Market Research

Preparing for information being mission-critical to the NHS

October 2011
BCS Health
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Executive Summary

1.1 Introduction

During 2011 BCS, the Chartered Institute for IT, has reviewed the theme of “preparing for information being mission-critical to the NHS” in order to demonstrate visible leadership. BCS Health wishes to help to smooth the consequences of releasing information based on NHS data to the public by helping to educate key stakeholders about what to expect when increased information (of varying quality) is exposed, and helping them to understand the fundamental importance and opportunity for improving data quality.

Mott MacDonald was commissioned by BCS Health to undertake market research and analysis to gauge opinion on the current state of healthcare information practices and to identify what lessons can be learned from other health systems and other sectors where similar types of changes have taken place, and how these might help prepare the English NHS for its own ‘information revolution’.

The research project consisted of three key activities:

- On-line survey (220 respondents);
- Desk-based research; and
- Stakeholder interviews (eight individuals from a range of relevant perspectives).

In addition, summaries from two related open debate events held by BCS Health in the autumn of 2010 were used as input.

1.2 Results

The following key findings were identified from across the various streams of research:

<table>
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<tr>
<th>Key Findings</th>
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<tr>
<td>The greatest anticipated benefit of exposing information about healthcare services to scrutiny is improved quality of care while the least important benefit is increased patient choice (implying that the mechanism by which transparency improves quality is not simply through enabling patient choice).</td>
<td>Survey, interviews</td>
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<td>The latest review of evidence for using publicly reported performance data to improve quality concluded that publicly releasing performance data stimulates quality improvement activity at the hospital level but that the overall effect of public reporting on effectiveness, safety, and patient-centeredness outcomes remains uncertain.</td>
<td>Desk-based research</td>
</tr>
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<td>All discourse about making information ‘mission-critical’ in the NHS should clarify what type of information is being referred to (e.g. financial, performance or quality information about health services, population health, clinical conditions or patient records), and at what level of aggregation (e.g. individual patient or clinician, organisation, or region).</td>
<td>BCS events</td>
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<td>People making choices about their medical treatment want information about the individual doctors (or teams) who treat them, information about their condition, and information to help them understand the risks associated with attending particular hospitals.</td>
<td>Desk-based research</td>
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<td>Face-to-face communication and web-based tools are the best methods for</td>
<td>Survey, interviews, desk-</td>
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<td>Key Findings</td>
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<td>communicating information about health services, while GPs and GP practices are the most natural starting point for doing so.</td>
<td>based research</td>
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<td>How information is presented to users is critical, and more information is not always better – there are a variety of information standards and data quality frameworks that can guide information providers.</td>
<td>Survey, interviews, desk-based research</td>
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<td>The greatest challenges to making information ‘mission-critical’ are cultural rather than technological, encompassing both the organisational culture within the NHS and the public’s engagement in using healthcare information.</td>
<td>Survey</td>
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<td>Greater flexibility to share information and greater health informatics competencies (across the whole workforce) are the most important factor for making the NHS information-driven, while more health information systems are the least important.</td>
<td>Survey</td>
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<td>The most likely risks for information being ‘mission-critical’ are that the NHS and the public will lack the capacity to process and make optimal use of information available. However, while it is considered likely, information overload for patients and the public would not have a major negative impact.</td>
<td>Survey</td>
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<td>The risks representing the greatest potential negative impact are those related to fraudulent, unethical or unsafe activity, including data recording practices that obscure or adjust the true meaning of information.</td>
<td>Survey</td>
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<td>There are many benefits to patients accessing their own health records, including improved data quality, improved clinician-patient relationships, and increased patient self-management capacity. There is less evidence about the benefits of patient control of their records, although “patient control” as a label has different meanings to different audiences at present.</td>
<td>Survey, interviews, desk-based research</td>
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<tr>
<td>There is greater interest in patients being able to perform practical transactions online with regard to their health record or care (e.g. check results, exchange emails with their clinicians) than in performing actions associated with ‘control’ (e.g. sharing records with other providers, inputting data directly).</td>
<td>Survey, desk-based research</td>
</tr>
<tr>
<td>There is general support for a wide range of decisions to be available to patients in relation to their NHS-created health records, including that patients be able to request that certain parts of their record be kept from general view.</td>
<td>Survey</td>
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<td>A sizeable cohort of stakeholders remains uncomfortable with the idea of relinquishing control of NHS-held records to patients so they may share their records with third parties without restriction.</td>
<td>Survey</td>
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<tr>
<td>Health records serve a number of purposes and therefore they are not solely a ‘patient’ record, including aide memoire, a medico-legal record and a means to action transactions.</td>
<td>Interviews, desk-based research, BCS events</td>
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<td>Face-to-face communication is the most effective way of communicating information about patients’ records, while web-based patient records and the availability of expert support available by phone to interpret information for the public will most effectively support patient control of their records.</td>
<td>Surveys, interviews, desk-based research</td>
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‘Access’ and ‘control’ of records are different issues, and it would be beneficial to move from the terms ‘control’ and ‘ownership’ to a focus on ‘obligations’, ‘uses’, and ‘rights’. Control of patient records needs to be seen in the broader context of clinician-patient relations and the model of care.

Many dimensions of data quality (and or information quality) have been identified in the literature, the majority of which are applicable in the healthcare setting. The key requirement is that data and information should be presented at the appropriate level and format relevant to its specified purpose.

While data is currently of variable quality in the NHS, this will not prevent its intended publication. However, data quality is expected to improve as data and information is examined and used more widely.

Advances in technology and information-sharing capacity and new models of information provision are raising new issues related to information security and patient confidentiality, particularly in an increasingly plural market of public and private sector providers and intermediaries.

Clinicians, managers, GP practices, information professionals and the public would all benefit from tailored education about how to access and use health information.

### 1.3 Conclusion

The research found that stakeholders feel there are a significant number of risks and challenges inherent in achieving the full vision of an ‘information revolution’. However, it also found that there are examples of successful information-sharing, exposure and patient record access, both within the UK and internationally (and from other sectors, particularly around providing web-based services). The impact of increased transparency about health services in England can be anticipated to be equally mixed, although survey respondents and interviewees appear to support it overall as delivering a net improvement on the quality of care provided by the health service.

In today’s changing NHS landscape, access to data and information will become increasingly more important to GP consortia in making healthcare commissioning decisions for their populations. GPs have a central role to play in delivering the “information revolution”, and they will require an increased ability to access data and to connect relevant information together, i.e. connecting appropriate systems in Primary Care, Secondary Care, Mental Health and Social Care. Time will tell whether the Government prioritises making the changes required to overcome the challenges and realise the benefits of truly making the NHS ‘information-driven’. The evidence suggests that the ‘information revolution’ is possible, with the right incentives and investment to create the capacity and focus required to achieve the vision.
2. Background

2.1 Introduction

The mission of the BCS, The Chartered Institute for IT, is to “enable an information society”. BCS Health was formed to cover all aspects of informatics in support of health. BCS Health has selected three key themes and key focus areas for strategy and policy in 2011 in which it expects to demonstrate visible leadership:

1. Preparing for information being mission-critical to the NHS
2. Integration and interoperability through opening up systems
3. Patient engagement and self service

The first theme for review was “Preparing for information being mission-critical to the NHS”. BCS Health believes that improving the use of information and technology in the NHS is critical to driving quality and productivity improvements. It believes that much of the NHS’s data is of a poorer quality than it ought to be, but that the only way to improve data quality is to expose it to clinical and public scrutiny.

BCS Health wishes to help to smooth the consequences of releasing information based on NHS data to the public by helping to educate key stakeholders about what to expect when increased information (of varying quality) is exposed, and helping them to understand the fundamental importance and opportunity for improving data quality.

Mott MacDonald was commissioned by BCS Health to undertake market research and analysis to gauge opinion on the current state of healthcare information practices and to identify what lessons can be learned from other health systems and other sectors where similar types of changes have taken place, and how these might help prepare the English NHS for its own ‘information revolution’.

This paper and an accompanying PowerPoint presentation are the principal outputs from this work.

2.2 Government Policy Context

In October 2010 the Department of Health (DH) published a consultation document, “Liberating the NHS: An Information Revolution” (DH, 2010a), setting out the Government’s thinking on the direction of travel for health informatics and anticipated issues in supporting the long-term vision for the future of the NHS as set out in the July 2010 White Paper, “Equity and Excellence: Liberating the NHS” (DH, 2010b) and incorporated legislatively in the Health and Social Care Bill 2011. It is also a companion document to the concurrent consultation document “Liberating the NHS: Greater choice and control” (DH, 2010c).

The ‘information revolution’ described by the DH represents a transformation of how information is collected, analysed and used in health and social care. Key proposals include developing a more open and transparent culture; enabling a range of organisations to offer service information to various stakeholders; and encouraging disparate information systems to be ‘joined up’ to facilitate information-sharing (rather than expecting all organisations to use the same information systems). Priority areas for the information revolution are identified in the consultation document as:

- Increasing the use of information and modern technology to create efficiencies;
- Increasing patient control of their health records;
- Increasing the role of outcomes-focused information about the quality of health services;
- Enhancing the role of informatics as a profession and a skill set;
- Increasing transparency about the quality and efficiency of health services; and
- Setting a national information strategy (following completion of the consultation process) (DH, 2010a).

With regard to the implementation of information systems to support this ‘information revolution’, the centralised approach to implementing information systems in the NHS adopted by the previous Labour Government has been replaced by a more ‘modular’ and locally-led approach to implementation, which still intends to maintain existing elements of the national infrastructure, e.g. Choose and Book (DH, 2010d).

The proposed Information Revolution in health and social care is part of a wider Coalition Government transparency agenda to increase the amount of data and information about public services published (Number10.gov.uk, 2010). However, the Coalition Government has indicated that there are no plans for additional funding to be made available to support this. Instead, it is exploring new models that involve partnerships with industry, and plans to attract a far wider range of information providers (DH, 2010a).

2.3 Methodology

2.3.1 Approach and Scope

The research project consisted of three key activities:
- On-line survey;
- Desk-based research; and
- Stakeholder interviews.

In addition, summaries from two related events held by BCS Health in the autumn of 2010 were also considered (‘The ‘information revolution’ and business transformation’, held 10 October, and ‘Challenges of sharing information for multiple purposes across local health economies’, held 4 November).

While there are several types of information that are relevant both to the health service and the proposed ‘information revolution’, this research project has focused primarily on information about health services (e.g. quality, efficiency and safety) and individual patients’ health records. Information about clinical conditions and on-line services (e.g. scheduling doctors’ appointments through the Internet) are also considered, although in less detail. This research focuses on the intentional publication of information about services, while still conscious of the increased risk of accidental disclosures in an increasingly joined-up and ‘on-line’ health system.

The overall level of adoption of clinical or other information systems and the overall effectiveness of health policies such as patient choice or performance measurement are outside the scope of this project, although some references are included.

2.3.2 Survey

An eighteen question survey was distributed electronically using the SurveyMonkey application (www.surveymonkey.com) using BCS Health and Mott MacDonald distribution lists.

The survey ran for two weeks from 29 November 2010 to 10 December 2010. 220 surveys were fully completed out of 319 that were started by recipients (69% completion rate).
Survey respondents represented a wide variety of NHS and non-NHS organisations, including NHS acute Trusts (16%), PCTs (16%), the private Informatics/Information Management industry (12%), Consultancy (10%), Arm’s Length Bodies (6%), Mental Health Providers (6%), Academia/Think Tank (6%), Strategic Health Authorities (5%), Central Government (3%), Community Providers (3%), GP Practice/Commissioner (2%) with another 15% representing a wide range of ‘Other’ organisations including international health organisations, e.g. Canada Health Infoway.

The majority of respondents were Informatics or Information Management professionals (54%), with additional representation from Management Consultancy (10%), Management/Administration (8%), Senior Executive/Board Members (7%), Clinicians (6%), and Academic/Policy Analysts (5%). One Patient Representative answered the survey. ‘Other’ represented 10% of respondents.

77% of respondents were members of the BCS and/or a BCS Specialist Group.

### 2.3.3 Desk-Based Research

Desk-based research was undertaken to seek answers to the following questions:

- What have been the experiences of information-sharing and information exposure in healthcare and in other sectors, both in England and internationally?
- What are the most important factors that give stakeholders (patients, public and health professionals) confidence and assurance in the quality and security of healthcare information?
- What frameworks have been developed to understand data quality and confidence?

Systematic searches were carried out on the following databases: MEDLINE (via PubMed), JSTOR, and Google. The Consumer & Communication and Effective Practice & Organisation of Care Groups within the Cochrane Collaboration were browsed for relevant guidance. All searches were carried out in November 2010 to January 2011 and were not restricted by date. Articles and websites cited were readily available on-line and published in English.

Key search terms included: “information exposure”; “information sharing”; “information disclosure”; “data quality”; and “data confidence”.

A number of case studies were developed based on the experiences of information-sharing and information exposure in other sectors, both in England and internationally. For each case study, a suggested learning or potential implication for the NHS was also identified. The full set of case studies can be found in the accompanying PowerPoint slides.

### 2.3.4 Interviews

30 – 60 minute telephone interviews were carried out with:

- Clinicians:
  - Primary Care Clinician, GP Practice
  - Acute Trust Clinician, District General Hospital, South East
- Thought Leaders:
  - Programme Lead for Data Quality, NHS Information Centre
  - Head of Programme, GP Extraction Service, NHS Information Centre
Interview Questions

(1) The government has proposed a step-change in making healthcare data more available to patients and the public.

(a) What do you think would be the benefits of exposing more health data and information?
(b) Would increased exposure of healthcare information drive improvements in the quality of information?
(c) What do you think would be the challenges/risks of exposing more health data and information?

(2) What needs to be done to improve confidence in healthcare information?

(a) For clinicians and other healthcare professionals?
(b) For patients and the public?

(3) What actions, services or system changes do you think would be required to engage patients, the public, clinical professionals, management and others in the proposed ‘Information Revolution’?

(4) How do you think patients would most like to access health information? In discussion with health professionals? By direct access to health information systems? Through facilitated services (portals)? Other?

(5) It has been suggested that patients should have more control of their records and influence over how their records are used.

(a) What should ‘more control’ mean?
(b) What do you think would be the benefits of giving patients greater control of their records?
(c) What are the potential challenges/risks in giving patients more control?

(6) Are you familiar with any good examples of information sharing and in using information to change practice, in the health care or other sectors, in England or internationally?

2.3.5 Limitations of Methodology

Only a limited number of survey respondents and interviewees were clinicians, and those clinicians who did participate were to some extent self-selected based on their interest in the topic and therefore are not necessarily representative of general clinical opinion.

Survey questions were phrased as clearly as possible but it was not entirely possible to avoid a degree of ambiguity or the potential for various interpretations of the concepts presented.

The broad scope of the desk-based research meant that no single topic could be exhaustively examined.
3. Information about Health Services and Clinical Conditions

3.1 Key Findings and Discussion

Information about health services may include information about activity levels, waiting times and other performance measures, clinical outcomes (including safety and effectiveness measures), patient and staff experience, financial information, or any other information that describes the quality or efficiency of health service delivery. Increased access to information about health services lies at the heart of the Coalition Government's 'information revolution', providing, as the consultation document calls it, "autonomy, accountability and democratic legitimacy". There will be a "presumption of openness", adopting a 'publish and improve' rather than 'polish and publish' approach and healthcare organisations will be expected to be open about mistakes (DH, 2010a).

England already has many existing sources of information about health services, from Quality Accounts to performance information available through the Care Quality Commission. Content is produced by various sources, including the government, NHS organisations, private companies, and patients and the public itself, e.g. www.iWantGreatCare.org. However, the Government believes that current data collections are not sufficiently patient-focused, and its intention is to prioritise outcome information over process measures. Patient-generated information will gain more visibility, along with staff feedback on quality of care, so that staff and patient experience can shape service delivery. Clinical teams and the public will have access to risk-adjusted assessments of clinical performance. Information for commissioning will support the planned restructuring of the NHS, including the transfer of commissioning budgets from PCTs to GP-led consortia, as well as the publication of assessments of how well commissioners are performing (DH, 2010a).

The concurrent patient choice consultation articulates the Government's belief that providing patients and the public with more information about services will support them in making better choices about where they receive services, which in turn will incentivise clinicians and organisations to raise their service standards.

NHS-generated information about clinical conditions, or 'consumer health information', is also considered in this section. Information about conditions, treatments and lifestyle choices is more widely available than ever before, with developments in information technology making it easier for the general public to access information that was previously dependent on professional gatekeepers. At the same time, service users and interest groups are generating their own sources of information, which may provide alternative views to those provided by health professionals (Barnes, 1999). England also has several well-established sources of information about clinical conditions, both for patients (e.g. NHS Choices) and for clinicians and other NHS decision-makers (e.g. Map of Medicine, NICE guidelines). However, tailoring this information for individual patients (e.g. Information Prescriptions), and helping patients to assess the quality of third-party information (e.g. through the Information Standard Scheme), is at an earlier stage of development and adoption. A detailed set of factors that can influence patient uptake of information about clinical conditions is available (Calvin & Karsh, 2009), as well as of eHealth services in general (Hardiker & Grant, 2009).
3.1.1 Benefits and Opportunities

Survey Q5: What are the most important benefits of exposing information about healthcare services to scrutiny? (ranking each answer between 0 and 5)

Interview Question #1: The government have proposed a step-change in making healthcare data more available to patients and the public. (a) What do you think would be the benefits of exposing more health data and information? (b) Would increased exposure of healthcare information drive improvements in the quality of information? (c) What do you think would be the challenges/risks of exposing more health data and information?

<table>
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<th>Responses</th>
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<td>Acute Hospital Consultant</td>
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| Information Professional | There are three different sets of requirements:  
  o Operational and management information for resource management (generally aggregate data)  
  o Patient level data for commissioning and performance management  
  o Information to support appropriate commissioning - requiring patient level data either in identifiable or pseudonymised form to allow linkage, support health needs assessment. Should be a standard ‘commissioning dataset’ for consistency and should be linked across agencies e.g. primary, secondary acute and mental health.  
  • QOF and commissioning outcome frameworks for regulators and commissioning boards.  
  • Information on care provision – outcome information at organisation, team and practitioner level to support patient choice. Needs to include an increasingly varied range of providers, including those who do not have ‘standard’ information systems such as private providers. |
| System Supplier | Creates the potential for organisations to benchmark themselves – a driver for quality improvement. |
| Healthcare Professional Association | Much will depend on how the data is analysed and presented. Will it be available at different levels of granularity, what population level will it be aggregated at, etc.?  
  • For patients there will only be benefits if the information is well presented and accompanied by metadata.  
  • For healthcare staff and researchers the benefits could be a wealth of data to use to improve clinical practice. |

Information about health services, particularly about the quality of health services, has three main purposes: to increase accountability, to support quality improvement activities, and to guide choice (Eisenberg, 2002). Both survey respondents and interviewees highlighted the potential for the increased
availability of information about health services to have a positive impact on the quality of care provided within the health service. Increased efficiency of services received the second lowest average ranking from respondents. While accountability was also considered an important benefit by survey respondents, patient choice was considered less important. As one interviewee pointed out, although increased patient choice is an often-cited benefit of increased information about services, in many parts of the NHS patients do not have access to many choices of provider, reducing its effectiveness.

Improved quality of care was also one of the most frequently cited opportunities to the open-ended survey question asking what opportunities arise from the NHS ambition to make information “mission-critical” (with separate 26 references, e.g. “will provide a “greater incentive to get it right rather than ‘it’ll do”). While increased efficiency received 13 free-text references, no respondents chose to make a free-text reference to improved patient choice.

Survey respondents and interviewees also generally recognised the potential benefits to health research and commissioning from increased information about health services, including patient pathway-based information, and through the aggregation of anonymised clinical data.

Experiences of information exposure in other sectors demonstrate that organisations may ignore problematic issues if they are not put under pressure to address them, and organisations or individuals that stand to lose from disclosing information may refrain from doing so unless compelled to. Exposing information about poor quality healthcare may create this increased pressure on healthcare organisations, although research cautions against applying lessons from other sectors too directly to the NHS – the impact of disclosing information has been shown to differ by sector and organisation type (Peccei, Bewley, Gospel, & Willman, 2003).

People have been found to have a very positive attitude to NHS Choices, HealthSpace and other government websites when they were demonstrated to them, and there is a high degree of trust in information from NHS websites (RaFT Research and Consulting, 2010), which is consistent with a recent UK study that found that while the quality of information about clinical conditions on the Internet was “very variable”, government sites were found to give “uniformly accurate advice” (Duncan, 2010).
3.1.2 Delivery

Survey Q14b: How effective are the following media for engaging patients with regards to the following information? (health service information)

![Graph showing effectiveness of different media]

**Interview Question #4:** How do you think patients would most like to access health information? (a) In discussion with health professionals? (b) By direct access to health information systems? (c) Through facilitated services (portals)? (d) Other?

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<td>GP</td>
<td>• The GP practice is best placed to engage with local communities. Generic information systems such as NHS Choices are too diffuse and not locally specific; information needs to be tailored to give maximum value to the local community. They have brought a number of disparate data sources together and enhanced these to give a collated view of useful information in one place.</td>
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</table>
| Acute Hospital Consultant | • Combination of self-guided access to standard sources such as patient.co.uk plus access to specific local systems.  
• Standard/corporate systems need to be user friendly and practically oriented, not too theoretical such as Map of Medicine. |
| NHS Information Professional | • This will vary from person to person. Some are happy to use an information system while others will need help from their GP or another facilitator.  
• Patients’ natural first point of contact is through their GP but GPs will have limited capacity to support patient access/engagement with information.  
• Without a common infrastructure it will be difficult to build a standardised approach through a portal. |
| Information Professional  | • GP practice is first point of call for most patients and is the logical gateway for patient engagement.  
• Engagement needs to be personalised, e.g. clinicians going through relevant care pathways with the patient, not just referral to generic information sources like Map of Medicine.  
• Practices will need the resource to support patient engagement – not necessarily just the GPs but may require other staff to facilitate.  
• GPs may be impeded in finding time for patient engagement if they are diverted onto... |
Markets Research

Preparing for Information
Being Mission Critical

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<th>Category</th>
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| Independent Consultant         | • GP practice is primary front door to information, but need time/resources to support this.  
• Many patients content to leave their care management to clinicians. Different channels needed for different people – a combination of standardised national/local information plus tailored/facilitated local information. |
| System Supplier                | • GP practice is the natural point of call.  
• A facilitated portal combining tailored local information, plus access from this to standard external sources – no need to maintain everything locally, but act as a portal to what is already available.  
• A locally facilitated service needs resources – either GPs themselves or other support staff within the practice.  
• The practice he supports gives patients a web-enabled view of their entire GP record – this view is also enhanced/tailored with hyperlinks from their data to relevant external data such as Map of Medicine. |
| Healthcare Professional        | Association • This will vary depending on the patient’s ability and access to IT, and the technical issues involved in security. Other mediums e.g. Braille print, speaking, will need to be considered for those with communication problems. |
| Patient Representative         | • The portal approach works well. The GP practice website contains a lot of valuable information but also gives access to external information such as NHS Choices, hospital website, Google – it is unlikely that most patients would find their way to these external sources independently. |

Face-to-face communication was identified by survey respondents as the best method for communicating health service information, although only marginally more so than web-based tools (it was a much clearer favourite for communicating patient record information). Interviewees noted that people have different preferences, and therefore various means of accessing health information, including face-to-face and electronic, need to be available.

Interviewees overwhelmingly cited GPs and GP practices as the most natural starting point for patients to access health information, although the viability of this was questioned under the current model of primary care provision, and if, as intended, the volume and diversity of available healthcare continues to increase.

There is much information available that needs to be presented to patients in the right way if it is to be effective (BCS event summaries) - the way information is presented can make a difference to how it is used (Boyce et al., 2010). A recent one-year study by the King’s Fund’s on the role of “nudges” and other information in helping patients choose a hospital found that people clearly wanted information about the individual doctor who would be treating them, information about their condition, and information which helped them to understand the risks they faced by attending a particular hospital (Boyce, Dixon, Fasolo & Reutskaja, 2010). This is consistent with other sectors, for example, the crime mapping initiative in West Yorkshire (Crosby & Rangecroft, 2006) also found that the public is interested in accessing data a very local level; presumably as this helps them understand its direct implications for them.

The King’s Fund research reinforces the importance of paying attention to what information is presented and how, and cautions against a mantra that ‘more information is always better’. A mix of both national and locally tailored information was recommended by interviewees, as well as personal face-to-face communication. The ‘average’ citizen does not exist, and on-line public input (e.g. ratings of health services by patients) cannot replace more structured information sources but rather can helpfully supplement them. People would like information on NHS websites to be given to them by health professionals (RaFT Research and Consulting, 2010), which is a reasonable expectation as clinicians are understood to be the designated experts on clinical conditions and health services.
3.1.3 Challenges, Risks and Issues

There are a wide range of challenges and risks associated with exposing information about health services to scrutiny and to realising the perceived benefits of doing so, including the viability of the health policy assumptions that underpin them.

**Interview Question #1:** The government have proposed a step-change in making healthcare data more available to patients and the public. (a) What do you think would be the benefits of exposing more health data and information? (b) Would increased exposure of healthcare information drive improvements in the quality of information? (c) What do you think would be the challenges/risks of exposing more health data and information?

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<th>Responses</th>
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<tr>
<td><strong>Acute Hospital Consultant</strong></td>
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<tr>
<td><strong>Information Professional</strong></td>
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<tr>
<td><strong>Independent Consultant</strong></td>
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<tr>
<td><strong>System Supplier</strong></td>
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<td><strong>Healthcare Professional Association</strong></td>
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3.1.3.1 Risks

Survey Q6a: Please assess the potential risks arising from exposing information about healthcare services to scrutiny -

Probability of Occurrence:

![Bar chart showing the number of respondents for each risk category (Low, Medium, High).]
Many of the risks suggested in the survey were rated as at least moderately likely and moderately serious. This is consistent with the literature, which identifies a wide range of unintended consequences of exposing healthcare information ranging from the “undesirable but not actively destructive (myopia and convergence) to the out-right corrupting (misrepresentation and fraud)” (Davies, 2005). For example, the star ratings implemented in the NHS in 2001 were reported to have introduced a number of unintended and dysfunctional consequences, including “tunnel vision and a distortion of clinical priorities, bullying and intimidation, erosion of public trust and reduced staff morale” (Mannion, Davies & Marshall, 2005).

The risks considered most likely by survey respondents were that both the public and the NHS would lack the capacity to process and make use of information more intensively. Despite being considered the most likely risk, ‘Information overload for patients and the public’ was considered to have the least negative impact, although it can be assumed that such an information overload would limit the realisation of benefits. It is noted that people “don’t like volumes of inconsistent or poorly organised information which can confuse as much as inform” (DH, 2010a). Existing sources of information are already under-utilised by the public – one recent study found most people had not heard of NHS Choices, HealthSpace or Easyhealth (RaFT Research and Consulting, 2010). The public naturally has limited time and a limited attention span, so if information is going to be used more effectively then it must somehow be simpler to obtain and act upon, perhaps through more locally specific and relevant information. The public appetite for more information, without accompanying changes in the context in which its delivered, may be less than the Government believes.
The risks representing the greatest potential negative impact to respondents were those related to fraudulent, unethical or unsafe activity, particularly ‘data recording practice that might hide the true meaning of information’ (also known as ‘data gaming’). ‘Data gaming’ can conceal potentially hazardous practice and endanger patients and staff. Research in other sectors, particularly tax avoidance and evasion, reveals some insights and may provide some suggestions for minimising gaming in healthcare (Mears & Webley, 2010).

‘Public loss of confidence in the health service’ was considered by survey respondents to be a risk of medium likelihood but with a high degree of impact. There is evidence already in the NHS of a “level of dissonance between public commitment to the values of the NHS and their direct experience of it” (Barnes, 2009). Exposing any further information about poor quality service or outcomes could further erode satisfaction with the health service. NHS performance is of great public interest and attracts considerable media attention, which could further affect public confidence in the health service. Reporting styles can be sensational – for example, in April 2010 the Daily Mail reported that the NHS was sending patient records to India in what they called “the latest privacy scandal to hit the NHS” (Martin, 2010). Interviewees also noted the risk of media sensationalism related to health service performance, which would exacerbate the risk of public loss of confidence in the NHS.

While exposing information to scrutiny may in some cases reassure rather than alarm the public (i.e. if it’s not as poor as they may have been led to believe by the media), it may also reveal the extent of a service’s failings, which in turn may undermine the viability of that service. If the Government wants to ensure that the organisation or service continues to exist then direct intervention may be required (as within the banking sector). Several of the case studies arising from the desk-based research highlight lessons about how public opinion can be swayed by the media or vocal interest groups rather than objective understanding (although ‘understanding of how the NHS works’ was only considered a moderate challenge by survey respondents). Even relatively non-controversial information can have significant consequences under the right circumstances. By what standards should the public judge the NHS and how should it interpret the information about health services that it is made available to it?

The risk of ‘unpredictable service demand due to increased choice’ was considered to be both moderately likely and of moderate impact – presumably this risk is associated with any increased impact of patient choice in service utilisation and is more related to the patient choice consultation than it is to the ‘information revolution’. While respondents saw ‘access to information limited by ability to pay’ as being the least likely risk of all the response options, inequality may arise from the inability of some patients to realise benefits from accessing information, e.g. due to a lack of IT skills.

Interviewees also raised the risks of information being falsely interpreted, e.g. by ‘amateur experts’, and the view that information about services is not currently fit for purpose as it lacks reliability and analysis/interpretation.

While ‘decreased confidence in health service information’ was only considered to be moderately likely, this risk is corroborated by the Information Standard claim that a 2007 DH survey found that three out of four people find it difficult to know which health and social care information to trust (The Information Standard, 2010). Other experience shows that when reported data is perceived as inaccurate then trust is lost – it would be difficult to achieve many benefits if the bulk of the information about health services made available was perceived as inaccurate. While the Government is planning to prioritise the use of outcome measures, these have been advantages and disadvantages relative to process measures (Davies, 2005). For example, while outcome measures are more meaningful, less open to manipulation and focused on the ultimate end goal (e.g. better health), they are also more difficult to attribute to particular individuals or
organisations, may be subject to long periods of time before realisation, and are more ambiguous. To use outcome measures as a marker of quality requires risk-adjustment which would naturally be a contested process, particularly if attention was genuinely paid to the results. Process measures require less risk-adjustment, are more immediately relevant to clinical teams, and can more quickly highlight issues in care (Davies, 2005). There is therefore a genuine risk that a focus on outcome measures at the expense of process measures will decrease the ability of stakeholders to make use of this information.

A related risk which was not included in the survey response options is the risk of demoralising NHS staff through the publication of performance indicators (Gould, 2003). Another additional risk highlighted by the literature review is the absence or incomplete availability of data altogether – in New Zealand the devolution of services from the Ministry of Health to healthcare provider organisations was challenged because the provider organisations were not supported with access to historical information on service provision (Kerr, Norris & Stockdale, 2007). This risk is applicable to the planned restructuring of commissioning services in the NHS, where there is a high risk of ‘corporate memory’ being diminished or lost in the closure of old commissioners and the emergence of new organisations. There has been some anecdotal evidence of NHS providers being reluctant to provide historical patient information to new private sector providers where services have been retendered as it breaches confidentiality. These are largely uncharted waters for the NHS, but the Coalition Government’s drive towards “any willing provider” will mean more private sector provision in the NHS than ever before, and an increased risk that information may be shared or withheld inappropriately.

3.1.3.2 Challenges

Survey Q8: What are the greatest challenges to making the health system information-driven?
Almost all of the survey response options about challenges were deemed to represent a genuine degree of challenge by respondents – very few attracted a ‘No challenge’ response. ‘Organisational culture within the NHS’ was considered a ‘major’ or ‘almost insurmountable’ challenge by 170 out of 232 respondents (73%), and a much greater challenge than the other response options. As the specific characteristics of the ‘organisational culture’ weren’t specified in the question, analysis will be subject to interpretation. Interviewees also cited culture, stating that the NHS culture does not currently value information sufficiently. Anecdotal evidence indicates that the managerial culture of the NHS is highly political and subject to short-term decision-making and planning – in such a culture, ‘spin’ can win out over information, with a culture of blame working against openness and transparency. In addition, the current NHS culture does not prioritise the capture of data or data quality. If, as the Common Assessment Framework case study indicates, the use of data in new and innovative ways is enabled by senior executive support, a range of measures to overcome barriers due to organisational culture will be required.

‘Resistance to sharing information’, which may also be seen as an organisational culture issue, was seen as a ‘Major’ or ‘Almost insurmountable’ challenge by 58% of respondents. This resistance is considered particularly acute among clinical professionals. American doctors have been shown to be anxious about publicly sharing information about individuals’ clinical performance (Davies, 2005), and there is evidence that GPs perceive comparative reports as a burden (Marshall et al., 2003). Professionals may wish to “protect” their practices from political and managerial interference and be uneasy about competition between practices (Marshall et al., 2003). BCS event participants pointed out that while hospitals are required to share patient information with GPs, there is no reciprocal arrangement for GPs to share information with hospitals. Some may resist sharing data on the grounds that it is not accurate enough, but this attitude could constrain attempts to improve its quality through increased attention to the messages it conveys. There is a need for a culture of reciprocal sharing based on obligations and trust with the best interests of the patient. Any objection to sharing data needs to be overcome, potentially through a statutory obligation to share data if contracting with the NHS, while the benefits of sharing information must be trumpeted. As the NHS incorporates more private sector provision, and potentially private sector commissioning, the challenge for open and transparent information sharing will increase significantly – the private sector tends to have a much lower acceptance of open information than the NHS does, particularly where there are considered to be commercial or reputational issues involved.

Technical and information-sharing challenges were the other main category of ‘Major’ challenges, including electronic data integration and interoperability (70%). The use of information technology is not as ubiquitous in the health service as it is in other similarly information-intensive sectors (for various reasons), and this clearly presents a practical challenge to implementing the Government’s vision. Different care professionals have various ways of expressing themselves and recording information so that shared records can create confusion and professional clashes. There is a need to better understand the different terminologies and cultures of different care professionals and how they can be accommodated whilst achieving a common degree of standardisation (BCS event summaries).

Interestingly, the ‘increased time demand on the clinician-patient interaction’ was not considered as significant a challenge as many others in the survey, but several interviewees noted that GPs don’t necessarily have the resources or time to engage effectively with patients.

While it may only be a moderate challenge, ‘awareness of information sources’ is a genuine challenge – one study found most people had not heard of NHS Choices, HealthSpace and Easyhealth (RaFT Research and Consulting, 2010). Interviewees also identified the lack of data in some sectors of the health system as a challenge to making information mission-critical. The National Quality Board found that 40% of
health programme budgeting areas (representing £20bn of annual expenditure), are without any nationally collected quality information (National Quality Board, 2010).

‘Patient and public confidence in information’ was considered the ‘least’ challenge by survey respondents, with 68 out of 233 (29%) citing is as only ‘Some challenge’. However, work by the Royal Statistical Society in 2003 found that both the public and public sector employees are “suspicious” of government performance statistics and suspect them of being used for political reasons and misrepresented by the media (Gould, 2003). People view public disclosure as a political initiative and are more inclined to trust their own experience or that of friends and family than to trust comparative data (Marshall, Hiscock & Sibbald, 2002). The public is concerned about what information on the quality of services means (National Quality Board, 2010). Trust is required around information processing and this will require a locally driven approach where there is an understanding and appreciation of the data (BCS event summaries).

### 3.1.3.3 Effectiveness

While survey respondents and interviewees confidently cited improved quality of care as a key benefit to exposing health services information, how much of an evidence base exists to support this hypothesis? And even if it does realise benefits, how cost-effective is this approach compared to other approaches to improving quality in healthcare?

Disclosure of information about quality of care in the NHS has been strongly influenced by the report card movement in the United States (Marshall et al., 2002). Cochrane reviews of the effects of audit and data feedback generally find that these approaches sometimes improve performance, but that any effects are variable and usually small to moderate (Davies, 2005). The latest systematic review of the evidence for using publicly reported performance data to improve quality (synthesising forty-five articles published since 1986 (27 of which were published since 1999) found a modest association between public reporting and health plan selection and the stimulation of quality improvement activity at the hospital-level; an inconsistent association between public reporting and the selection of hospitals and individual providers; and an inconsistent association between public reporting and improved effectiveness at the hospital-level. Evidence on the impact of public reporting on patient safety and patient-centredness was “scant”, particularly about individual providers and practices. It concluded that publicly releasing performance data stimulates quality improvement activity at the hospital level but that the overall effect of public reporting on effectiveness, safety, and patient-centredness remained uncertain (Fung, Lim, Mattke, Damberg & Shekelle, 2008).

Although assessing the effectiveness of the policy of patient choice is not the purpose of this research, survey respondents’ perspective of the limited benefit of information on improving patient choice has been reflected in literature – one review of quality has found that while expressing interest in health service data, the public do not appear to use them to any great extent when making decisions (Davies, 2005). In the US, referring doctors in primary care also seem to make little use of the data, even when these data seem to offer very specific guidance (e.g. mortality rates of individual surgeons) (Davies, 2005). A 2007 DH (DH, 2007) report found on patient choice found that location or transport considerations were most frequently cited as key factors in choosing a hospital. The King’s Fund’s research found that people find it difficult to make trade-offs between quality, safety, patient experience and location, suggesting that the government should be cautious about the ability of patients (apart from those who are highly numerate) to make these complex decisions without some decision support. (Boyce et al., 2010). The King’s Fund suggests that patients may benefit from information that reassures them that hospitals meet a minimum set of required standards (Boyce et al, 2010). While they found that making people more aware that the quality of hospitals differs, and giving them opportunities to practise making a choice, appears to help people make better
decisions, they also found that forcing patients to consider trade-offs between the quality of hospital may increase their dissatisfaction with the choice they make.

While interviewees and survey respondents believe that the public is interested in information about the quality of services at an individual clinician level, disclosure of individual clinician performance is controversial in terms of data quality and the ethical issues associated with publishing it, while there remains little evidence of how access to individual surgeon performance data impacts patient decision-making (Henderson & Henderson 2010). There needs to be an evidence-based approach to the public reporting of comparative performance information in future. Simply allowing all the information currently held about the quality of care to be put in the public domain will not result in people making informed choices (Boyce et al, 2010).

The Veteran’s Health Administration’s track record in improving quality demonstrates that increased use of information is more effective when accompanied by other changes in the health system, which is consistent with the current approach and the full vision of the White Paper. For example, the Government believes a greater focus on outcomes will develop “information of a new and powerful kind”, but this information won’t be powerful if it is not used by NHS professionals or the public, or if they are distracted by too many other competing priorities, or if it is not reliable or meaningful data.

In terms of information about clinical conditions, some members of the public don’t believe there would be any benefit in getting more information on their health condition (RaFT Research and Consulting, 2010), while others face a number of barriers to accessing health information on-line, including increasing age and low socio-economic status (RaFT Research and Consulting, 2010).
3.1.4 Implementation

Survey Q17: Please rate the importance of the following for making the NHS information-driven:

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<th>Number of Respondents</th>
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<td>26</td>
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Interview Question #3: What actions, services or system changes do you think would be required to engage patients, the public, clinical professionals, management and others in the proposed ‘Information Revolution’?

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<th>Responses</th>
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<td>Information Professional</td>
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<tr>
<td>Main issue is that users must have trust in the source of the data.</td>
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<tr>
<td>Information must be meaningful to patients and must support real choice – no point offering comparative service information if patients don’t really have a choice.</td>
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<tr>
<td>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 or diluted with devolution of commissioning to GP consortia. Skills resource gap needs to be addressed.</td>
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| Independent Consultant |
| GPs are the key point of engagement. |
| General public awareness can be addressed through advertising campaigns, but patients need a more personalised approach. |

| System Supplier |
| Needs a local approach, not a one-fits-all national approach. National systems tend to start with good intentions but don’t keep up as not sufficient impetus to maintain them – other priorities emerge. |
| GP/GP consortium led local initiatives are more effective as there is local relevance and interest. |

| Healthcare Professional |
| This requires all the services to work together to agree what comes first. |
Responses

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<tr>
<td>• There is no point in having a publicity campaign for patients/public if the information is not ready or the quality is poor. It needs to start at the source of the data which is the health record.</td>
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<tr>
<th>Patient Representative</th>
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<tr>
<td>• Patients contribute directly to the practice website and share their own local experience and advice, e.g. ‘how do I go about accessing out of hours services?’</td>
</tr>
<tr>
<td>• Patients also run local initiatives, e.g. survey of health information needs for young people, to inform local service provision and tailor information on the website e.g. to provide relevant, reliable web links.</td>
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More flexibility to share information was considered the most important requirement (relatively) for making the NHS information-driven, while more health information systems were considered the least important. However, all suggested factors were recognised as important and relevant to making the NHS information-driven. There is a concern of a lack of health informatics skills, both among information professionals and the wider NHS clinician and other staff groups, for example, a lack of analytical capacity to produce and present meaningful information. Staff and the public also need a greater awareness of health information sources, and a means of certifying the quality of available health information.

3.1.5 Conclusions

The health service, along with the rest of the English public sector, is working out how to rapidly expose its data to drive service improvement. The overall view is that exposing data to public scrutiny will improve the quality of care in the health service. The ability of the health service to realise the potential benefits from increased transparency will depend on how well it overcomes the recognised challenges and manages the risks, i.e. on how it is actually implemented and communicated. For example, the level of aggregation of data is an important consideration as the benefits, risks and requirements at each level (e.g. individual patient, service or organisation) vary, and the public is interested in having more information to the individual clinician level.

GPs are perceived as the key starting point for engaging patients around health information, and even in a plural market of information providers there appears to remain a role for the government in providing reliable information about services and clinical conditions, even if there remains some mistrust about government ‘spin’ on the information.

Although the NHS already has considerable information about health services and their performance, as well as a formal regulatory environment, this wasn’t enough to prevent poor standards of care in Mid-Staffordshire NHS Foundation Trust from developing and persisting. The NHS has many standard practices for monitoring and improving quality, patient safety and the patient experience (e.g. clinical governance, local and national audits, complaints/PALS), but the value of these processes has not been entirely realised, at least in examples like Mid Staffordshire. It may be that making even more information available will only be effective if it is part of a broader plan for addressing the underlying causes of these failures, i.e. if the broader NHS restructuring is an effective driver of improved quality and productivity.
4. Patient Access To and Control of Health Records

4.1 Key Findings and Discussion

UK policy and law entitle people to access their health records, with specific exceptions, as set out under the Data Protection Act (1998). Rights of access are also set out in the NHS Constitution (2009), and sharing relevant information with patients is generally considered good practice in healthcare. Newer approaches require that record access go beyond the legal obligations by offering routine access to patient records, enabling a partnership to promote good health care (Royal College of General Practitioners, 2010). By April 2011 the Government plans to enable patients to have increased access to and control of their health records, starting with their GP records and extending over time to all provider-held health records. The intention is for patients to determine who else can access their records, to be able to see changes when they are made to their records, and for it to be simple for a patient to download their record and pass it, in a standard format, to any organisation of their choice.

In addition, the ‘information revolution’ is about providing on-line services that are more efficient and convenient for patients and carers. Local and international examples identified by the Health Foundation show that such functionality might include:

- Secure messaging between clinicians and patients;
- Scheduling appointments;
- Reviewing and correcting records;
- Seeking a repeat prescription;
- Detailing who health service providers should contact in case of emergency; and
- Updating advanced directives (The Health Foundation, 2009)

There are already existing examples of patients both accessing and ‘controlling’ their own health records within the English health service, both at a local and a national level, including HealthSpace, a free, government-led on-line personal health organiser that is available to adults living in England, and the Summary Care Record (SCR), which is intended to provide healthcare staff with easy access to patients’ essential health information (and which will also be accessible to patients through HealthSpace). There are also condition-specific information systems for accessing record information on-line (including renal, maternity, and diabetes). Portable patient records are well established in certain clinical areas, including antenatal care. Some English GP practices already provide their patients with electronic access to their health records and a number of on-line services (such as ordering repeat medications).

There are also numerous international examples of patients accessing their health records on-line, particularly in Scandinavia and the United States. Scandinavian providers have been motivated by various government requirements for electronic health records (e.g. Finland has passed a law that requires public and private health care providers to adopt a national patient record system by April 2011 (Brewin, 2009)). In the US, new federal rules require clinicians and hospitals to give patients electronic copies of their lists of medications, lab results, and other pertinent information in order to qualify for billions of dollars in subsidies that are being made available by the federal government. E-mails between doctors and patients are covered by some major health plans in the US. Both Kaiser Permanente and the Veteran’s Health Administration are models of good practice of giving patients access to and control of their records.

Both paper-based and electronic access to patient records have been viewed positively in studies of patients’ experiences (Royal College of General Practitioners, 2010), with patients finding them useful, acceptable and easy to access (RCGP, 2010). In 2003, a NHS-commissioned survey of the general population (Health Which? & NHS National Programme for IT, 2003) found that the idea of having access to their health records was welcomed by the majority of those surveyed. The ability to see recent test
results, the ability to look at their medical history at any time, and the facility for a GP to book appointments at hospitals and clinics during the appointment was felt to be important by the greatest proportion of survey respondents (63%, 60% and 60% respectively). There is evidence that patients also generally “welcome the idea of adding to their records”, e.g. entering their blood pressure information (RCGP, 2010). Clinical professionals also appear to support patient record access – the ten principles for effective record access put forward by the Royal College of General Practitioners recommend that health professionals encourage patients to access their records; withhold information only in exceptional cases allowed by law; and develop tools to allow patients to access their records electronically (RCGP, 2010). However, the RCGP still says that “many health professionals” have concerns about direct record access, including the risk of inappropriate patient access to third-party information (RCGP, 2010).

4.1.1 Benefits and Opportunities

Survey Q4: What are the most important benefits of increasing patient control over their health records? (ranking each answer between 0 and 6)

![Average Ranking]

Higher quality clinical care: 4.24
Higher quality health records: 3.98
Increased patient self-management: 3.95
Increased accountability of services: 3.15
Increased efficiency of services: 2.99
Greater health promotion and prevention: 2.86

Interview Question #1: The government have proposed a step-change in making healthcare data more available to patients and the public. (a) What do you think would be the benefits of exposing more health data and information? (b) Would increased exposure of healthcare information drive improvements in the quality of information? (c) What do you think would be the challenges/risks of exposing more health data and information?

GP
• Exposure of information is wholly beneficial. His practice has given patients full access to their records for the past 5 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’.

Acute Hospital Consultant
• Patient access to their own records should be enabled – this already happens in antenatal care where the patient holds and carries the record and it is updated by clinicians. Also diabetic patients commonly have access to their records.

NHS Information Centre Professional
• Data views of patient level, aggregate and service/performance data need to be addressed separately – trying to achieve a combined approach is likely to muddy the situation as each category has different uses/benefits/concerns.

Independent Consultant
• Making patients partners in their care – shared responsibility, sensible decisions, and better detail/accuracy for clinicians. More patient involvement likely to lead to improved correctness/completeness.

Patient Representative
• Patients are enabled to take care of their own health; the point of continuity is the patient, who moves between different clinicians who don’t have the full picture and don’t
necessarily talk to each other. Patient-held records enable the patient to ensure that clinicians are able to take a holistic view of their care.

- Shared view avoids treatment duplication and waste, e.g. unnecessary repeat blood tests.
- Patients 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 by phone rather than requiring a visit.

Survey respondents perceived quality, both of health records and of health care delivery itself, to be the most important benefits of increasing patient control over their health records. Accountability and efficiency were seen as less important, while an improved public health function was considered the least important benefit. This is consistent with both the interviews and desk-based research findings.

The GP interviewee claimed that providing his practice’s patients with full access to their records for the past five years has been “wholly beneficial”, while a 2004 consultation of 100 Oxford-based patients viewing their on-line EMIS electronic records for the first time found that it was easy for patients to understand their records, although 42% requested explanations of medical terms (Pyper, Amery, Watson & Crook, 2004).

There is evidence that a system of ‘anytime access’ encourages good-quality record keeping, with the patient ability to review information that has been recorded about them having a rapid and positive impact on information quality (RCGP, 2010). The GP interviewee also reported improved accuracy and completeness of records in his GP practice. Public access to new types of information is reducing fraud and errors within credit data, analogous to patients identifying errors in their electronic health records. At least 70% of patients in the Oxford study found at least one error or omission (most of which were trivial, e.g. missing postcodes or outdated phone numbers), although 23% of patients found an error or omission that could be described as important (Pyper et al., 2004).

Another key benefit of patient record access is improved patient-clinician communication (RCGP, 2010). A number of studies with patients have shown that patients believe that electronic access improves their relationships with clinicians by breaking down barriers and improving their confidence in clinicians (RCGP, 2010). A study of patients who had direct access to their records over the Internet in Sweden also found it increased patients’ confidence and trust in physicians (Eklund & Joustra-Enquist, 2004). The Oxford study found it improved the doctor–patient relationship by improving consultations, reassuring patients, and encouraging them to be better informed about their own health and health care (Pyper et al., 2004).

Patient record access was also perceived by survey respondents as an opportunity for greater patient involvement in their care, which was also reflected by the GP interviewee. Patients perceive accessing their record as an opportunity to develop a “medical record that reflects their perspectives, fostering an environment of open dialogue and partnership, and supporting continuity of care” (RCGP, 2010). It is perceived by patients as improving the self-monitoring of long-term conditions, prompting when vaccination boosters are required and clarifying prescriptions (Pyper et al., 2004). Portable patient access to their health records, e.g. via a SmartPhone, could also be helpful in Emergency Departments (ED) and in other urgent care situations.

While the benefits of patient record access have been documented, the benefits afforded by direct patient ‘control’ of records have received less attention to date. Survey respondents demonstrated a preference for more practical functionality (ordering prescriptions, booking appointments and checking results) than, for example, the ‘ability to input into records directly’. Applicable learning from the desk-based research into other sectors indicates that the public will increasingly come to expect transactional public services to be available on-line, including in healthcare. The health service can learn from the experiences of other government functions by carefully considering what transactions could most usefully be carried out on-line.
and investing accordingly – a transaction or technology need not be expensive or complicated to provide a lot of value. Further evaluation of the benefits of other aspects of ‘control’ will be required.

4.1.2 Defining ‘Access’ and ‘Control’

Survey Q9: What should patient ‘control’ of their NHS-created health records (paper and electronic) include?
Survey Q10: Under what circumstances should health and social care professionals be able to limit a patient's control of their own patient record?

Survey Q11: Which electronic health records should patients be able to access?
Survey Q15: What electronic services would offer the most value to patients?
Interview Question #5: It has been suggested that patients should have more control of their records and influence over how their records are used. (a) What should 'more control' mean? (b) What do you think would be the benefits of giving patients greater control of their records? (c) What are the potential challenges/risks in giving patients more control?

<table>
<thead>
<tr>
<th>Responses</th>
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<tbody>
<tr>
<td><strong>GP</strong></td>
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<tr>
<td>• Patients should be able to copy, carry and share their records – his patients can access their records via internet using PC/iPhone etc. and can share these with who they like – this is a benefit when visiting A&amp;E or other care locations.</td>
</tr>
<tr>
<td>• The challenges and risks are more apparent than real – he has addressed these directly via his practice website. They have had no issues during the 5 years they have been giving patients access to their records. The barriers are attitudinal rather than legal or technical.</td>
</tr>
<tr>
<td>• Practices should not be able to ‘hide’ data – opt-out of information sharing can disadvantage patients and at worst could cover up misdeeds (his practice used to be Harold Shipman’s)</td>
</tr>
<tr>
<td>• Patients should be able to identify errors and request corrections / deletions but not make these changes themselves.</td>
</tr>
<tr>
<td><strong>Acute Hospital Consultant</strong></td>
</tr>
<tr>
<td>• Patients should be able to view their full record and share their records with whoever they wish – secondary care records as well as GP records, but some sections could be excluded such as third party data and other sensitive data.</td>
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<tr>
<td>• Web access would be beneficial, particularly to support treatment when away from home.</td>
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<tr>
<td><strong>NHS Information Centre Professional</strong></td>
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<tr>
<td>• Difficult question. Really needs to separately consider ‘who can see my data’ and ‘who can make changes to my data’ – e.g. corrections, deletions. Patient access needs to be supported by robust processes. We shouldn’t let patients edit out things that are correct but are ‘uncomfortable truths’.</td>
</tr>
<tr>
<td>• Some GP systems are already configured to support patient access.</td>
</tr>
<tr>
<td><strong>Information Professional</strong></td>
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<tr>
<td>• Access yes, but control is a dangerous term. Many parties, including the patient, are contributors to care records and these records serve a number of purposes – they are not just a ‘patient record’.</td>
</tr>
<tr>
<td>• Contributors should be able to edit and change their own part of the record but not others. Patients should have a right to add and change some parts of the record but do not have overall ownership and should not be able to block use of the record.</td>
</tr>
<tr>
<td>• Patients should be able to hold and share their records. Should be able to choose providers and carry records between them.</td>
</tr>
<tr>
<td><strong>Independent Consultant</strong></td>
</tr>
<tr>
<td>• Should not be able to directly edit records but should be able to exercise control of what is shared e.g. through sealed envelopes.</td>
</tr>
<tr>
<td><strong>System Supplier</strong></td>
</tr>
<tr>
<td>• Patients should be able to share what they like.</td>
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<tr>
<td>• Should be able to annotate/add information but not edit/delete entries made by others.</td>
</tr>
<tr>
<td><strong>Healthcare Professional Association</strong></td>
</tr>
<tr>
<td>• What should more control mean:</td>
</tr>
<tr>
<td>• According to Christine Connelly it means patients being able to say who has access to their record, but there is no context to this statement. Does it mean when a patient is admitted to a surgical ward they can block access to their mental health record? Does it mean a nurse whom the patient doesn’t like will be excluded from the record and his/her colleague won’t? This matter needs more debate and clarification.</td>
</tr>
<tr>
<td>• What do you think would be the benefits of giving patients greater control of their records?</td>
</tr>
<tr>
<td>• Some patients could benefit by feeling that they have more control over their life and being able to see all the information held within a record could facilitate their communication with clinicians. This is likely to be those with long term conditions, maternity patients and parents. The ability to request prescriptions and make appointments is one of the benefits most cited but doesn’t really mean the same as controlling. Access to information about immunisation history, screening and a summary would be beneficial for people who travel regularly but again doesn’t need full control.</td>
</tr>
<tr>
<td>• What are the potential challenges/risks in giving patients more control?</td>
</tr>
<tr>
<td>• Not all patients have the skills and access to IT so would need more support if they are not to be disadvantaged. In circumstances where clinicians and patients do not agree it has to be documented and this requires difficult discussion.</td>
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</table>
Survey responses for this research project showed general support for a wide range of actions to be available to patients with relation to their NHS-created health records. 20% of respondents felt that all suggested actions be supported. The ability to ‘Request that certain parts of their record be kept from general view’ was the most popular individual option (supported by 97% of respondents). Patients also believe they should have the right to give or withhold consent for professionals to access their electronic record (Pyper et al., 2004). The Oxford study identified three main views: “the majority wish to give access to all health professionals; a few want to give a general consent for doctors but have the option of giving specific consent for other health professionals, such as nurses and physiotherapists; and a very small number want to restrict access to named health professionals only”. The Health Which? and National Programme for Information Technology report also found that patients wanted to control the information available to other healthcare professionals (Health Which? & NHS National Programme for IT, 2003). However, interviewees pointed out it may be a challenge to limit access by specific named clinicians/staff to specific parts of individuals’ health records – is this degree of control really practical?

There was general recognition of legitimate limits to patient ‘control’ –, the majority of respondents believe that where there are legal (74%) or clinical (68%) reasons for limiting control it is appropriate.

‘Share records outside the NHS (whenever patient wishes, under any circumstances) only had 51% of respondents' support while to ‘Share records outside of NHS (for specific purposes, as agreed between patient and clinician)’ attracted far more support (81%), indicating that a sizeable cohort of stakeholders remains uncomfortable with the idea of fully relinquishing control of NHS-held records to patients or other third parties.

BCS event participants pointed out that health records serve a number of purposes, and therefore they are not solely a ‘patient’ record. For example, they may act as an aide memoire, a medico-legal record and a means to action transactions (BCS event summaries). The Health Foundation recommends in that so health records can continue to meet health professionals’ needs in caring for the patient (as they are a shared resource for patients and health professionals), patients should not be able to delete information from their record (The Health Foundation, 2009). However, The Health Foundation does believe that patients “should be able to make notes on their records, highlighting errors that can then be changed and challenging judgements” (The Health Foundation, 2009).
4.1.3 Delivery and Implementation

Survey Q14: How effective are the following media for engaging patients with regards to the following information?

**Patient’s own health records:**

![Graph showing effectiveness of different media for engaging patients with their own health records.]

Survey Q16: What investments would most effectively support patient control of their electronic records?(ranking between 0 and 6)
Interview Question #3: What actions, services or system changes do you think would be required to engage patients, the public, clinical professionals, management and others in the proposed ‘Information Revolution’?

**GP**
- His practice has taken a proactive approach in engaging patients through talk sessions, on-line videos, a patient representative group.

**Acute Hospital Consultant**
- 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.

Patient access to their health records could be achieved by a number of means, including paper records, spoken presentation of the record contents in the consulting room or clinics, through touch screens in waiting rooms, or by logging into electronic information systems. Patients may choose to access their records in many environments, e.g. at home, in GP practices, hospitals or community clinics, pharmacies, or libraries, and be either alone or with family, carers or others. Other media that may be increasingly available for accessing electronic records include kiosks (in a variety of settings) or via mobile phone, MP3 or iPod (RCGP, 2010). However, survey results reflected a degree of uncertainty as to how effective these new tools would be in engaging patients with their health records. Face-to-face communication was considered by survey respondents to remain the most effective way of communicating information about patients’ records to them. This could be a reflection of two things: that people remain stuck in the familiar ways of doing things, or that traditional face-to-face communication is simply the most effective way of communicating. In the field of economics there is debate about whether information technology can be used to “store and reproduce information” so that more people to gain knowledge without the need to interact with more knowledgeable individuals (Mansell, 2008). Kerr et al. (2007) argues that while converting data into information is generally an “explicit, repeatable and easily conveyed procedure”, generating knowledge from information is more difficult and frequently consists of “tacit processes” that are more difficult to replicate.

4.1.4 Challenges and Issues

As with exposing information about health services, there are many challenges associated with the patient record access and control agenda.

**Interview Question #1:** The government have proposed a step-change in making healthcare data more available to patients and the public. (a) What do you think would be the benefits of exposing more health data and information? (b) Would increased exposure of healthcare information drive improvements in the quality of information? (c) What do you think would be the challenges/risks of exposing more health data and information?

**Acute Hospital Consultant**
- Information Governance as currently applied as a barrier to increased availability and sharing of data. The UK healthcare approach is wrongly modelled on the banking paradigm of personal control that doesn’t allow other to access. Healthcare needs a partnership approach around a shared record to facilitate team working and rapid response.

**NHS Information Centre Professional**
- 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.
- Personal data – will only be seen as valuable if available at the right level of detail. SCR and HealthSpace not seen as useful by those who have engaged as too little on there to be of real use.

**Independent Consultant**
- The challenges are how to handle sensitive data and using appropriate terminology. Information needs to be provided in appropriate format – plain English where appropriate, but clinicians must be able to use professional terminology and shorthand – patients who are engaged soon learn what they need to if there is appropriate engagement.

**Patient Representative**
- Aware of concerns about potential misuse/confidentiality concerns, but thinks this is no different to other areas of life where we accept that we must share data to get a service,
In addition to the challenge of actually defining patient ‘control’ of health records, ensuring that all patients can take advantage of the benefits of accessing their health records, including those who may not currently have the computer skills to do so is a challenge. The real-world challenges faced by Kaiser Permanente in their implementation of ‘e-Clinical Services’ are illustrative: cultural issues, with clinicians reluctant to include patients and resistance to using e-mail; technical issues, particularly the integration of disparate information systems into an integrated view; and process issues, in this case, the logistics of assigning user log-ins and passwords (Sittig, 2003).

While improved clinician-patient relationships are one benefit of patient record access, some health professionals are concerned about its impact on the duration of consultations (RCGP, 2010). ‘Increased time demand on the clinician-patient interactions’ was identified as a ‘moderate’ or ‘major’ challenge to ‘making the health system information-driven’ by 69% of survey respondents, which may apply both to sharing information about health services and to patient access to and control of records. As suggested by the GP interviewee, the experiences of those who already provide patients with electronic access could provide some recommendations for overcoming this challenge.

Many patients have concerns about receiving new information, especially if it contains abnormal results or bad news. The majority would prefer bad news to be held back until they could be informed directly by a health professional. (Pyper et al., 2004), again demonstrating the continuing value of face-to-face communication.

A three-year evaluation of HealthSpace concluded that patients perceived the application as neither useful nor easy to use and its functionality aligned poorly with their expectations and self management practices. Patients were disappointed with the amount and type of data available, the need to enter data themselves, and the limited options for sharing these data with their clinician (Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2010). Policy makers’ ambition for HealthSpace to lead to “empowered patients, personalised care, lower NHS costs, better data quality, and improved health literacy” were not achieved over the duration of the evaluation (Greenhalgh et al., 2010). This failure does not negate the overall value of web-based patient records (in fact, survey respondents identified web-based patient records as the most effective investment to support patient control of their records), but it does indicate that the specific functionality and usability of these applications will impact on their effectiveness and their ability to realise predicted benefits.

4.1.5 Conclusions

Although opportunities for patients to view their health records have increased, uptake is fairly low, with many patients relying on their care providers to provide face-to-face information (RCGP, 2010). However, there is evidence that providing direct patient record access improves the quality of health records, improves relationships between doctors and patients, and increases patient self-management of their condition(s). As with increased access to information about health services, some people do not believe that there would be any benefit in seeing their health records (Pyper et al., 2004). This is only natural, as people’s preferences will vary, but highlights that patient access to and control of their records is not a panacea.
There is an ongoing debate about what exactly patient ‘control’ means – it may be a useful shorthand term, but as the survey results indicate, there are a variety of perspectives about what it is really shorthand for, for example, only 51% of respondents thought patients should have the right to freely share their records outside of the NHS. When a clinician records some information on a patient and references family members or others, the question arises whether it is still a patient record (BCS event summaries). Both patients and clinicians have distinct roles and responsibilities with respect to health records. The BCS event summary recommended that the debate move on from discussion around “control” and “ownership”, and focus on “obligations”, “uses” and “rights” (BCS event summaries).

The Health Foundation has pointed out that “giving patients control over their health records is necessary but not sufficient to shift the balance of power within the health sector from the service provider to the patient” (The Health Foundation, 2009). Control of patient records needs to be seen in the context of clinician-patient relations – the debate about patient records is therefore also about the model of care (The Health Foundation, 2009).
5. Cross-Cutting Themes

5.1 Data Quality and Confidence

The issue of data quality cuts across both information about health services and patient control of health records. For example, most information about health services is built up through the aggregation of information about individual patient episodes of care and health record data. The DH Informatics Review in 2008 found that the quality of data in the NHS is not consistently adequate to “support policy, service planning, commissioning and performance management decisions” (NHS Information Centre, 2009). In many cases, data is collected but is difficult to access and does not generate information for decision-making (National Quality Board, 2010). A 2002 Audit Commission report attributed poor data quality to the NHS organisations that collect, record and process health data, finding that data quality has been viewed “with disinterest by clinicians and managers”, and left to Informatics professionals to resolve (Audit Commission, 2002).

There have been several investigations into the quality of information in the NHS (DH, 2004) as well as strategies for improving it. The DH has stated its commitment to developing confidence in information provided through all systems, with measures such as a quality grading scheme to support the assessment of data quality and to support quality grading all national information reporting (DH, 2004).

Interview Question #2: What needs to be done to improve confidence in healthcare information? (a) For clinicians and other healthcare professionals? (b) For patients and the public?

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<th>Responses</th>
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<tr>
<td>GP</td>
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<tr>
<td>• Patient empowerment - Make records available to patients, encourage patients to look at available standards such as Map of Medicine so patients can see that their treatment is in line with best practice and are equipped to discuss their care with clinicians.</td>
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<tr>
<td>• Drive quality through incentives – QOF has been the driver for improved completeness and quality of GP recorded data – but there is a danger that non-incentivised stuff gets sidelined (e.g. no incentive to record osteoporosis data as there is no link to payment).</td>
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<tr>
<td>Acute Hospital Consultant</td>
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<tr>
<td>• Lack of confidence in general healthcare data tends to be about how it might be used/misused – it’s often more about having confidence in the organisation than about the data itself.</td>
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<tr>
<td>• Engagement with patients and development of a partnership position where patients have trust in the care team. Encouraged by giving patients the ability to question and ask for corrections/updates to records.</td>
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<tr>
<td>NHS Information Centre Professional</td>
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<tr>
<td>• Aggregate and service data should be generally available but must be supported by proper explanation and qualification (e.g. confidence limits) if it is to be useful.</td>
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<tr>
<td>• Data quality needs to be enforced at point of collection through data standards, validation and enforcement, e.g. an enforced requirement to complete mandatory items.</td>
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<tr>
<td>• 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.</td>
</tr>
<tr>
<td>Information Professional</td>
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<tr>
<td>• Information presented must be at the appropriate level and format for its intended usage.</td>
</tr>
<tr>
<td>• There is a systemic problem with healthcare information systems in English healthcare in that information for management is expected to be derived from information collected for care delivery. In other countries/settings management systems are separate and more fit for purpose.</td>
</tr>
<tr>
<td>• Long term aim should be to keep running current systems but develop future system in parallel – real time care pathway data to support patient care, management systems to support operational planning and delivery.</td>
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<tr>
<td>Independent Consultant</td>
</tr>
<tr>
<td>• Culture must value information.</td>
</tr>
<tr>
<td>• Information needs to be fit for purpose and not seen as a threat – danger of</td>
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Many dimensions of data quality (and or information quality) have been identified in the literature, the majority of which are entirely applicable in the healthcare setting and need to be considered. The key message emerging from the desk-based research is that data and information should be presented at the appropriate level and format for its intended usage, including metadata, i.e. that it be ‘fit for purpose’ (Australian Bureau of Statistics, 2009).

While data quality may be poor in the NHS, it will not prevent the intended publication of health data. The more information is used the better its quality will become – those analysing data for information are often the first to identify when it isn’t fit for purpose (Kerr et al., 2007). Clinicians and managers need to see a clearer link between the data they collect and the information they receive and react to in return – increased use of health data and information may help create this incentive for improved data collection, management and presentation, leading to a culture in the health service that does value information.

Ultimately, although data quality and user confidence in data quality is important, the greatest confidence issue may be related to the health service itself, i.e. confidence in the quality, safety and efficiency of its services, and this being more transparent to public scrutiny, rather than in the quality of the data it produces.

### 5.2 Privacy, Security and Information Governance

While security and confidentiality issues were not explored directly in the survey or interviews, the desk-based research and the BCS events raised some considerations. Current relevant legislation and regulations have been built around a paradigm where data is collected for known and specific purposes, including the Data Protection Act. Participants of the first BCS event concluded that the UK and Europe need to take a fresh look at data sharing legislation and regulation so that it can accommodate newer paradigms of sharing information. There is existing guidance on information-sharing, including guidance from the Information Commissioner (The Information Commissioner’s Office, 2010), the Department of Schools, Families and Education (HM Government, 2008), and the British Medical Association toolkit (BMA, 2009). The DH also has an ‘Information Charter’, which identifies the standards that patients can expect with regards to how it manages patients’ personal information (DH, 2010e). However, advances in technology and information-sharing capacity are raising new issues. For example, the use of the Health Analytics application in Outer North East London to stratify patients by their risk of illness has raised issues around what level of patient consent is required when previously disparate datasets are joined, and whether successfully identifying patients ‘at risk’ by doing so constitutes a primary or a secondary use of data (BCS event summaries). Clarification is also required as to whether it is legitimate to re-identify the patient without consent when new concerns are coincidentally discovered in pseudonymised datasets. There are several separate consultations underway that are relevant to health data sharing, including the Information Commissioner’s proposed Data Sharing Code of Practice.
There is a degree of debate as to the level of concern amongst the public about the security of their health
data. The Health Foundation (2009) claims that “clinicians and NHS managers are consistently more
cconcerned about the impact on security and confidentiality of patient access to their health and care record
than are patients”, and the RCGP reports on a study that found although patients have some concerns
about accessing their records over the Internet, security issues weren’t a significant concern (RCGP,
2010). Previous research has shown that patients are concerned about issues of security but this appears
to be a “minority issue” (RCGP, 2010). However, Pyper et al. (2004) claim that many of their study
participants were concerned about data hacking. While maintaining the confidentiality of their health
information is an expectation of patients and the public, but a range of incidents of lost confidential patient
information are reported across the NHS annually, including both paper-based and digital information. In
2008 Norman Lamb, MP and former Liberal Democrat Shadow Health Secretary, claimed that the health
service is “among the worst offenders for data loss, reporting as many incidents as the entire private
sector” (Russell, 2008). In June 2010 the Information Commissioner’s Office (ICO) published a list of the
1,007 breaches since 2007, of which 305 were the responsibility of the NHS (Jowitt, 2010), indicating that
despite an apparent low level of public concern about security and confidentiality of health information, the
risk of accidental exposure still remains. Unfortunately there is a tension between providing a ‘joined up’
public service and integrated health services, and reducing the risk of accidental disclosure of patient
information. For example, the WikiLeaks exposure of US embassy cables wouldn’t have been possible if
the US government had not implemented a shared system to improve communication amongst its staff.

5.3 Private Sector Involvement

The Government has indicated that they do not intend to provide additional funding and investment to
support their vision. Rather, they are exploring new models that involve partnerships with industry, and
thereby plan to attract a wider range of information providers (DH, 2010a). Embracing this ‘any willing
provider’ model creates new risks and potential conflicts related to the ownership of and access to patient-
level data. Firstly, while the Government wants to encourage multiple providers of service information, the
National Quality Board recently found that currently “responsibility for collecting data is spread across
different organisations, resulting in duplicate responsibilities, and clear scope for rationalisation” (National
Quality Board, 2010). Increasing the number of information providers could simply duplicate activity further
without simplifying anything. Secondly, as patients and users are given control of their records, the market
is expected to develop new products to bring together information they need in a suitable format.
Sustainable business models will need to be developed to enable this. However, ‘access to information
limited by ability to pay’ was considered unlikely by survey respondents, indicating that a user-subscription
model is not anticipated by stakeholders. (There is also a general sense that patients should not incur any
financial costs in accessing their health records (RCGP, 2010)). What other business models are available,
and how publicly acceptable would they be? For example, how appropriate would the public find
advertising-based models for delivering increased information about health services and/or patient health
records? A degree of caution about the role of the commercial sector is reflected by the survey
respondents. In addition to the acceptability of new business models, third-party providers may introduce
further ‘spin’ or move away from a public-spirited approach to information provision. In addition, could
private companies having access to patients’ health record data then cross-reference this information with
their other commercial databases and interests? Is the legal framework in place to protect against this if
required? Sharing data and information more widely between providers and across sectors increases the
risk of accidental confidentiality breaches, breaches or data losses which can’t generally be ‘undone’.

The public itself may be concerned about their data being managed by private providers. Pyper et al.
(2004) found that patients were concerned about the potential commercial exploitation of their data,
particularly the potential for non-medical staff, other public sector service providers, employers, insurers,
computer hackers, etc., to access their data. They wanted to “trust the process of anonymisation” and to be assured that if the NHS sold their data the “revenue would be used to benefit patients” (Pyper et al., 2004). If the role of the private sector in providing health information expands in line with Government intentions there will be a number of consequences in terms of patient confidentiality, patient control of records, and sustainable business models to deliver new services without incurring direct patient costs.
### 6.1 Key Findings

The following key findings have been identified from across the various streams of research:

<table>
<thead>
<tr>
<th>Key Findings</th>
<th>Source</th>
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<tr>
<td>The greatest anticipated benefit of exposing information about healthcare services to scrutiny is improved quality of care while the least important benefit is increased patient choice (implying that the mechanism by which transparency improves quality is not simply through enabling patient choice).</td>
<td>Survey, interviews</td>
</tr>
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<td>The latest review of evidence for using publicly reported performance data to improve quality concluded that publicly releasing performance data stimulates quality improvement activity at the hospital level but that the overall effect of public reporting on effectiveness, safety, and patient-centeredness outcomes remains uncertain.</td>
<td>Desk-based research</td>
</tr>
<tr>
<td>All discourse about making information ‘mission-critical’ in the NHS should clarify what type of information is being referred to (e.g. financial, performance or quality information about health services, population health, clinical conditions or patient records), and at what level of aggregation (e.g. individual patient or clinician, organisation, or region).</td>
<td>BCS events</td>
</tr>
<tr>
<td>People making choices about their medical treatment want information about the individual doctors (or teams) who treat them, information about their condition, and information to help them understand the risks associated with attending particular hospitals.</td>
<td>Desk-based research</td>
</tr>
<tr>
<td>Face-to-face communication and web-based tools are the best methods for communicating information about health services, while GPs and GP practices are the most natural starting point for doing so.</td>
<td>Survey, interviews, desk-based research</td>
</tr>
<tr>
<td>How information is presented to users is critical, and more information is not always better – there are a variety of information standards and data quality frameworks that can guide information providers.</td>
<td>Survey, interviews, desk-based research</td>
</tr>
<tr>
<td>The greatest challenges to making information ‘mission-critical’ are cultural rather than technological, encompassing both the organisational culture within the NHS and the public’s engagement in using healthcare information.</td>
<td>Survey</td>
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<tr>
<td>Greater flexibility to share information and greater health informatics competencies (across the whole workforce) are the most important factor for making the NHS information-driven, while more health information systems are the least important.</td>
<td>Survey</td>
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<td>The most likely risks for information being ‘mission-critical’ are that the NHS</td>
<td>Survey</td>
</tr>
<tr>
<td><strong>Key Findings</strong></td>
<td><strong>Source</strong></td>
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<td>and the public will lack the capacity to process and make optimal use of information available. However, while it is considered likely, information overload for patients and the public would not have a major negative impact.</td>
<td>Survey</td>
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<tr>
<td>The risks representing the greatest potential negative impact are those related to fraudulent, unethical or unsafe activity, including data recording practices that obscure or adjust the true meaning of information.</td>
<td>Survey</td>
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<td>There are many benefits to patients accessing their own health records, including improved data quality, improved clinician-patient relationships, and increased patient self-management capacity. There is less evidence about the benefits of patient control of their records, although &quot;patient control&quot; as a label has different meanings to different audiences at present.</td>
<td>Survey, interviews, desk-based research</td>
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<td>There is greater interest in patients being able to perform practical transactions on-line with regard to their health record or care (e.g. check results, exchange emails with their clinicians) than in performing actions associated with ‘control’ (e.g. sharing records with other providers, inputting data directly).</td>
<td>Survey, desk-based research</td>
</tr>
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<td>There is general support for a wide range of decisions to be available to patients in relation to their NHS-created health records, including that patients be able to request that certain parts of their record be kept from general view.</td>
<td>Survey</td>
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<td>A sizeable cohort of stakeholders remains uncomfortable with the idea of relinquishing control of NHS-held records to patients so they may share their records with third parties without restriction.</td>
<td>Survey</td>
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<td>Health records serve a number of purposes and therefore they are not solely a ‘patient’ record, including aide memoire, a medico-legal record and a means to action transactions.</td>
<td>Interviews, desk-based research, BCS events</td>
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<td>Face-to-face communication is the most effective way of communicating information about patients’ records, while web-based patient records and the availability of expert support available by phone to interpret information for the public will most effectively support patient control of their records.</td>
<td>Surveys, interviews, desk-based research</td>
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<td>‘Access’ and ‘control’ of records are different issues, and it would be beneficial to move from the terms ‘control’ and ‘ownership’ to a focus on ‘obligations’, ‘uses’, and ‘rights’. Control of patient records needs to be seen in the broader context of clinician-patient relations and the model of care.</td>
<td>Desk-based research, BCS events</td>
</tr>
<tr>
<td>Many dimensions of data quality (and or information quality) have been identified in the literature, the majority of which are applicable in the healthcare setting. The key requirement is that data and information should be presented at the appropriate level and format relevant to its specified purpose.</td>
<td>Survey, interviews, desk-based research</td>
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### Key Findings

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<th>Key Findings</th>
<th>Source</th>
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<tr>
<td>While data is currently of variable quality in the NHS, this will not prevent its intended publication. However, data quality is expected to improve as data and information is examined and used more widely.</td>
<td>Desk-based research</td>
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<tr>
<td>Advances in technology and information-sharing capacity and new models of information provision are raising new issues related to information security and patient confidentiality, particularly in an increasingly plural market of public and private sector providers and intermediaries.</td>
<td>Desk-based research, BCS events</td>
</tr>
<tr>
<td>Clinicians, managers, GP practices, information professionals and the public would all benefit from tailored education about how to access and use health information.</td>
<td>Interviews</td>
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### 6.2 Discussion

The thinking about the role of data and information in the NHS is rapidly changing due to arguably the most significant restructuring of the NHS since 1948 and the ever-evolving world of digital technology. The Government has articulated an ambitious vision for expanding the use of information across the NHS, from exposing more information about health services in order to drive improvements in quality, to more direct patient control of the content and use of their NHS-created health records, both paper and electronic. The Government claims that this “revolution” is needed so that what is currently seen as good practice in various pockets of the NHS will become standard practice throughout (DH, 2010a). In addition, public expectations about their ability to perform relatively basic transactions (e.g. schedule an appointment) on the Internet can be expected grow in line with general trends across society, increasing pressure for the NHS to leverage modern technology and be more accessible in its delivery of services. However, it is probably increased exposure of information that is the most fundamental aspect of this vision, and to making information ‘mission-critical’ to the NHS, although there are concerns about whether the current quality of health data is adequate for meeting the Government’s ambitions.

BCS Health believes that improving the use of information and technology in the NHS is critical to driving quality and productivity improvements. The market research found that other stakeholders feel there are a significant number of risks and challenges inherent in achieving the full vision of an ‘information revolution’. However, it also found that there are examples of successful information-sharing, exposure and patient record access, both within the UK and internationally (and from other sectors, particularly around providing web-based services). There are also examples of controversial information exposure – including parliamentary expense details, Gap clothing labour conditions, climate change academics’ approach to sharing complex research, and American Foreign Service reports, all of which have led to changes in practice, some of which have been positive (e.g. improved labour conditions, increased clarity about the appropriate use of taxpayer money to support MP’s lifestyles while in office), and others which have been more mixed (e.g. ‘Climategate’ decreasing public confidence in scientific warnings about global warming; school league tables in England improving pupil performance but risking a more narrow approach to education). The impact of increased transparency about health services in England can be anticipated to be equally mixed, although survey respondents and interviewees appear to support it overall as delivering a net improvement on quality of care.

The research also shows that the health service is not unique – more data and information is being made available across many sectors internationally, and there is an appetite among some members of the public...
to review this information and to use new technologies to access and analyse it. The literature also provides some evidence about how people interpret different types of information (e.g. based on who is providing, its degree of complexity, etc.), and this may be useful for the health service to consider.

In today’s changing NHS landscape, access to data and information will become increasingly more important to GP consortia in making healthcare commissioning decisions for their populations. GPs have a central role to play in delivering the “information revolution”, as they do in delivering other key aspects of the Government’s agenda. They will require increased efficiency in accessing data through the linking of healthcare systems to connect relevant information together, i.e. connecting appropriate systems in Primary Care, Secondary Care, Mental Health and Social Care. There have been many valued developments in information technology and management in the health service in recent years which have led to an infrastructure that can be leveraged to support this integration and information-sharing ability.

The NHS is a complex system of organisations and interest groups, and subject to a high degree of media and political attention. It is easy for validated information or thoughtful objective analysis to be sidelined in favour of spin or headlines. While technology has changed significantly, there has always been a tension between secrecy and openness (Kettle, 2010), which is reflected in the Secretary of State Andrew Lansley’s recent refusal to reveal the DH’s risk register for the planned NHS restructure (Campbell, 2011), which seems to contradict the purported transparency agenda. Questions remain about the Government’s degree of commitment to the ‘information revolution’, particularly without additional funding. As one survey respondent suggested, if it were a true commitment, “there would be root and branch support for investment in information systems”. Time will tell whether the Government prioritises making the changes required to overcome the challenges and realise the benefits of truly making the NHS ‘information-driven’. The evidence suggests that the ‘information revolution’ is possible, with the right incentives and investment to create the capacity and focus required to achieve the vision.
Appendices

Appendix A. References

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Appendix A. References


http://www.jdi.ucl.ac.uk/news_events/conferences/past_conferences/fourth_nat_map_conf/fourth_nat_map_abstracts_full.php


