Setting data standards and standards for recording information will be amongst these core functions.

There is a real tension between the government policy on local decision-making and local accountability and mandatory national standards. We underline the case for national standards to ensure that information holds its meaning accurately and maintains consistency across the health and social care system for clinicians, patients and the public, commissioners, regulators and government. There are very real issues at stake around patient safety, patient choice, service efficiency and public accountability.

**Overarching mechanism**

The consultation notes the requirement to establish an ‘overarching mechanism to oversee the range of standards and to ensure these support the Information Revolution’. This ‘mechanism’ is not fully explained nor specified.

‘Central orchestration will help facilitate, regulate and incentivise market participation.’

*Individual perspective from the BCS crowd source*
The establishment of such an overarching mechanism is received by the standards community with mixed reactions of both hope and concern and consequently such an objective will need to be taken forward carefully in the coming information strategy. Informatics standards, including information and interoperability standards, must not exist in a vacuum separated from the business domain they operate in.

There is a need for single overarching approvals and/or assurance body covering health and social care. The NHS Commissioning Board does not have remit over social care or population health. The overarching body would therefore need to be directed by the Secretary of State for Health, the only one with authority over the whole landscape. We believe that it would be a serious mistake if the ‘mechanism’ did not apply accountability to the existing bodies involved in health informatics.

Such a mechanism must at least be required to engage stakeholders from the whole community, being able to resource and react with clinical, service and standards bodies as and when appropriate. This may not be required for all standards, but there does need to be a means where the appropriate conversation can be had and an authoritative decision made, when and if the need arises.

**Setting expectations**

Compared with other sectors, the health and social sector has an immature approach to standardisation. For example, participation and utilisation of standards are far behind the levels of the construction and building industries. The health care informatics standards industry has too little input from operational health care people.

The value of closer links between the standardisation stakeholders is apparent, but insufficient resourcing in this area restricts cooperation. The fact that the standardisation efforts are primarily volunteer efforts involving a relatively small number of experts means that they can have a narrow view on priorities and operate on the basis of ‘what can we do with the available resources’ rather than ‘doing what needs to be done’.

There is a major issue to do with understanding speed of development, implementation and beneficial impact of standards. Even when adopting fast track techniques, developing new standards using the usual consensus style approaches will take a minimum of 18 months, and that is assuming a relatively stable environment and a mature specification as a starting point. In contrast, there will be quick wins in taking up existing standard products and localising them by the use of formal profiles.

It is impractical as well as wrong to suggest that all the various standards agencies should drop everything and concentrate on one or two things necessary for the English strategy. Their programmes and activities are often international in scope. However, articulating requirements and priorities, fully engaging in projects and working together to avoid costly duplication would be mutually beneficial. Experience in CEN (the European Committee for Standardisation) is that small, fixed-length, part-time paid project teams can be highly effective.

Furthermore, culturally the problem of adoption is immense. In general, the interpreting, adapting and applying of ‘solutions’ that work well in one place for implementation, in another is known to be a complex task. If the originating domain is different from health, then the task will be much more complicated; any implementation will be less straightforward, and is likely to require extensive localisation before it becomes usable or useful. Standards, if they originate from elsewhere without involvement of the intended target user, may not be fit for the local situation. Implementation assistance is often required even in the most precise specifications, such as those for interoperability standards.
Interoperability

It is true that many of the standards stakeholders are interested in the ‘interoperability’ aspects of standardisation. However, much of the current agenda are already active and therefore more difficult to change. Interoperability standards are key as the ‘devolved’ approach of interoperability work undertaken as ‘bespoke projects’ in multiple trusts and hospitals creates unnecessary replication, with higher costs and an increased silo mentality. Full interoperability is an argument for national standards rather than piecemeal approaches. The most obvious case is the NHS number – the most fundamental of standards is still only mandatory in name.

The Interoperability ToolKit (ITK) is a very important approach. What started out as an idea to have of a library of ‘apps’ has begun to morph into a toolkit for interoperability. In an environment of limited central funding, a small, specialist team to oversee and develop the toolkit and coordinate quality control in interoperability testing is a good central investment. Industry funding is likely to be leveraged into this work by responding to market demand for integration profiles set out against very specific-use cases (e.g. send microbiology test reports to a regional centre for monitoring hospital acquired infection). Much has been achieved in this way with Integrating the Healthcare Enterprise (IHE), which has been particularly successful in the US.

‘As well as having a central body focusing on standards, this body should also be the mechanism by which common technology (in particular integration and interoperability) requirements can be qualified and once confirmed, openly published.’

Individual perspective from the BCS crowd source

Informatics standards as good practice

Proponents of standards and standardisation find it difficult to articulate benefits and the feedback loop on use, and impact is fractured and sometimes non-existent. Metrics for standards and for evaluating their implementation are either not sufficiently developed or, where they are, they are not yet widely used in this domain. The fragmented feedback loops of standards usage, value, risk, scale, granularity and implementation should be closed and collected as an evidence base from which future efforts can learn.

Tooling, which can directly execute or animate specifications, is not in widespread use. Accreditation and certification as well as evidence-based implementations will be very important in the forthcoming strategy, but the details will need careful attention.

The breadth and complexity of available standards and their road maps is confusing and standards bodies are often poor at marketing and educating/training people in the use of the standards (primarily a resource constraint).

More focus on clinical leadership is needed, and achieving real, clinically valuable, implementations is fundamental, such as the semantically sound data transfer with GP2GP messaging and the Royal College of Physicians’ record standards work. These two examples of clinical work are globally important examples on the road to coherent aggregateable data.

Accreditation and certification

Accreditation and certification schemes have been set to a very high standard in the National Programme for IT and, as a result, are expensive for ICT suppliers. Setting the bar too high will diminish innovation in the market, will differentially inhibit smaller ICT suppliers and will cost too much to maintain.
**Informatics standards**

**Information standards specialists**

The standards community is relatively small, highly specialised and works largely on a volunteer basis. Many specialists in the standards community are external to the NHS. Given the central importance that informatics standardisation must have, support and recognition of the role is necessary, along with adequate funding. Largely volunteer effort is not sustainable, given the resulting informatics agenda.

**New information standard requirements**

The Information Revolution and its empowerment of patients, clinicians and managers will set in motion the requirement for information management standards and guidelines to rapidly be put in place.

10.2 Recommendations

**Role of the centre – an ‘overarching mechanism’**

(77) We recommend that the centre should take a coordination and facilitation role in developing informatics standards and an enforcement role in ensuring that these standards are applied through an ‘overarching mechanism’ as described below.

(78) We recommend a single overarching approvals and/or assurance body for informatics standards, directed by the Secretary of State for Health, covering health, social care and population health. We recommend that the overarching body has the following remit:
- to oversee the selection, development and mandation of the use of new standards;
- to rapidly establish a minimum set of standards and guidelines for information collection, production, storage and use by the different actors across health and social care. These standards and guidelines should be built on existing good standards and set against a clear vision for the future;
- to oppose requests for incompatible or unnecessary new standards and recommend de-establishment of existing standards where these are seen to conflict with the information strategy or add unnecessary burden;
- to profile existing standards to provide comparatively quick results. Development should only be done if a gap and requirement can be evidenced, and should fund UK or international work where appropriate;
- to act as a coordinating/steering body for health and care standards working with the NHS and suppliers to identify business issues and find workable solutions that can be adopted nationally to create hegemony, lower cost, support interoperability and promote best practice standards at the national level;
- to oversee the development and application of the ITK and the testing environment to ensure interoperability standards are effective and the operation of the ‘kite marking’ function is not a blockage to market entry;
- to have authority over the NHS Commissioning Board, the health regulators and quality inspectors to ensure that the standards agreed are enforced through contract and inspection.

**Setting expectations**

(79) We recommend that a standards road map is quickly established and published as an open, iterative document with efficient processes to update and disseminate to ICT suppliers and others.
(80) Expectations of standards and standardisation should be better managed by health and care systems and realistic projects should be undertaken to demonstrate value. Too much hype will undermine future work and satisfaction with any outcomes. This will help to drive the faster adoption and development of necessary standards and avoid ‘perfect’ as the enemy of ‘good enough’.

**Interoperability**

(81) We strongly support the NHS CIO’s commitment to the NHS number and urge that it be mandated in health. Commissioning, regulation and financial penalties for non-use by all care providers should be applied. As per Chapter 8 we recommend that the information strategy determines how key patient identifiers will be linked or shared across health and social care. The result may require legislative change.

(82) We recommend that central funding should continue to support the Interoperability ToolKit (ITK) and efforts should be made to leverage industry funding where there is market demand for integration profiles against specific use cases. The Integrating the Healthcare Enterprise (IHE) integration profile ‘standards’ should be exploited as a powerful lever for interoperability, and adoption of their extensive work will save development costs and implementation costs with conformant vendors, accelerate innovation and help to ensure global interoperability.

(83) Building up an evidence base of standards implementation will support better metrics for informatics standards and move towards development of maturity models across the standards development life-cycle. The use of standards should be considered as part of the evidence base that should be established to drive good practice. The National Outcomes Framework\(^{20}\) should be investigated to see whether it can be expanded to usefully apply to informatics solutions and standards to provide a common presentation of assessed outcome.

(84) Technical standards for records and terminology should be closely coordinated with the record-keeping practices/requirements and must not inhabit totally independent worlds. Otherwise the end result will be duplication, misunderstandings and inoperable systems.

**Accreditation and certification**

(85) We recommend that ICT supplier accreditation schemes need to keep standards high, but also to keep barriers to entry low. ITK accreditation is a good recent example that has allowed rapid innovation from ICT suppliers – this accreditation scheme should be maintained and extended as a ‘kite mark’ for interoperability. Integrating the Healthcare Enterprise’s Connectathons and processes to support accreditation and certification, with an emphasis on implementation should be regarded as good practice and we recommend that these processes should be reviewed with a view to being utilised.

**Information standards specialists**

(86) Given the central importance that informatics standardisation must have in the Information Revolution, funding is going to be required and should be provisioned for, as the function is currently mainly provided by a voluntary standards community.

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Informatics standards

Recommendations from other chapters:

- We recommend that the role of the centre should include:
  - clear roles for the centre and the marketplace in terms of information management. This must offer an integrated view of the health market and the supply chain that will come together to deliver information services;
  - the core functions of setting data and indicator standards, deciding and controlling national data requirements;
  - ensuring better informatics impact assessment at the earliest stages of Department of Health policy development.

- We recommend maximising reuse of standards being adopted by global ICT suppliers as this will accelerate importable innovation to the UK market and reduce the costs of implementation. We recommend adoption of initiatives such as Integrating the Healthcare Enterprise and Continua Health Alliance, which are ICT supplier-driven initiatives to self-select standards for practical interoperability.

- We recommend that existing patient information standards such as The Information Standard be more widely publicised and adoption encouraged.

- We recommend that guidance be put in place on the safe handling of patient data for patients who are storing and sharing their personal medical data, including sample sharing agreements.

- We recommend the creation and enforcement of clinical standards/guidelines for record-keeping, data recording and sharing, with intercollegiate standardisation across Royal Colleges and professional societies to ensure that information is comparable and terminology consistent.

- We recommend that data standards/guidelines for sharing structured medical record data with patients are put in place and that these should strongly encourage the use of plain English in medical notation.

- The information strategy should determine a minimum set of information that is agreed with the clinical profession and has value to the care process. This should be ready for when the NHS Commissioning Board and GP commissioning consortia are formally launched.

- The information strategy should determine a minimum set of information that is agreed with the health and care professions and has value to the care process, ready for NHS Commissioning Board and GP commissioning consortia launch.
11. Privacy, security, information risk management and assurance

This is one of the most complex and sensitive areas of informatics policy. It raises strong emotions amongst clinicians, researchers and epidemiologists, who argue that they can do greater good for society with better access to information. It equally raises strong emotions amongst patients who believe that they should control who sees personal detail about them, and clinicians who believe that, when they gather personal information about a patient, it is for a specific, agreed purpose with their patient and not to be used by anyone who thinks they can make use of it. Interestingly, the problems here go to the heart of the government’s ‘no decision about me without me’ mantra. If the balance of relationship between clinician and patient is made more equal, the conversation about use of data will be a natural one, and patients will understand what the NHS wishes to do with their data and consent will be obtained properly. Information governance is more about culture than it is about technology.

Privacy is a fundamental right in an information society and BCS has well-established positions on the principles and practices that embody a mature approach for policy-makers and professionals looking to balance this right in complex systems and against other constraints.

The relationship between patients and clinicians caring for them is founded on trust, and a key element to that trust is the guardianship of any information given by patients to clinicians. To maintain trust, the sharing of care data about patients should approximate to what is known about patients’ expectations. At the same time, the NHS should raise patient awareness of how their data is and can be used, especially for secondary purposes, and why this is important.

Patient care, health service management and health-care-related research rely on the sharing of data about patients, most of it collected by clinicians during the delivery of health care. The drivers to protect data and maintain privacy can often be seen as impediments to normal, efficient operation. Yet where privacy is designed in rather than an afterthought, the requirements to protect, share and operate efficiently can coexist. In fact, designing with privacy in mind can produce solutions with other benefits.

In a complex and dispersed multi-organisational system like the NHS, privacy is defined by the aggregation of decisions made at all levels, but can be dominated by those made at a local level. Experience in the security domain both inside and outside of health indicates that measures to protect patient information will be worked around if they impede or prevent day to day clinical activity. A delicate balance must be struck between onerous safeguards and efficiency or accessibility in the clinical environment.

Organisational culture is perhaps the most important and difficult aspect to get right in the context of privacy and data sharing. Attitudes in the NHS towards patient information are well developed, but may be embodied in current systems rather than consciously understood by all the individuals involved. In a real information revolution the culture will need to evolve rapidly to deal with a new environment. Sharing will take place across care boundaries, with patients and through anonymous data sets. This will fundamentally change the dynamics and relationships in the health and social care arena.
The practicalities of privacy in the NHS can often come down to where identity management and clinical practice meet. Identifying a patient correctly in a range of clinical circumstances is critical to life and wellbeing, as well as to less life-threatening but nonetheless important aspects such as entitlements. There is the potential for a great deal of use of pseudonymisation to increase privacy and flexibility of service delivery, but this cannot be at the expense of patient health and wellbeing. Digitisation and aggregation of patient information will also introduce new risks and dynamics that affect wellbeing in other ways. Consequently, getting identity management right in the NHS is one of the most important pieces of the Information Revolution, and it must be done well.

Unfortunately, there is no formulaic solution to privacy and identity in health, but the conversations with stakeholders need to be sustained and deep, resulting in solutions that are 100 per cent fit for the next 50 years of health information management, and a culture to match. With that element right, others can be fixed. Without that element, all the others will suffer.

‘Information governance as currently applied is a barrier to increased availability and sharing of data. The UK health care approach is wrongly modelled on the banking paradigm of personal control that doesn’t allow others to access. Health care needs a partnership approach around a shared record to facilitate team working and rapid response.’

Acute hospital consultant clinician

11.1 Issues

Changes in information governance frameworks

There is a need to define the changes in information governance (including legislative changes as necessary) that are required to maximise the use of information and deliver benefits, and to consult extensively on the specific implementations of these changes. Where primary legislation is required, lessons may be learned from the Identity Cards Act (2006) and Coroners and Justice Act (2009) over early engagement with stakeholder groups.

The basic premise should be that the sharing of personal health care data that identifies patients, or carries a significant risk of being used to do so during a secondary use, should only be shared with patient consent. Any exceptions must be justified and authorised. The least objectionable authorisation is by law or at the request of a court.

At present there are a number of situations where it is not clear whether patient data is being shared appropriately. For example, a detailed care record being shared by general practice, community health and others is currently being implemented in three of the five English clusters. Is one domain (e.g. community health) entitled to see the data held by another (e.g. general practice), if they are not providing care for the patient without patient consent? Even if they are providing care, should they be entitled to see all the information held by the other domain?

It is not clear whether the use of identifiable data from multiple sources to forecast likely individual health is a primary or secondary use. It is also unclear whether data from one source can be revealed to another, for example can hospital and community health data about a patient be revealed to a GP who is caring for the patient, but maybe was not when the non-GP episodes occurred?
Identifiable, individual, patient-level data is also used to assess care quality. Such data would be used to detect individual patient outliers that may represent a clinical problem. This data differs from the aggregated audit data on an individual as it cannot be made public without breaching patient confidentiality. It needs to be scrutinised at a patient-level to monitor and ensure safe practice.

**Use of tools and standards to change practice and culture**

Well-developed tools and standards exist to enable evaluation of security and privacy risks, such as are contained in the HMG Security Policy Framework or the Information Commissioner’s Office’s (ICO) privacy impact assessment protocols. The BCS Personal Data Guardianship Code is another tool that enables organisations to proliferate good practice, and is aimed at a non-technical audience.

The NHS needs to take good practice from these examples at the highest levels and implement as far as possible through standards. Yet it also needs to promote a culture consistent with privacy and security at all levels and this will require tools and training that can be used down to the lowest level of the organisation to self-assess impacts and promote good practice.

**Reducing collection, storage and processing of personal information**

Ultimately, the best way to reduce privacy impacts and security requirements – and hence costs as well – is not to collect, store or process personal information in the first place. In many, if not all, clinical contexts this may sound ridiculous, but this is an extension of what is often done manually when passing data across care boundaries – where only the relevant clinical information is passed. Positive changes in working practices combined with technology can lead to a very different risk profile, if the need for privacy and security is taken into consideration at all stages of design and implementation.

Technology and techniques described as ‘privacy-enhancing’ are generally those that enable transactions or access to services while minimizing the exchange, storage and processing of personal information. These methods can challenge assumptions and conventions about where and when personal information needs to be stored or processed – enabling solutions that would be impractical or even impossible using conventional methods.

The objective is to create a balance between the need for access to individualised clinical information for prevention, treatment or research, the right of the patient to agree how their personal information is used and the ability of technology to avoid the proliferation of copies of an individual’s personal data.

**Building trust versus technical consent**

Consent – specifically meaning around data rather than consent to treatment – has some difficulties in the health arena. Unless clinicians are prepared to consult without records (and without generating any) or conduct surgery without notes, then consent to data use must often be given automatically with consent to treatment. This is a pragmatic necessity, but whether it is meaningful consent to use data is questionable, and it certainly does not represent a choice.

Informed patient consent is seen as a feature of courteous discourse and a mark of respect. It is only meaningful when someone has a real choice and, in the public’s eyes, implied consent is no consent.

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22 Use of Personal Health Information in Medical Research, IPSOS Mori, 2007, commissioned by the Medical Research Council. Public Perspectives on the Governance of Biomedical Research: A qualitative study in a deliberative context, University of Surrey, 2007, commissioned by the Wellcome Trust.
23 Public Perspectives on the Governance of Biomedical Research: A qualitative study in a deliberative context, University of Surrey, 2007, commissioned by the Wellcome Trust.
Informed means that the patient knows what kind of data is being sought and for what purpose(s), when and how often it will be collected, who will use it, who is responsible for it and how long it will be retained. Significant changes to these, particularly the data being sought and the purpose(s), should trigger a request for re-consent.

So standard, all-or-nothing, fair processing notices that are required for treatment do not represent much of an engagement with patients as to how their data is used – for clinical or for secondary financial/reporting purposes. Research purposes are often the only area where patients are given real choices and consent may be meaningfully withheld. It is not clear that the interests of patients are well served by making research purposes a data protection ‘whipping boy’.

The question is whether consent in this context is the real issue. Transparency about use is vital, and fair processing notices do help in that regard (and place limits that staff must understand and follow), but consent and choices over data use should be meaningful – or not given the appearance of independence from consent to treatment. Instead, it may be more appropriate and more useful to give visibility (that is, enable patients to see who is accessing records and why) and maintain alignments between data use and patient/clinician trust relationships.

As an example, GPs already provide partial snapshots of records to secondary care and incorporate back hospital reports and test results. Greater visibility of transactions and the ability for both patients and clinicians to mark up record components as sensitive (making use of sealing/locking) could allow GPs to meaningfully converse with patients about data use, and together achieve a more informed balance.

Where gathering of consent is a tick-box exercise it is a waste of effort, and can undermine trust relationships rather than build them. Yet simply stripping the requirements away in law could be dangerous. It is conceivable that legislative changes may be necessary for a mature approach to health information, but changes should be made to support and enhance trust relationships rather than simply to remove safeguards that are perceived as impeding sharing and efficiency.

Consent comes in three major variants:

- Explicit consent for each sharing request. This is seen as the gold standard by the public, but involves contacting all potential subjects, which may be impossible or expensive to do.

- One or more generic advanced consent, which may be qualified – for example, for all research purposes that are not about birth control. The consent could be held as part of the electronic data controlled by the patient’s GP or as part of the national patient demographic service entry for the patient.

- Last and least, an informed opportunity to opt out, no opt-out being taken as consent. The challenge here is to make sure that all potential subjects are aware of the opt-out and the consequences of using it. The opt-out should also be easy to use.

Three surveys on patient attitudes all clearly indicate that patients wish to be asked for consent when patient-identifiable data is used for secondary purposes. This may not be so hard and fast where use is by the care provider to which the data was originally provided. The only exceptions are where the source accepts that sharing is required by law or regulation, in the vital interests of the patient, in the public interest or is requested with an order made under section 251 of the NHS Act 2006.

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25 Use of Personal Health Information in Medical Research, IPSOS Mori, 2007; commissioned by the Medical Research Council. Public Perspectives on the Governance of Biomedical Research: A qualitative study in a deliberative context, University of Surrey, 2007; commissioned by the Wellcome Trust. Share With Care, NHS Information Authority and Which?, October 2002.
When data is aggregated, pseudonymised or anonymised, the majority of patients are generally content for it to happen without their consent, or if not, with awareness of a genuine opt-out facility, or with a general, possibly qualified, advance consent. The challenge with a general consent will be matching the secondary purpose with any qualifications the patient has expressed. The more sensitive the data is perceived to be, the greater is the grade of consent considered necessary.

**Risk awareness for anonymous or aggregated data**

De-identified and aggregated data sets may still represent a risk to personal privacy, either by analysis of the data or through combination with other identifiable sets of data. This does not appear to be a widely shared understanding.

All patient data, whether personally identifiable or not, must be subject to measures to ensure security and maintain appropriate integrity and accuracy. Aggregate data will always pose a risk of identification – a risk that should be minimised.

Data sources as diverse as blog comments and local crime statistics can be used to triangulate information and re-attach an identity to anonymous or aggregated data. A live example of this is use of Netflix movie rental data – that may be profiled for sexual preference – combined with comments on the Internet Movie Database website to re-identify individuals.26

Anonymised aggregate data that may include only a small number of patients who have a rare condition or come from a defined population, may allow an individual to be identified by inference or linkage with another publically available data set.

To be harmful, re-identification does not have to have 100 per cent chance of success; an 85 per cent chance of identifying a specific individual’s sexual preference or a household with a teenage abortion is more than enough to cause harm.

Consequently, de-identified data sets passed to researchers should be treated in a similar way to identifiable patient information in terms of security and restricted access. A simple recommendation is to ensure that language used does not imply that de-identified equals ‘de-risked’. Some large comprehensive pooled longitudinal sets of anonymous/pseudonymised patient data secondary (such as DIN, THIN, GPRD) are so rich (and therefore open to patient identity inference) that they are tantamount to identifiable.

Publication of aggregated information should also pass through a protocol to minimise the risks of re-identification. As it is not possible to evaluate every other data set that is available on the internet now or maybe in the future, it is not possible to remove all risks of publication, but they can be dramatically reduced.

As so much of the Information Revolution relies upon regular publication of large amounts of aggregated data, it is vital that re-identification does not easily take place – both in the interest of any individual involved and for the wider success of the strategy.

**Coercion**

Enabling patients – or larger numbers of clinicians – to remotely access health information presents the prospect of many exciting benefits, but some specific risks to some vulnerable groups. Patients and clinicians could be subject to coercion to gain access to records for a wide variety of reasons. This risk exists already to some extent, but patient access to records will open up opportunities for coercion far beyond what

currently exists – and out of the sight of clinicians and others. The benefits should be actively pursued, but with significant thought and planning to remove or reduce risks to vulnerable groups.

Coercion can present an extreme risk to particular vulnerable groups who have sought help – for example, abused partners. It can deter patients from seeking help, treatment or accurately reporting history. Sexual health and relationship history are obvious areas, but there may be others. Whilst the number of patients affected may be small, the threats to life, safety, wellbeing and prosperity could be huge.

There may also be a set of hard-to-predict behaviours that emerge around, for example, insurance or employment where it is important to have legislation and regulation in place upfront. Employers and insurers may ask for specific information under some circumstances, but they could not and should not be given direct, unfettered access to health records – and it may be prudent to turn the making of such a request into a civil or even criminal offence.

Techniques already exist to counter coercion that could be put into use systematically for health records. Records could be locked, preventing remote patient access, but this could of itself present some dangers. More subtly, secondary pass-codes could be issued by clinicians or even self-generated that would give partial or dummy health information. These could even be used as ‘panic’ signals by patients. An abusive partner could never tell that a pass-code was secondary, as it could give access to the full record – except for parts related to abuse.

There are a wide range of vulnerabilities and needs that patients may have that are impacted by free access to records and these must be designed upfront to prevent very serious harm.

**Self-management of extracted data by patients**

The full complexities of allowing patients to download their records – as distinct from viewing them on a system under NHS control – are not yet well understood. Positions taken thus far indicate that patients must accept full responsibility for any further use of data once it is out of direct NHS control. This may currently be the only practical option and the freedom it provides may produce the greatest innovation. Third parties providing services to store or use this data will of course be covered by the Data Protection Act and other relevant legislation – provided they are based in the UK (or Europe in some cases). However, there is a question as to whether this aligns responsibility with capability and there may be a duty of care to provide information, tools and accreditation for systems that meet agreed minimum requirements to hold such information.

“We are aware of concerns about potential misuse/confidentiality, but this is no different to other areas of life where we accept that we must share data to get a service, e.g. online banking, applications for pension etc. Benefits outweigh the risks and the risks can be managed with good advice and good practice, e.g. strong passwords, changed regularly.”

*Patient representative*

**Patient data access**

Individual patient data will be used on a large scale to support commissioning (including needs assessment) and payment by results. It is not clear how much of this will be patient-identifiable or how widely it will be shared. This needs to be made clear in the government’s proposals.
11.2 Recommendations

**Changes in information governance frameworks**

(87) We recommend that the information strategy defines the changes in information governance (including legislative changes as necessary) that are required to maximise the use of information and deliver benefits; and consults extensively on the specific implementations of these changes.

(88) Guidelines must be clear when care professionals should share identifiable patient data in order to create anonymous merged data sets for secondary purposes. They must also be clear when it is legitimate to re-identify the patient without consent when new concerns are coincidentally discovered in pseudonymised data sets, as a care professional would normally do under their duty of care.

(89) Clarifications and changes required as a result of the information strategy should be spelled out in a NHS information governance framework.

(90) If legislative changes are required to support a mature approach to health information, then these should be made to support and enhance trust relationships rather than simply to remove safeguards that are perceived as impeding sharing and efficiency.

**Use of tools and standards to change practice and culture**

(91) The NHS needs to promote a culture consistent with privacy and security at all levels, as part of the implementation of ‘no decision about me without me’. This will require tools and training that can be used down to the lowest level of the organisation to self-assess impacts and promote good practice.

(92) The need for privacy and security should be taken into consideration at all stages of design and implementation and, along with positive changes in working practices combined with technology, can lead to a very different risk profile for the care organisations and individuals.

(93) We recommend that the NHS continues to evaluate adoption of ‘privacy-enhancing’ technologies and techniques. These methods can challenge assumptions and conventions about where and when personal information needs to be stored or processed, enabling solutions that would be impractical or even impossible using conventional methods.

**Building trust and protecting the public**

(94) Consent and choices over data use should be meaningful – and where applicable not given the appearance of independence from consent to treatment. Instead, it may be more appropriate and more useful to give visibility (that is, enable patients to see who is accessing records and why) and maintain alignments between data use and patient/clinician trust relationships.

(95) We recommend that information systems that hold identifiable patient information for their care should enable patients to protect very confidential information in a ‘sealed envelope’, whence it may not be shared without the patient’s explicit consent.
Significant thought and planning to remove or reduce risks of coercion, especially to vulnerable groups, is required, particularly around a patient’s decision to release their personal health record to a third party. Consideration should be given to whether legislation is required to protect the vulnerable from potential coercive behaviours by insurance companies, employers and others.

**Risk awareness for anonymous or aggregated data**

The information strategy and guidance should alert that de-identified and aggregated data sets may still represent a risk to personal privacy, either by analysis of the data or through combination with other identifiable sets of data.

We recommend that where anonymous data is placed in the public domain for further analysis, limits should be set on the minimum size that a sample set can be before risking inadvertent personal disclosure. These minimum sample sizes should be incorporated into the access interfaces to databases that the NHS is offering directly to the public and this should be a contractual condition of the release of a data set to a third party who wishes to offer data interrogation tools to the public.

We recommend that de-identified data sets passed to researchers should be treated in a similar way to identifiable patient information in terms of security and restricted access.

**Commission information requirements**

We recommend the development of a commissioning information strategy as an early task of the formation of the NHS Commissioning Board. With considerable new and important information flows required to develop commissioning to the level that the government expects, the strategy needs to make it clear how much data will need to be patient-identifiable and how widely it will need to be shared to support commissioning.

Recommendations from other chapters:

- The information strategy contains a description of clear information governance processes that can be adopted efficiently and consistently locally, with liabilities and risks for each party identified to allow ICT suppliers and others investing in the market to understand the risks and liabilities of re-using information in the delivery of services and enabling transparency across organisational borders.

- We recommend that work is carried out with patient and carer groups, and others, to simplify and make consistent a consent model (for information to be accessible to others) across England and liaise with other countries on the essential elements of a universal consent model. It needs to include consent for both direct care and secondary uses.

- Robust and easily comprehensible audit trails of who has been accessing their medical records are an essential, cost-effective tool for helping patients manage risk associated with sharing their medical data.

- We recommend that guidance is put in place on the safe handling of patient data for patients who are storing and sharing their personal medical data, including sample sharing agreements. The guidance could advise on: procedures and technology to minimise the risk of coercive access; best practice for systems design for comprehensive and clear audit trails; and the technological implications of various
models of patient-limited record sharing in conjunction with clinicians and patients to determine what is feasible technologically and in various care settings.

- The information strategy provides clear guidance on data access to address the required access by commissioners to routine primary care data, social care data and clinical audit data; creation of anonymous linked data sets to understand the whole health system; required access to national data sets to allow benchmarking; and making key clinical registers appropriately available.

- The information strategy should make it clear that sharing data in order to create anonymous aggregate data sets for the purposes of business change, management and governance is appropriate, but that risks need to be mitigated through security standards and technologies. Local organisations should be empowered to work within security, privacy and information governance standards to share data with each other, patients, social care and others, without the need to seek prior approval from central agencies.
Preparing the NHS for an information revolution

BCS report on the NHS Information Revolution consultation on proposals

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