

National study

The right information, in the right place, at the right time

A study of how healthcare organisations manage personal data



September 2009

About the Care Quality Commission

The Care Quality Commission is the independent regulator of health and adult social care services in England. We also protect the interests of people whose rights are restricted under the Mental Health Act.

Whether services are provided by the NHS, local authorities, or private or voluntary organisations, we make sure that people get better care. We do this by:

- Driving improvement across health and adult social care.
- Putting people first and championing their rights.
- Acting swiftly to remedy bad practice.
- Gathering and using knowledge and expertise, and working with others.

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Summary

Why did we carry out the study?

Healthcare organisations in England handle large amounts of personal information every day, including information about patients and some 1.4 million staff. The good management of personal information is crucial to the delivery of high quality healthcare.

Good information governance means having efficient and effective structures, policies and practices in place to ensure the confidentiality and security of the records of patients and service users. In this study, we looked explicitly at the quality of information and how information about individuals (both clinical and non-clinical) is used to shape their care, because these are also key measures of good information governance and have an impact on the quality of care that patients experience.

Our approach

Our study looked at information governance in healthcare organisations in light of increased awareness of its importance and issues beyond the headlines generated by recent breaches in data security. The study aimed to:

- Analyse the performance of healthcare organisations in relation to information governance, to identify those parts of the health service that comply with good practice and those that perform less well.
- Analyse and describe how information governance has changed between 2006 and 2009.
- Analyse and describe those elements of information governance that affect the quality of care for patients.

- Identify how organisations overcome the barriers to managing personal information effectively.

We looked at all NHS trusts in England and some selected healthcare organisations in the independent sector (those that provide care predominantly for NHS-funded patients). We examined national data to see what organisations have said about their own information governance systems, and we listened to the views of patients, carers and voluntary organisations (that advocate on behalf of patients). We also visited selected healthcare organisations to explore in more detail the barriers to good information governance.

This report reflects the work carried out by the Healthcare Commission up to March 2009. However, it links closely with the approach that the Care Quality Commission will be taking to join up care for people. We want to see different services – across health and social care – working together to join up each person's care, so that they have a positive experience of care and their outcomes are improved. In this study, and others carried out this year, we identified weaknesses in the provision of information about a person's ongoing care needs when they are transferred between care settings (for example, delays in sending information to GPs after discharge from hospital). It is important that timely and complete information is provided to people, their family or carers, and to health or social care services when they are transferred, so that every person can be given the ongoing care they need. This should be done with regard for people's right to confidentiality and with appropriate consent.

Key findings

Meeting basic standards and the more detailed aspects of information governance

Most NHS healthcare organisations have improved their systems and processes for managing personal information between 2006 and 2009. However, while the basic systems may be in place, some of the more detailed elements that help to ensure safe, high quality care, are missing.

In the NHS, the performance of primary care trusts (PCTs) and ambulance trusts is generally lower than that of acute (hospital) trusts and mental health trusts. In particular, it is of concern that 22 out of 152 PCTs (14%) and two out of 11 ambulance trusts were unable to comply with at least one of the basic information governance standards for more than one year between 2006/07 and 2007/08.

The NHS operating framework 2009/10 recognises the important contribution of good information governance systems to the efficient delivery of healthcare. The framework sets out 25 questions that all providers of NHS-funded healthcare are expected to meet by March 2010. We found that at March 2009, the majority of NHS trusts (about 70%) did not meet all of these requirements and will therefore have to improve aspects of their information governance to meet this goal.

Both NHS and independent sector organisations need to improve the way they manage patients' medical records. In the NHS, problems relate to how records are stored and disposed of. In the independent sector, there are deficiencies in the detail recorded in patients' records, particularly the multi-disciplinary records in mental health care settings. Incomplete or inaccessible information is a risk to the quality and safety of care for patients.

In general, we found that all organisations met the basic standards on seeking consent to share patients' information and on keeping information confidential.

The right information – improving the quality of data

Information governance is about managing information for the benefit of patients, and the quality of that information is just as important for their care and for the funding of organisations (where payment for patient care is dependent on the accuracy of information collected on the number and type of procedures carried out) as the systems that manage it.

Some areas of healthcare, such as mental health, have improved the quality of data they collect and provide. But overall performance is patchy. While an organisation may provide data of adequate quality overall, it is too often the case that some departments or services within that organisation have inadequate data and systems. In addition, some mandatory data sets, such as the Mental Health Minimum Data Set, are submitted incomplete.

To improve the quality of care and choice available to patients, the Government has encouraged a wider range of organisations to provide services (including NHS social enterprises, independent sector and voluntary organisations). However, the systems for collecting and analysing data from these different sectors have developed separately, and this has hampered comparisons of performance between them.

Information in the right place – keeping information confidential

The confidentiality of personal information has been the subject of media and policy interest.

The NHS staff surveys have showed that most staff (over 80%) are confident that patients' information is treated confidentially in their organisation. However, 30% of staff (40% in ambulance trusts), report that they have not been trained to handle information confidentially.

Furthermore, NHS patients and staff have differing views of how well organisations ensure confidentiality. Approximately 30% of patients say they were not always given enough privacy when they discussed their condition or treatment. The

patient groups we spoke to also expressed concern about staff discussing patients in open plan offices, corridors and lifts, or being able to see patients' details written on notice boards in wards.

Information at the right time – sharing personal information effectively

Sharing personal information effectively is a fundamental part of an integrated healthcare system. The most common concern we found was the need for hospitals to improve the quality and timeliness of information sent to a patient's GP when they are discharged from hospital. Most GPs who responded to a survey conducted by the NHS Alliance believed that this compromised the safety of patients.

When we visited healthcare organisations, we found support for the principles of sharing information between health and social care providers, but there were technical and cultural barriers to this. Some healthcare staff perceived social care staff to be working to different protocols, which made sharing information problematic. Patients have reported that they are happy for their medical information to be shared with other healthcare professionals, but some are less willing for information on their health to be shared with social care professionals.

There is some evidence that sharing information is made easier by being clear about the level of information to be shared, who it will be shared with and for what purpose (for example, is it demographic data or information on medical conditions such as HIV status or mental health history?).

The right information, in the right place at the right time – using information to personalise care

Generally, organisations do not systematically use information that may be unrelated to a patient's clinical needs to tailor their care to their individual needs or those of their family. For example, when partially sighted patients request that correspondence is provided in large print, it is rarely supplied in this format. However, there are notable exceptions, with some mental health providers (NHS and independent sector) who appear to have an ethos and systems that are tailored to the needs of individual patients. For

example, they ensure that outpatient appointments are arranged in appropriate facilities if patients have mobility difficulties, or that they are seen only by male or female staff because of the nature of their mental health condition and experience.

Failure to use personal information in this way can result in poor quality care, including delays in getting care (through missed appointments) and loss of privacy and independence (if carers need to read letters or accompany patients to an appointment). Fundamentally, we found that this was an area of healthcare that is not viewed as part of the 'mainstream' information governance agenda.

Overcoming the barriers to managing personal information effectively

We identified some common barriers to managing personal information properly. These relate to the impact of organisational change, conflicts between good information governance and national guidance and systems, the responsiveness of nationally-developed systems to local conditions, the information governance issues that are national priorities, investment in staff and technology, the condition of local information governance networks and cultural and technical barriers to sharing information.

Summary of recommendations

Healthcare providers and commissioners

- Senior managers (including those at board level) should include a wider range of performance indicators in their board assurance framework and reports that cover data quality and assurance, as well as monitoring the timeliness of data submissions.
- Providers and commissioners should develop their information governance systems in partnership with the patient and public groups in the organisation. The information governance team (including the Caldicott Guardian) should be held accountable for developing these systems and monitoring whether they are delivering personalised care consistently.

- All healthcare providers need to understand how their staff perceive the risks of breaching information governance rules. They should use this information to make sure that staff understand the risks and consequences of poor information governance by tailoring the training for staff accordingly.
- Commissioners should ensure that their process for tendering and monitoring contracts with providers improves the quality of care for patients by including appropriate measures of personalised care.
- Commissioners should also make sure that assurances on confidentiality training and competence are included as part of the process for tendering and monitoring contracts.
- All organisations that develop national guidance and systems that may impact on information governance should consult the board. This would help to minimise confusion and establish the board as an authoritative central source of guidance on information governance issues.
- The board should help to promote the efforts of the Information Centre to harmonise the data collected from NHS and independent sector providers to ensure that patients have the data needed to make informed choices about their care.
- The board should promote transparent central analysis and reporting of incidents related to the management of personal information.

Strategic health authorities (SHAs)

- SHAs should revitalise local information governance networks to help improve cooperation between healthcare organisations (both NHS and independent sector) and other organisations.

Local involvement networks (LINKs)

- LINKs could improve considerably the quality of care, and patients' experience of care, by campaigning for the better use of patients' information. They should develop and monitor measures to ensure that good practice is developed with particular groups of patients (perhaps with specific groups of service users) and that this is embedded throughout the healthcare organisation.

The National Information Governance Board for Health and Social Care

- This board should advise on the technical and cultural barriers to staff working together across health and social care sectors. It should explore the attitudes and concerns of patients about sharing information between these sectors. It should develop practical models for implementing information sharing agreements throughout the wider health economy.

Connecting for Health

- Should continue to develop the tools that support the performance assessment and management of information to reflect patient care pathways (for example, mental health services) and outcomes for patients such as the safety and quality of care.
- External validation and audit (by NHS internal audit or external auditors) of healthcare organisations' self assessments using these tools should be mandatory.

The UK Council of Caldicott Guardians

- Should encourage all health and social care organisations to have a designated Caldicott Guardian working as part of a wider information governance team. Caldicott Guardians should try to understand the reasons why patients and staff view confidentiality of personal information differently. This should help to shape appropriate training for staff and contribute to a shared understanding with patients of the issue of confidentiality.

Regulators

- Should include the quality of local information within their performance assessments and whether and how personal information is transferred across care pathways for the benefit of patients.

Introduction

“Information is a key asset, and its proper use is fundamental to the delivery of public services”

Handling information risk, Cabinet Office letter on data handling procedures in Government, 6 March 2008.

Having access to accurate personal information and sharing it securely and efficiently is essential for the high quality healthcare we expect. The good management of personal information also underpins the Care Quality Commission’s vision of high quality care that:

- Is safe.
- Has the right outcomes, including clinical outcomes.
- Is a good experience for the people who use it, their carers and their families.
- Helps to prevent illness, and promotes healthy, independent living.
- Is available to those who need it, when they need it.
- Provides good value for money.

It is worth considering the vast scale of the health system and the amount of information involved in providing this care: during 2007/08, there were over 14 million first outpatient attendances in hospitals in

England. In a typical week, 1.4 million people receive help in their home from the NHS.¹ In total, 1 million people see someone in the NHS every 36 hours.² Care pathways for patients may involve different organisations, including advice provided over the phone, care from staff in GP practices or healthcare staff outside the NHS in services run by independent healthcare providers and staff who are part of the social care sector employed by local authorities or voluntary sector organisations.

Advances in technology, such as telemedicine, mean that patients can access care such as radiology from specialists who may not be in the same physical locality as the patient. High quality medical images can be transmitted via high speed computer networks from the patient to the specialist.

It is not only patients’ information which is stored or shared. The NHS is one of the world’s largest employers with close to 1.4 million employees, and the personal details of each of these people must also be managed effectively.

The volume and complexity of information managed by an increasingly mixed economy of healthcare organisations is impressive. However, the systems and processes needed to manage personal information must continue to develop in order to keep pace.

In this context, the National Programme for IT (NPFIT) aims to deliver computer systems and services that improve how information about patients is stored and accessed. NPFIT is a 10-year programme launched in 2002, the core element

being the NHS Care Records Service. The Programme also includes many other elements, including X-rays accessible by computer, electronic transmission of prescriptions, and electronic booking of first outpatient appointments. These systems have the potential to provide patients with access to their electronic patient record and diagnostic test results, their personal care plans and tools to help support improved 'self-care'.

The way in which personal information is handled by Government departments and agencies and private organisations is a high profile issue. The watershed moment came in November 2007, when two unencrypted disks containing the personal details (including bank details) of 25 million people appeared to have been lost by HM Revenue and Customs. Following this, reviews of data handling across Government have identified duties and deadlines for compliance with specific information governance systems, and processes and policies across public services, including the NHS. The final report of the review of data handling procedures in Government was published in June 2008. The Department of Health has made clear its expectations of NHS trusts and other health bodies through a series of letters to chief executives.³

The structures, policies and practices that are used to ensure the confidentiality and security of personal information are collectively called information governance. The National Information Governance Board for Health and Social Care (NIGB) says that when information governance is "correctly developed and implemented, it enables the appropriate and ethical use of information for the benefit of individuals and the public good".⁴

This report summarises the findings of work carried out by the Healthcare Commission during 2008/09 to:

- Assess the performance of healthcare organisations to identify which parts of the health service comply with good information governance practice and standards, and which parts perform less well.
- Analyse and describe how performance has changed between 2006 and 2009.
- Analyse and describe the elements of information governance that make a difference to the quality of care for patients.
- Identify the issues that affect how well organisations manage information governance.

The work focused on NHS trusts and on specific areas of the independent healthcare sector that provide care predominately for NHS-funded patients in England.

The report is based on analysis of the compliance of healthcare organisations with basic standards on information governance set by the Government, and on information from interviews with staff in 12 organisations and with a variety of patients, carers and voluntary organisations that advocate on behalf of patients. We have also used the findings of other regulators and researchers wherever possible.

The report draws overall conclusions and makes recommendations aimed at improving information governance and how this can be better integrated with other providers of care to improve the overall care of patients.

1. How well do healthcare organisations manage personal information?

We found that most NHS trusts have improved their systems and processes for managing patients' information between 2006 and 2009. However, the performance of healthcare organisations varies according to the type of services they provide and the specific element or issue relating to the management of personal information examined. The broad systems may be in place to manage patient information adequately, but some of the detailed

elements that help to deliver safe, high quality care are missing.

Healthcare organisations are expected to meet a number of basic national standards when managing information about patients (see Appendix B). There is also a toolkit that helps organisations to examine in greater depth and assess their ability to handle personal identifiable information (see box 1 for more

Box 1: Connecting for Health information governance toolkit

The information governance toolkit (IGT) is an assessment tool that supports organisations and individual health practitioners in ensuring compliance with the legal and regulatory requirements of handling information. The most recent version (Version 6) of the IGT was released in June 2008 and its completion is mandatory for NHS organisations.

There are a total of 62 questions in this version and the number varies according to the type of trust or practitioner, with questions grouped into six themes.

Organisations assess their level of performance or compliance with each question using the overall standard statement or the criteria listed under each standard. Some organisations have their self-assessment and supporting evidence validated by an auditor, usually from NHS internal audit or an external company of auditors.

The levels of compliance are summarised as:

- 0 - Not effectively engaged with this requirement
- 1 - Planning and preparing to meet the requirement
- 2 - Meeting the requirement
- 3 - Independent audit to validate that the requirement is met

As well as being a performance assessment tool, the IGT is used to determine whether an organisation may have access to the N3 network (the national network providing fast broadband connection to NHS systems, providing secure access to patient records and high quality visual images). For example, independent healthcare organisations must have achieved at least a level 2 score across all IGT questions if they have a contract with the Department of Health to provide services to NHS-funded patients.

detail). The aim of good information governance may be summarised by the acronym 'HORUS' where personal information is **held** securely and confidentially, **obtained** fairly, efficiently and lawfully, **recorded** accurately and reliably, **used** effectively and ethically and **shared** appropriately and legally.

Analysis of compliance with the basic or core standards for both NHS and independent healthcare organisations enables us to examine the broad systems in place to manage patients' medical records, the consent of patients to share their information, and patient confidentiality (see Appendix B for more information).

Compliance of NHS trusts with basic standards

As part of the annual health check of performance, NHS trusts must declare their level of compliance with a number of standards set by the Department of Health in *Standards for Better Health*, published in 2004 and updated in 2006. Our analysis of trusts' declarations of compliance with the relevant core standards shows that most NHS organisations

manage patient information consistently well. These trusts have a systematic and planned approach to managing patients' records. They keep patient information confidential and only share it with the patient's consent.

However, primary care trusts (PCTs) and ambulance trusts do not perform as well as acute trusts (hospitals) and mental health trusts in meeting the basic standard on managing patients' records (core standard C9) and some of these trusts have been non-compliant with this standard and/or the other relevant core standards for two consecutive years.

Table 1 shows that almost all trusts (over 90%) declared compliance with core standard C13c in relation to systems to keep patients' information confidential during 2006/07 to 2007/08.

The percentage of acute trusts, mental health trusts and PCTs declaring compliance with the standard on consent to share information (core standard C13b) increased from over 90% to almost 100% between 2006/07 and 2007/08. However, two out of the 11 ambulance trusts did not declare compliance with this standard during this time.

Table 1: The proportion of each type of NHS trust declaring compliance with relevant core standards in 2006/07 and 2007/08

	C9 Records management		C13b Consent to share personal information		C13c Confidentiality of personal information	
	2006/07	2007/08	2006/07	2007/08	2006/07	2007/08
Acute trusts	94%	93%	96%	96%	99%	99%
Mental health trusts	90%	93%	98%	100%	100%	100%
PCTs	68%	76%	94%	97%	95%	95%
Ambulance trusts	67%	73%	83%	82%	100%	100%

By comparison, almost a quarter (24%) of PCTs and (27%) of ambulance trusts did not comply with the records management standard (core standard C9) in 2007/08. The percentage of compliant PCTs has improved between 2006/07 and 2007/08. However, it is still lower than for acute and mental health trusts, and this has been the case over the three-year period between 2005/06 (when there were over 300 PCTs) and 2007/08, when the number of PCTs was halved as a result of trust mergers.

In fact, 14% (22 out of 152) of PCTs and two out of the 11 ambulance trusts have failed to comply with at least one of the relevant core standards for more than one assessment year. The comparable figures for acute trusts are only 2% (three out of 169) and in mental health trusts 3% (2 out of 59).

Some trusts are visited as part of the annual health check, either because information suggests a risk of an undeclared lapse in compliance with a core standard, or because the trust was chosen at random for follow-up. In 2007/08, the Healthcare Commission inspected 79 trusts against one or more standards. Fourteen trusts were inspected for their compliance with the patient confidentiality standard, (C13c). Five of these trusts did not have sufficient evidence to support their assessment of compliance with this standard. In general, these trusts did not have systems to review and justify the use of patient information. They also lacked evidence that they were monitoring whether staff complied with the Data Protection Act 1998 or the NHS Code of Practice on Confidentiality. Eight trusts were inspected for their compliance with the patient records standard (C9), and four of these trusts were found to be non-compliant. Generally this was due to lack of evidence of monitoring the safe disposal of patient records and a lack of staff training.

Compliance of independent sector organisations with basic standards

Most organisations in the independent sector created, stored and disposed of patients' records adequately and they kept patients' information confidential. Any deficiencies related to the details

of how records were completed and whether they sought and recorded consent for the medical record to be shared with the patient's GP or dentist.

We inspected independent organisations providing acute services, mental health services and hospices in 2007/08, to test their compliance with the Government's National Minimum Standards (see Appendix B for a description of the basic standards for independent healthcare organisations). It is important to note that all these inspections were targeted at establishments where the risk assessment suggested a lack of compliance with one or more of the basic standards.

None of these establishments were assessed as being non-compliant with the national minimum standard on confidentiality of information (C31), nor how records were stored or disposed of, (standard C29). Non-compliance, at low levels only, was focused on standard C30, which deals with how patients' records are completed (whether they are legible, and the health professional has dated and signed each entry) and shared, with the patient's consent, with their local GP or dentist.

We also inspected 10 independent sector organisations providing acute services to NHS patients against the criteria in national minimum standard C30. These were a mix of independent sector treatment centres (ISTCs) and acute hospitals carrying out hip/knee procedures where at least 50% of the patients were NHS-funded in 2007/2008. We found one of these facilities to be deficient in this standard. Reviews of acute care provided by independent sector treatment centres^{5,6}, found that most centres visited as part of the study had evidence of regular monitoring of the standard for patient record-keeping.

We inspected 47 mental health establishments against standard C30 and 11% failed to comply with this standard. The main failings related to a lack of integration of multi-disciplinary care records and medical records that were found to be incomplete. Finally, we inspected four hospices against standard C30 and one hospice failed to meet this standard. In this hospice, the deficiencies related to incomplete

patient records and records where the consent to share the medical record with the patient's GP was not recorded.

In summary, most NHS and independent healthcare organisations comply with the basic standard relating to their ability to ensure that they seek consent when personal information is shared. Most healthcare organisations meet the basic standard on keeping patient information confidential. In a small number of inspections of NHS trusts, we found deficiencies in the evidence of systems to review and justify the use of patient information and in the monitoring of whether staff were complying with the Data Protection Act 1998 and the NHS Code of Practice on Confidentiality. The main area and sectors where there is persistent failure to meet the basic standards relates to the systems of PCTs and ambulance trusts to ensure that patients' records are created, stored and disposed of properly (this includes providing training for staff).

Our inspections of independent healthcare organisations found deficiencies in how patients' records, particularly multi-disciplinary records for mental health patients, were completed and filed.

If medical records are incomplete, disorganised or are not stored properly, then the care of patients may be

compromised because the right information may not be readily available to help inform their treatment and care. If records are not disposed of properly, patients' confidentiality may be compromised.

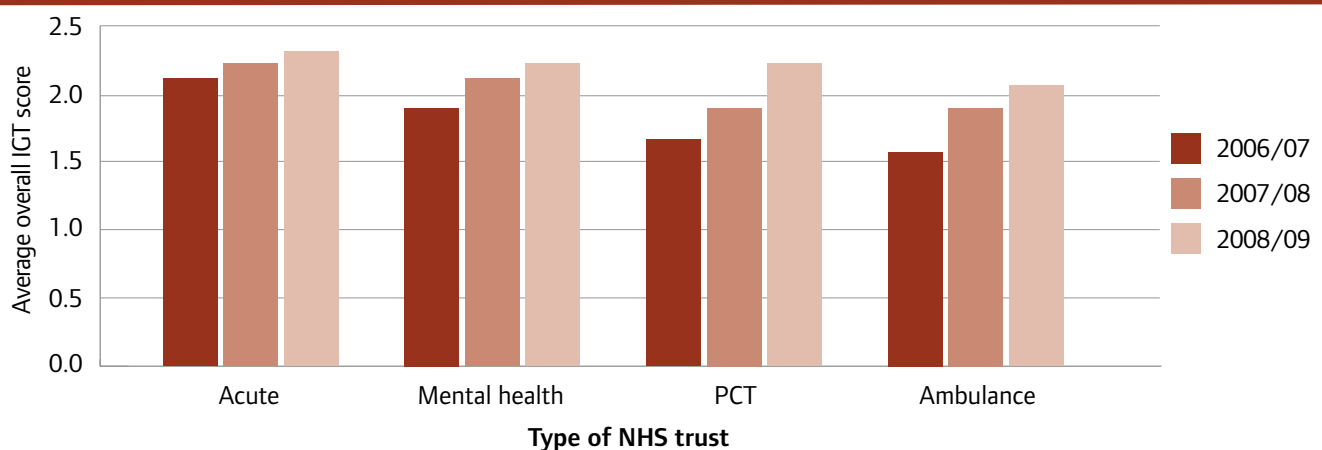
Performance in the detailed elements of information governance

Analysis of the information governance toolkit (IGT) enables us to look in more depth at specific issues (see box 1 on page 10 for more details of the IGT).

We looked at how NHS trusts assessed their own performance using the toolkit and how this has changed between 2006/07 to 2008/09.* The conclusion from the IGT analysis of how trusts in different sectors perform is similar to that from the core standards analysis. In general, the scores of acute and mental health trusts are marginally higher than the scores for PCTs and ambulance trusts (see figure 1).

The average overall score for each type of trust masks variations in the performance of individual trusts; a minority of acute trusts have low average scores (less than 1.5) and a minority of PCTs and ambulance trusts have high average IGT scores (above 2.6).

Figure 1: Average overall IGT score for each type of NHS trust 2006/07 to 2008/09



Note: We calculated an average score from the ratings of the individual elements of the IGT and therefore each question was given an equal weighting. The maximum average score could in theory equal 3 (where all of the IGT questions had a rating of 3).

* We decided not to include an analysis of IGT assessments before 2006/07 because the IGT was revised substantially after the 2005/06 release. We also decided to look at assessments at trust level and not for individual GPs.

Figure 2: Trends in average score for each theme in NHS trusts, 2006/07 to 2008/09

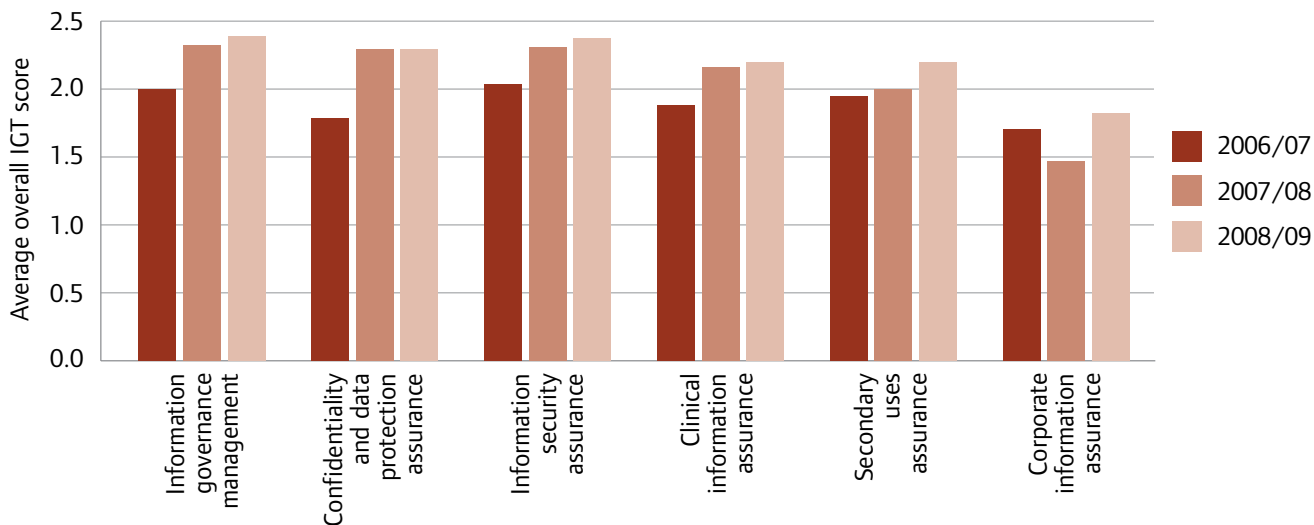
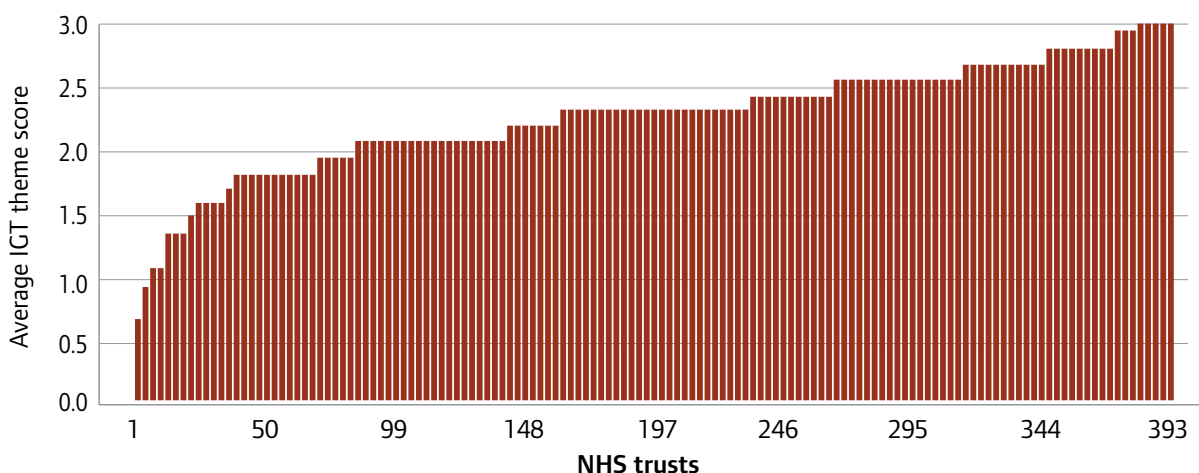


Figure 2 shows that all types of NHS trusts have gradually improved their IGT average scores across the six information governance themes between 2006/07 and 2008/09. Figure 2 also shows that the elements of the IGT on which trusts find it harder to provide assurance relate to clinical information, secondary uses (where patients’ information is used for purposes other than direct care, for example for audits or monitoring of waiting time targets) and corporate information.

The requirements relating to ‘corporate information’ concern information about the trust rather than information specific to patients. By contrast, the requirements relating to ‘clinical information’ ask organisations to provide assurance that they have

systems and processes to ensure that patient information is of high quality – a single integrated record for an individual patient, with an NHS number (a unique 10-digit number issued to each patient registered with the NHS in England and Wales) that is used on all clinical correspondence, regular audit and monitoring of the quality and tracking of patient records. ‘Secondary uses’ relate to specific issues around clinical coding and the accuracy of clinical records. Figure 3 shows that approximately one in five trusts have an average score for the ‘clinical information assurance’ part of the IGT of less than 2, the remaining four fifths of trusts score 2 or above. A similar proportion of trusts have an average score of less than 2 for the

Figure 3: Distribution of IGT scores, Clinical Information Assurance, 2008/09



‘secondary uses assurance’ theme.* It is of concern that a number of trusts are not making faster progress in these areas, which are fundamental to the safety and quality of patient care.

It is possible that the higher scores for the IGT themes on general information governance management and patient confidentiality and data protection are a result of these issues being in the spotlight, and therefore a focus for improvement, since November 2007.

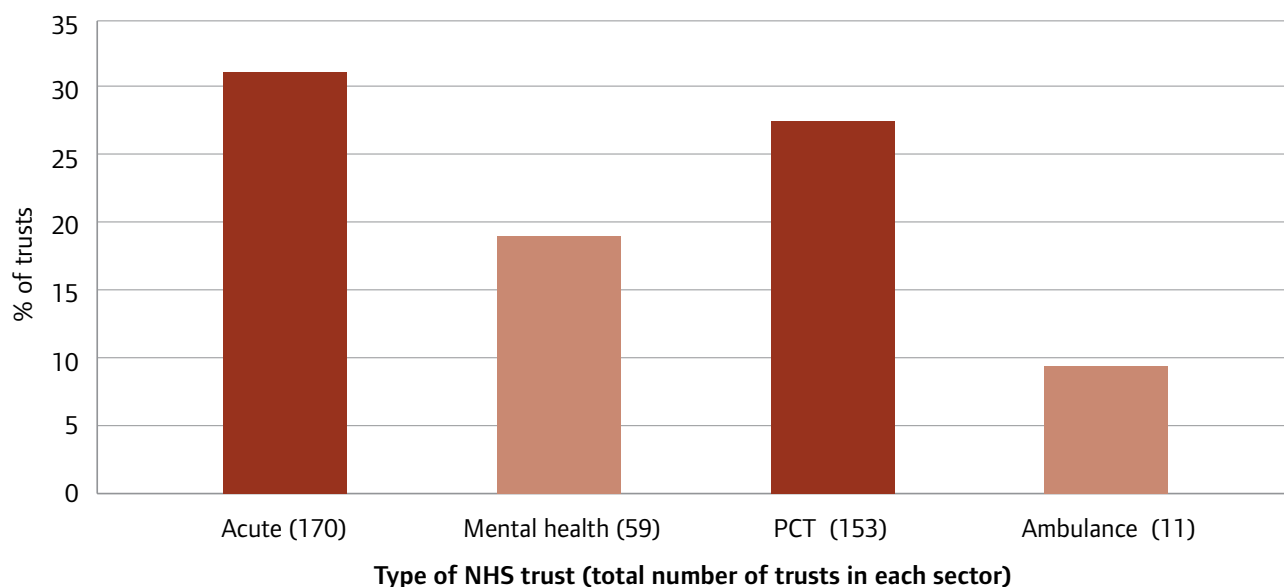
The NHS operating framework sets out priorities for the year ahead, as well as changes to NHS structures and financial objectives. Improvement to the systems and processes to manage personal information was one of the national priorities in the 2008/09 framework.⁷

The operating framework for 2009/10 states that all NHS providers must achieve a level 2 score against a set of 25 questions in the IGT.⁸ The expectation is that trusts will achieve these scores by the end of March 2010, by carrying out a baseline assessment

using version 7 of the IGT by the end of July 2009. They are expected to update this assessment by the end of October 2009 and make a final submission of the IGT at the end of March 2010. By looking at the performance of NHS trusts against these 25 questions in the IGT for 2008/09, we wanted to see the scale of action needed to meet the requirements for the 2009/10 operating framework (see figure 4). We found that a minority (just over 30%) of NHS trusts, by their own assessment, score level 2 for all of the 25 key requirements in the IGT. In other words, most trusts (over 70%) have started the 2009/10 operating framework period being unable to meet all 25 key requirements of the IGT.

The elements of the IGT with which most trusts say they do not comply at level 2 relate to the systems in place to ensure that when ‘person-identifiable’ data is processed outside the UK, it complies with the Data Protection Act 1998 and Department of Health guidelines.** Also approximately 30% of acute trusts, mental health trusts and PCTs, do not have a designated Senior Information Risk Owner (SIRO) to

Figure 4: Compliance of NHS trusts in 2008/09 with all 25 of the 2009/10 NHS Operating Framework information governance requirements



* Ambulance service trusts do not have to complete the secondary uses assurance theme questions and were therefore excluded from the analysis of this theme.

** A number of factors such as capacity to process data and cost may mean that organisations process personal information using companies based outside the UK. The 8th principle of the Data Protection Act 1998 states that, “Personal data shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data”.

take ownership of the trust's information risk policy as defined in question 121 of the IGT. Six of the 11 ambulance trusts say they do not have a strategy in place to ensure that they record the correct NHS number for each patient and that it is used routinely in clinical communications.

The 2009/10 operating framework states that all bodies that provide or support the provision of NHS services have to meet and be able to demonstrate compliance with key information governance requirements. Independent sector organisations have to achieve a level 2 rating to gain access to the N3 network so that they can communicate with NHS systems (see page 10). This is a considerable incentive as it allows them to access NHS contracts* among other things. Information from Connecting for Health shows that 60 independent sector organisations have registered and started to submit their assessments against the 2008/09 IGT, 11 of which have had their submissions approved by Connecting for Health (Connecting for Health has examined their assessment, and where level 2 has not been achieved an action plan is in place). Thirty-six commercial third party organisations (non-NHS organisations that provide service to NHS bodies but are not directly employed by the NHS) have started their submissions, 15 of which have been approved.

Finally, the IGT is a self-assessment and its score summary (see box on page 10) implies that to score 3 for a question, the organisation should have had its assessment independently validated. During our visits, we found that those organisations whose assessments were validated by NHS internal audit, or by other auditors, were convinced that this provided important challenge and rigour to the management of person-identifiable information. Unfortunately the number of organisations that have their assessments validated is not collated centrally and was not made available in time for use in this report. These organisations valued the

scrutiny by auditors compared with the approach in some organisations where assessments are 'peer reviewed' by another NHS trust in the locality. External validation also gave the IGT credibility as a performance assessment and benchmarking tool. This is consistent with the findings by NHS London, one of the 10 NHS strategic health authorities. NHS London commissioned an external audit of information governance capability, which involved the auditors examining the evidence behind a sample of trusts' IGT assessments. The audit reduced the scores of eight out of nine trusts examined.

The performance of NHS trusts in both compliance with the basic standards and the detailed elements of managing personal information properly has improved steadily over the last three years. However, some sectors of the NHS, such as PCTs and ambulance trusts, have made slower progress towards compliance with basic standards and the more detailed elements of information governance. In PCTs, this may have implications for their capacity to monitor and stimulate improvements in the performance of the organisations from which they commission care.

In terms of a performance management tool, the IGT has progressed from being a voluntary submission to one that is mandatory for all NHS trusts. In March 2009, most trusts lacked compliance at level 2 with all these elements, but the requirements of the NHS operating framework 2009/10 should stimulate them to improve during 2009/10.

Higher average scores for the information governance management, confidentiality and data protection, and information security themes may be due to the raised awareness of the risk posed to organisations by deficiencies in systems to keep patient information confidential and secure.

* For example, the standard contract for providing acute services for NHS-funded patients includes schedules which state that the service provider must have the IT infrastructure to support the 'Choose and Book' electronic referral service.

2. The right information – improving the quality of data

“People don’t realise that poor data is bad for patient care, bad for funding and bad for reputation...”

The Information Centre’s Data Quality Programme website, May 2009.

The importance of high quality data

If the personal information managed by healthcare organisations is to benefit patients, it must be of good quality. Poor quality data have a number of detrimental effects on care, for example:

- **Incomplete, inadequately analysed data can lead to serious failures in service.** One of the six themes in the Healthcare Commission’s *Learning from Investigations* report relates to governance and the use of information.⁹ In the trusts that were the subject of investigations, data generated was not sufficiently detailed to identify serious problems, or information was collected but was not analysed adequately or the data were not used to inform decisions.

The lack of timely and effective monitoring using complete data was one factor in the delays in identifying and responding to the seriousness of the *C. difficile* infection at Maidstone and Tunbridge Wells NHS Trust.¹⁰ Similarly, the investigation into Mid Staffordshire NHS Foundation Trust found that the trust’s

arrangements for the collection, reporting, analysis and use of clinical data were poor.¹¹ This meant that it could not track or link what happened to individual patients with the type of care provided (for example, surgery for a particular condition in a particular theatre). When national databases such as the Hospital Episode Statistics (HES) revealed relatively poor results, the trust concluded that inaccurate coding was the likely explanation for its high mortality rate.

- **Poor demographic data results in duplicate and confused entries on patient record systems.** The Personal Demographics Service (PDS) has reported that poor quality demographics may result in a patient having more than one NHS number, or the same NHS number being assigned to more than one patient. A consequence of incorrect and mixed medical records may include missed screening requests and even cancelled operations. One of the drivers behind the migration to the NHS Care Records Service is to improve the quality of data through the creation and use of a single master patient index.
- **Confused patient identity numbers compromise safe care as treatments may be administered to the wrong patient.** The National Patient Safety Agency and Connecting for Health issued a ‘Safer Practice Notice’ in September 2008 instructing trusts to use the NHS number as the national patient identifier.¹² This followed reports on over 1,300 incidents between June 2006 and August 2008 resulting from confusion and errors about patients’ identifying numbers. Many of these incidents

involved local numbering systems. While no deaths or cases of serious harm to patients had been reported, healthcare staff commented that this was causing significant risk to safe care.

- **Inadequate record-keeping results in poorly planned care.** The joint investigation into services for people with learning disabilities in Cornwall Partnership NHS Trust revealed that record-keeping was so poor that it prevented effective care from being provided.¹³ Even when there is no failure in the service, poor record-keeping can compromise personalised care. The Healthcare Commission's review of inpatient mental health services found that 50% of the care plans sampled did not record the service user's views and concluded that this was an urgent issue that needed to be addressed in order to provide personalised care.¹⁴
- **Poor data inhibits the commissioning, monitoring, planning and financing of services.** One of the findings from the investigation into maternity services at North West London Hospitals and the national review of maternity services was that poor quality data on activity in a specific service and poor clinical record-keeping meant that the PCTs commissioning their services were unlikely to have adequate information to monitor the quality of services and plan to meet future needs.^{15,16}

The Audit Commission analysed Payment by Results (PbR) data from all acute trusts in England.¹⁷ PbR is the funding system used to pay hospitals for the majority of different types of procedures they carry out. The price for the procedures, such as surgical operations, is determined by how many procedures are carried out and the type and severity of the illness or injury being treated. The PbR data therefore underpin the financial, clinical and commissioning information in the NHS. The Audit Commission found coding errors in the assignment of the Healthcare Resource Group (HRG) code, and subsequently the accuracy of payments. (The HRG code is assigned to procedures, for example types of knee surgery, which have similar costs). The

average HRG error was 9.4%, but this ranged from 0.3% in some trusts to 52% in others. Although in most cases the net financial impact of these errors was close to zero, in some trusts the coding errors had a significant financial impact. The errors were caused by clinical coding carried out using only discharge summaries as full clinical records were not available; by illegible or poorly structured case notes; and electronic patient records with insufficient information to create a clinical coding.

The Health Informatics Unit at the Royal College of Physicians has published generic standards for record-keeping, which have been adopted by the Academy of Medical Royal Colleges.¹⁸ This work was funded by Connecting for Health and recognises that standardised records are essential in order for electronic patient records to ensure good quality and safe care, and reliable clinical information on patients for secondary purposes including clinical and epidemiological research. The next step will be to ensure that if these standards are adopted, they are implemented throughout the healthcare organisation.

Service and sector-specific concerns

Data in hospital episode statistics (HES) relating to maternity should contain 'delivery episodes' for the mother and 'birth episodes' for the baby. These statistics should be recorded whether the baby was delivered in hospital or at home. However, the Information Centre reported that coverage of hospital and home deliveries was incomplete compared with the birth registration data compiled by the Office of National Statistics.¹⁹ In addition, the HES data relating to episodes of 'babies' did not correspond to episodes of 'deliveries'.

Detailed reviews of specific services have also revealed deficiencies in data management that impact on the care of patients. In a review by the Healthcare Commission, 40% of the trusts providing maternity services did not have information systems that complied with Connecting for Health standards and 17% of trusts had no maternity information system at all.¹⁶ This meant that healthcare staff did

not have adequate information from which they could assess and compare practice. Only 15% of trusts had a system covering both antenatal and postnatal care, which could affect the continuity of care of women and their babies.

Historically, data from mental health services were lower in quality than that supplied by acute trusts, but this has now improved and these sectors supply data of comparable quality. In 2006/07, the median overall score for the Information Centre's data quality indicator was 92% for acute trusts and 92.5% for mental health trusts. The percentage of useful coding on patient's ethnicity in HES for NHS mental health providers has improved from 62% in 2002/03 to 94% in 2007/08.

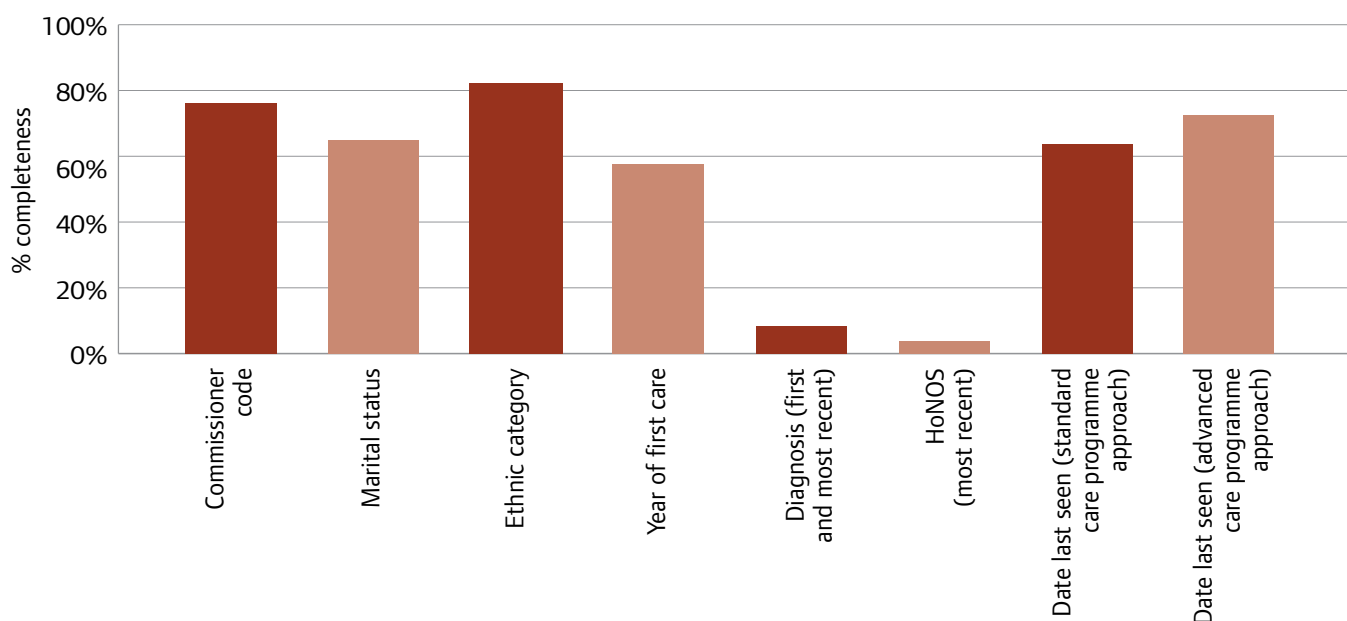
However, there are still deficiencies in the quality of some mental health data. The Mental Health Minimum Data Set (MHMDS) became a mandated data return for all NHS providers of specialist adult mental health services in 2003. This data set was designed to capture information on the wide range of different care that service users may receive over an extended period of time. The data cover inpatient, outpatient and community care. It is a complex data set geared to the complexities of mental health services. Figure 5 shows that parts of the MHMDS are poorly populated, for example information on diagnosis and the Health of the Nation Outcome Scales (HoNOS).²⁰

Care of NHS patients by independent sector providers

The healthcare reforms in England included mechanisms to encourage a wider range of service providers by commissioning care from the private and voluntary sector, as well as setting up new NHS social enterprises. This aimed to increase capacity, bring more innovation and new ways of working and provide patients with more choice.²¹ However, there is a need for a unified data collection system to help support patient choice, which should be informed by comparable published information on the relative performance of all healthcare providers.

The NHS and independent sector have largely separate and different practices and systems for collecting and using healthcare data. However, work is in progress to align the various data systems. For example in April 2009, the Independent Healthcare Advisory Services (IHAS) contracted Dr Foster Research to develop a clinical indicator and data management system. One of the aims of this system is to enable data on patients to be collected and key performance indicators (KPI) to be calculated. This will enable comparisons of performance between independent sector organisations, as well as between independent sector and NHS organisations. The Information Centre regularly publishes information

Figure 5. The percentage completeness of selected data fields in the Mental Health Minimum Data set (MHMDS), 2007/08



on the quality of data submitted to the Secondary Uses Service (SUS). The report for quarter 3 2008/09 includes data from 94 independent sector sites providing care to admitted patients and 106 sites providing outpatient services for NHS-funded patients.²² The report concludes that there have been consistent improvements in the levels of valid data. The average proportion of valid data for admitted patients was 91.5% and 86.8% for outpatients. However, there are still deficiencies in the valid codes for ethnic category and also for primary diagnosis in the admitted patient care data. The primary diagnosis code is particularly important to ensure that the correct tariff under PbR is paid.

The analysis of data quality shows that some healthcare sectors have gradually improved their performance, for example the improvements in data quality in mental health service providers. However, improvements are patchy and while an organisation as a whole may be compliant with basic standards, it can have poor performance in specific services, such as maternity, or specific elements of data handling such as the elements of the MHMDS. Finally, there must be comparable data from NHS and independent sector providers if patients and health service commissioners are to make properly informed choices.

3. Information in the right place – keeping information confidential

“You have the right to privacy and confidentiality and to expect the NHS to keep your confidential information safe and secure.”

The NHS Constitution, January 2009.

This right is laid out in the NHS Constitution published in January 2009 and builds on Article 8 of the European Convention on Human Rights and the UK Human Rights Act 1998.

Views of staff and patients on confidentiality

The vast majority of NHS staff are confident that information is treated confidentially in their organisation. In the NHS staff surveys in 2007 and 2008, over 80% of staff agreed or strongly agreed with the statement that patients’ information was treated confidentially by staff in their trust.

However, patients may not share the same definition or perception of confidentiality as staff. Table 2 shows the results of the annual surveys of adults who were inpatients in an acute or specialist NHS trust and shows that approximately 30% of patients say they were not always given enough privacy when they discussed their condition or treatment.

Staff training and awareness of information governance

In the 2008 NHS staff survey, nearly a third of all staff said they had not had any training in how to treat patient information confidentially (Table 3). In particular 43% of ambulance trust staff said they had not had training within the last 12 months or more than 12 months ago. This is surprising since all 11 ambulance trusts declared in 2007/08 in their information governance toolkit (IGT) return that information governance was part of their induction training for new staff. These trusts also said they had systems in place to ensure that they provided role-specific information governance and they scored themselves at levels 2 or 3 for both these questions on the IGT. Having said this, training figures have

Table 2: Inpatient survey question “Were you given enough privacy when discussing your condition or treatment?”

	2002	2005	2006	2007
Yes - always	68%	71%	70%	69%
Yes - sometimes	21%	22%	22%	22%
No	10%	8%	9%	9%

Source: National NHS patient survey programme. Survey of adult inpatients in the NHS 2007

improved steadily over the last three years, with most staff (65%) responding to the NHS staff survey saying they have been trained either in the last 12 months or more than 12 months ago. Many of the sites we visited provided training that was tailored for different staff groups who may work night shifts or who do not have access to computers in the course of their work.

In the 2008/09 IGT submission, 96% of NHS trusts stated that they had clear guidance for staff on the disclosure of patient information. During our visits to trusts, we found examples of organisations that had developed their own materials including pocket-sized guides, leaflets, newsletters and intranet-based materials to reinforce good information governance practice.

Serious data losses from the NHS

There have been a small number of serious incidents where healthcare organisations have lost personal information. This issue regularly attracts media attention. However, the number of incidents are not put into the context of the substantial number of patients treated by the NHS, and the large NHS workforce. Media stories also rarely distinguish between losses of encrypted and non-encrypted data. When an encrypted laptop is lost, it is the physical asset that is lost and not the personal data.

In the Information Governance Assurance Programme from NHS Connecting for Health, all NHS organisations must categorise and report all losses of personal information even when the loss affects a single individual. These incidents are summarised in individual annual reports from trusts and the most severe incidents (for example more than 100 people affected, or where particularly sensitive data are lost) are reported by the organisation to the Information Commissioner’s Office (ICO).^{*} This practice of reporting openly is in contrast to other parts of the public sector (where losses of 1,000 records or more are reported to the ICO) and many private companies.

The Information Commissioner has the power to serve an enforcement notice if he is satisfied that a data controller has contravened or is contravening the data protection principles. The notice sets out the steps that the data controller must take to comply with the relevant requirements of the Act. It is criminal offence if the data controller fails to comply with a notice. Between April 2008 and April 2009, the ICO served 28 Data Protection Act enforcement notices.

Half (14 out of the 28) the enforcement notices during this period related to incidents in NHS trusts in England. Seven of the 14 NHS incidents were as a result of theft of laptops, memory sticks or desktop computers from NHS premises, even when the offices were locked. This illustrates some of

Table 3: NHS staff survey question: “Have you had any training, learning or development (paid for or provided by your trust) in how to handled confidential information about patients or service users?”

(Base: all staff)	2005	2006	2007	2008
Yes – in the last 12 months	35%	32%	31%	38%
Yes – more than 12 months ago	26%	27%	29%	27%
No	34%	36%	33%	30%
Not applicable	5%	6%	6%	4%

Source: National NHS staff surveys 2005, 2006, 2007, 2008.

^{*} The ICO is the UK’s independent public body set up to protect personal information and promote public access to official information. All public and private organisations are legally obliged to protect any personal information they hold, and may be required to notify with the ICO. Public authorities are also obliged to provide public access to official information.

the challenges faced by NHS trusts in managing information from premises which are often open to everyone, the majority of which were not purpose-built for data security.

Almost all incidents in the 14 NHS trusts involved electronic devices that were not encrypted, despite clear instructions since January 2008 that unencrypted person-identifiable data cannot be held in electronic format in the NHS.²³ In addition, 298 out of 393 NHS trusts stated in their 2008/09 IGT return that they had procedures for ensuring that mobile computing and teleworking were conducted in a secure manner. In one case, a memory stick was encrypted but the password was written on a post-it note attached to the memory stick. Effective data security is a combination of technological solutions to physically block the use of unencrypted devices and the protection of premises from opportunistic theft. In addition, work is needed to change the cultural attitudes of thousands of individual staff who are willing to take a risk by using their own unencrypted memory stick without perhaps realising that this contributes to a larger collective risk to the whole organisation.

All the healthcare organisations we visited as part of the study had policies stating that staff should not use memory sticks to store person-identifiable data unless they were encrypted or password-protected. Most of these organisations had adopted tactics to ensure that staff did not use unencrypted memory sticks, for example by holding amnesties where memory sticks could be exchanged for encrypted devices, or by carrying out 'spot checks' and confiscating unencrypted devices. Many organisations had installed technology to prevent memory sticks from being used in the organisation's computers. Some organisations were introducing 'thin client' computer workstations where data are held on a central server and not on the individual computer, so that personal information will not be lost if the computer workstation is stolen. It is important to raise awareness of these points since some patients have cited lack of confidence in the security of personal

information as a reason to opt out of the Summary Care Record*, even though these records will not be held on removable storage devices.

All the organisations we visited took breaches of information governance policies seriously and staff involved in minor incidents had been disciplined and, in serious cases, had been dismissed.

Though the focus has been on the danger posed by unencrypted electronic media, two of the 14 NHS trusts served with enforcement notices lost information about staff that was in paper form (staff payslips). At the moment, a great deal of person-identifiable information is still held and transported in paper format. Where electronic systems have been introduced, for example the electronic staff record system, these have not replaced paper records entirely. A number of organisations that work with the NHS do not have access to secure NHS email. Patient referrals for treatment by organisations providing mental health services or palliative and end-of-life care in the independent healthcare sector are usually faxed using a dedicated fax line in a 'safe haven' (a place where person-identifiable information can be held, received or communicated securely). Healthcare staff still carry paper files with patient records, especially when they deliver services in patient's homes or from different hospital and clinic locations.

Data security is not only about protecting electronic information. Organisations need to physically protect records through code lock protected bags, filing cabinets and designated 'safe havens' as well as transporting records in covered containers.

This section has focused on the most serious losses of personal information that were reported by NHS trusts to the ICO. We sought information on all serious untoward incidents (SUIs) from Connecting for Health as part of this study in order to give a balanced picture of the proportion of SUIs graded 3 to 5 (most serious) compared with the more minor incidents. Unfortunately, despite a formal request

* The Summary Care Record is part of the NHS Care Records Service and will hold information such as allergies, current prescriptions and other information that the patient agrees to include. It is planned that records will be accessible to patients through a secure internet connection service called 'HealthSpace'.

in January 2009 for these data, the information was not supplied in time for this report.

In summary, the systems and processes to keep personal information confidential are complex. They combine technological and physical solutions to restrict access to personal data, which is a challenge when these data are stored in buildings that aim to be open and welcoming to the public and where staff have to transport paper records to use in community settings, including patient's homes. There is also a cultural aspect to confidentiality, including different attitudes and experiences of patients compared with staff, as revealed by the surveys of patients and staff. Healthcare organisations have to rise to the challenge of some 30% of staff who say they have not been trained to handle information confidentially. This figure is even worse in ambulance trusts. Training programmes and supporting materials have to be designed to address these issues.

4. Information at the right time – sharing information effectively

The NHS Constitution, published in January 2009, states that the NHS aspires to be an integrated system of organisations and services that work together to provide and deliver improvements in health and wellbeing. Sharing personal information effectively and with proper consent is a fundamental part of this integration and joint working, and the NHS Care Record Guarantee 2007 includes a commitment that health information that identifies the patient will not be shared without the patient's consent except in certain specific circumstances. While the principles may be in place, there are still technological and cultural barriers to sharing information effectively between health professionals and patients, and between NHS staff and staff in local authorities or in private and voluntary healthcare organisations.

Sharing information between health professionals

Inappropriate sharing of personal information has been the focus of much attention, but the care of patients can also be compromised when information is not shared efficiently between health professionals.

After being treated by a specialist, information about the treatment and care of a patient should be communicated to their GP to ensure suitable follow-up or continuity of care.

The NHS Alliance surveyed GPs about the quality and timeliness of information received when a patient is discharged from hospital.²⁴ Poor results both in the 2006 and 2007 surveys led to new provisions in the NHS Standard Contract in 2008

and 2009/10. From 1 April 2008, all new contracts require providers of hospital care to ensure that GPs receive discharge information within 72 hours of a patient's discharge. In the 2008 survey, 71% of the 572 respondents said that discharge information was provided late "very" or "fairly" often. Sixty-eight per cent of GPs also reported that late discharge information had compromised the safety of patients. In addition to discharge summaries arriving late, the information in the summary is often of poor quality with inaccurate or missing details such as the patient's name, the investigations carried out and their results, the diagnosis and any follow-up needed.

The surveys of NHS patients asked those who had been referred to a specialist in the previous 12 months whether the specialist appeared to have all the information about their condition or treatment (see Table 4 on the next page). The majority reported that the specialist did appear to have all the information. In the best performing trusts, 76% of people were completely satisfied with the information the specialist had, compared with 48% in the lowest scoring trust.

Our site visits suggest that there are a number of reasons why organisations do not share patients' information. We found that different departments within an organisation had their own forms and letters. The organisations we visited in the NHS and independent sector were standardising their documentation gradually, often as a result of the introduction or development of electronic record systems. We found examples of PCTs and acute trusts working together to develop standardised GP referral letters and discharge summaries. In the

Table 4: The percentage of respondents to the question: “When you first saw the person you were referred to, did s/he have all the information about you and your condition or treatment?”

	2004	2005	2008
Yes - completely	63%	62%	63%
Yes - to some extent	29%	29%	28%
No	8%	8%	8%

Source: National survey of local health services 2008, Healthcare Commission.

same way that GPs complain about the quality of discharge summaries, so their acute and mental health colleagues criticise GPs for the poor quality of information in referral letters. To address this, some trusts had developed reciprocal arrangements in their contracts concerning GP referrals and discharge information.

Example of notable practice: Sheffield Teaching Hospitals NHS Foundation Trust and Sheffield Care Trust

This acute trust and the integrated mental health and social care trust have worked together to enable information about patients with learning disabilities to be shared. This means that the records of patients with a learning disability are flagged so that if a person needs treatment from the acute trust, staff can plan their care appropriately. Information on the access to a range of services by people with learning disabilities is readily available to the trusts providing and commissioning care.

In addition, the link between the care trust and the acute trust means that if a patient who has been discharged from the care trust is treated at the A&E department, it is clear to staff how they were risk-assessed for discharge or leave, and what support arrangements are in place.

The care trust also alerts individual GP practices with the details of all patients with learning disabilities who are registered with their practice.

The learning disabilities case register, maintained by the care trust, is one of the longest standing and most comprehensive registers in the country. It has been used to plan and commission new services for people with learning disabilities and to provide support for their carers. For example, there is a post dedicated to ensuring that the physical health needs of people with learning disabilities are met, that there is specialist care for people with challenging behaviour and specialist care and treatment for those with epilepsy.

Relationships between NHS and independent healthcare organisations

The review of care provided by ISTCs carried out in 2007 found that there was tension, even hostility, from some NHS staff towards ISTCs, which made it difficult to establish joint systems and processes for managing care pathways for patients.⁵ It found that some NHS organisations were not satisfied with the discharge information provided by ISTCs. However, this seems to have improved, as the 2008 NHS Alliance survey suggests that ISTCs perform better than their NHS counterparts in providing discharge information 72 hours after patients are discharged.

During our site visits, we found both technological and cultural barriers that made it difficult for organisations in the independent sector and the NHS to share information about patients. Technological barriers included a lack of access to the secure NHS email system by staff in the independent sector and local authorities, including social care staff. The absence of a common patient identifier such as the NHS number was also cited as a barrier.

There were also cultural barriers to sharing information, with some staff in the independent sector reporting that NHS staff refused to share patient information with them, despite the fact that the independent sector organisation was caring for NHS patients. However, we found examples of NHS and independent sector organisations working together to build systems so that patient information could be shared electronically in a secure way. Many organisations were also developing information-sharing agreements across the local health economy. These agreements operated at strategic, managerial and operational levels.

Relationships between healthcare and social care organisations

Healthcare staff in both sectors said that it was difficult to share information with colleagues in social care and that this was not solely due to lack of compatible systems. Some healthcare staff felt that social care staff worked to different standards

on information governance. This is despite the work by the Cabinet Office and the Department Health on sharing information between health and adult social care organisations.²⁵ Health professionals held the view that social care staff sent correspondence with person-identifiable information in a way that they felt would not happen in healthcare organisations. We could not judge the validity of such statements nor how widespread these views are within healthcare organisations.

In our work with patients and carers, we found a willingness for personal information to be shared within the health system, but there was marked resistance to sharing health information with staff in social services, especially between organisations working with women in maternity services.

The Institute for Insight in the Public Services carried out research on public attitudes to data sharing in public services. The study found that 47% of respondents would not be happy for their information to be shared with other public services. Interestingly the respondents were more willing for their health information to be shared between health professionals across the country or with other public services once they understood how the information would be used.²⁶ Ninety-one per cent of respondents were willing for their health records to be shared with other health professionals if it meant that their medical history would be available when they needed medical care outside their local area. We found at our site visits, and through our work with voluntary organisations, that there were concerns about who has access within the health service to sensitive health information such as HIV status and treatment for mental health conditions. We found that this was an issue among healthcare staff who may themselves, at some point, also use health services in the same area in which they work.

Sharing information between clinicians and patients

The NHS Constitution includes a pledge to share with patients any letters sent between clinicians about their care. This helps patients to understand their condition, and enables them to take control

of their own health and make decisions about their treatment. It also helps patients to correct any errors in the information held about them.

There has been a steady improvement in the last three years in the proportion of people who say they were given copies of the letters sent between their GP and hospital staff. However, the majority of patients in the NHS (60%) do not receive these letters and this figure is the same whether the letters are sent by GPs to hospital staff or vice versa.²⁷ There is wide variation – in the best trusts, 78% of patients said they received copies of all the letters, and in the worst trusts only 8% of patients reported they had received copies of these letters.

By contrast, significantly more patients treated in ISTCs (60%) did receive copies of the letters sent by the ISTC to the patient’s GP.⁵

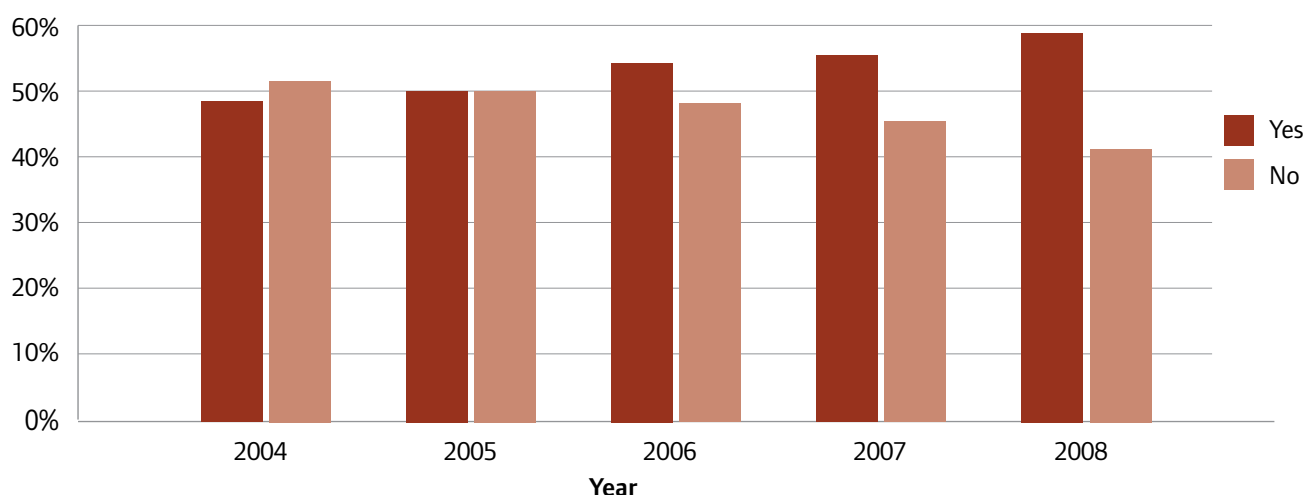
Since 1991, the way in which mental health care is provided has been shaped by the Care Programme Approach (CPA). An important part of the CPA is the development of a care plan that identifies the patient’s needs and explains their care. This care plan should be shared with the person who uses the mental health service. The NHS has been surveying

people who have been referred to a psychiatric outpatient clinic or a local community mental health team since 2004.²⁸ Figure 6 shows that the proportion of patients who have been offered a copy of their care plan has increased over the last four years. However, even after four years, in 2008, only 59% said they had received or been offered a copy of their care plan.

Our work with patients and their carers in a variety of settings suggests that some health professionals do not share information about the treatment or care of a patient with the person’s family and cite ‘patient confidentiality’ as the reason why they withhold information. Table 5 shows results from the survey of mental health patients carried out by the Healthcare Commission, which suggests that most families (over 70%) do receive some information about a family member, but nearly a third of respondents do not and would have liked some information.

Surveys of staff and patients suggest that there have been improvements in the way that information is shared between health professionals and patients and their carers. However, there can be great variation in performance between individual organisations.

Figure 6: Percentage of respondents answering the question: “Have you been given (offered) a copy of your care plan?”



Source: National survey of local health services 2008, Healthcare Commission.

Table 5. Percentage of respondents answering the question: “Has a member of your family been given enough information from health and social services about your mental health problem?”

	2006	2007	2008
Yes - definitely	39%	39%	41%
Yes - to some extent	32%	31%	32%
No, but they would have liked some information	31%	29%	27%

Source: National survey of local health services 2008, Healthcare Commission.

In summary, the sharing of personal information between health professionals and with staff working in non-NHS settings (independent healthcare, social care and local authorities) is more problematic. There are technical barriers posed by systems which are not integrated (such as lack of access to NHS email systems by independent sector providers and social care providers) and also the lack of streamlined documentation such as standard discharge summary templates and referral letter templates. The NHS Alliance survey suggests that progress is still slow on ensuring that high quality information is sent in a timely fashion between hospital care providers and GPs, despite the requirements of the NHS contract. It is particularly worrying that the majority of GPs responding to the survey believed that late discharge information had compromised patients’ safety. Differences in attitude may also create barriers to sharing information between health professionals, patients and carers, between NHS and non-NHS health professionals, and between those in health and social care settings.

5. The right information, in the right place, at the right time – using information to personalise care

One of the aims of good information governance is to ensure that information is used for the benefit of individuals. Building and improving systems to support information governance underpin the delivery of personalised, responsive services. During our site visits, we found that parts of the healthcare system used patient administration systems and other policies and practices to deliver personalised care to each patient. These organisations ensured that they used information such as a patient's disability or their cultural background to systematically shape the patient's care. An example would be to ensure that correspondence is always sent to partially sighted patients in the format that they requested, or ensuring that wheelchair users are always treated in premises that are accessible. However, we found that this represented only a pocket of notable practice, particularly mental health services, and was largely absent in providers of acute services and some PCTs. The consequences for some patients of this gap in care range from inconvenience and delays in care, to loss of privacy and independence.

The Royal National Institute for the Blind (RNIB) commissioned research on how healthcare services provide information for people who are blind or partially sighted.²⁹ RNIB wanted to see how the situation had changed in the 10 years after their original research, which showed that the health information needs of blind and partially sighted people were not being met. They reasoned that policy and legal changes, such as the Disability Discrimination Act 2005, should have resulted in improvements. The RNIB survey included 600

blind and partially sighted people* as well as 500 healthcare professionals, and sought the views of PCTs and health boards in the UK. The findings on whether information about a patient was used to shape their care were stark.

Table 6 shows that the majority of blind and partially sighted people were not sent information in a format they could access, despite the healthcare organisation being aware that the patient was blind or partially sighted.

The survey showed that when using healthcare services, most blind and partially sighted people were not asked how they would prefer to access information. To make matters worse, even when blind and partially sighted people request that information is given to them in a certain format, it is rarely supplied in this way, as shown in table 7 opposite.

The RNIB's research identified how such failures in healthcare information systems impacted on the care of blind and partially sighted people. They found that 27% of blind respondents and 28% of blind or partially sighted respondents who could not read print reported that they had missed an appointment because information had been sent in a format they could not access.

Even when appointments are not missed, treatment or care may be delayed because of failures by the healthcare organisation to communicate effectively. One of the case studies featured in the report is of a patient at a diabetes clinic who was asked verbally to remember both the date of their next appointment and

* The 600 participants were selected at random from a pool of 10,000 people who are on the RNIB database, comprising people who have contacted RNIB to use one of their 60 services. Potential respondents were screened to ensure that the sample of 600 comprised equal numbers of men and women, was representative of different geographic locations and socioeconomic groups, and represented those who could and could not read print.

Table 6: Accessibility of health information by context

Healthcare setting/context	% receiving a format they cannot read
GP services (number of patients given non-verbal personal health information)	72% (382)
Hospital outpatients (number of outpatients given non-verbal personal health information)	74% (170)
Hospital inpatients (number of inpatients given appointment information in non-verbal format)	77% (102)
Urgent care (number of A&E patients given non-verbal information)	80% (30)
Community pharmacists (number of people provided with general health information in non-verbal format)	69% (26)
Information about prescriptions (number of people provided with prescription information in non-verbal format)	81% (283)

Source: RNIB Health information for blind and partially sighted people, March 2009

Note: Only those patients who received information in a potentially readable format were asked whether it was a format they could read themselves. In this context, 'readable' means information in a format that people can go back to again. Therefore, audio tape/CD was included, but information provided face-to-face and by telephone was excluded.

Table 7: Formats in which respondents need prescription information and the formats actually given

Format requested	% requesting this format	% receiving information in this format
Large print	40	1
Audio tape	36	Less than 1
Oral information face to face	24	57
Standard print	7	45

Source: RNIB Health information for blind and partially sighted people, March 2009

also to fast for 12 hours before the appointment so that a particular blood measurement could be taken. The patient attended the next appointment but forgot to fast so the blood test could not be carried out.

When RNIB held focus groups to explore these issues, they found that blind and partially sighted people were regularly expected to get a sighted person to read their personal information and convey this to them. This included the outcome of screening tests, and results in a loss in privacy and independence, which is the very opposite of a personalised health service.

It is important to distinguish between general health information (for example a leaflet about a disease or health condition such as diabetes, which may be available in different formats and languages) and information that is specific to the patient and may make a difference to the way in which care is provided for that patient (for example, patient X is a wheelchair user or patient Y is partially sighted and is able to read correspondence in large print). We found in our site visits that this was a distinction that most acute trusts and PCTs did not make. These organisations told us about their activities with blind

and partially sighted service user groups to produce general health leaflets in a format accessible to blind and partially sighted people, or leaflets about visual impairment. They could also point to examples of practice developed for specific services, such as the ophthalmology service's ability to produce letters in formats accessible to partially sighted patients. However, the same practices were not followed in the rest of the organisation. This meant that there was little or no monitoring of whether outpatient clinics or GP services could produce correspondence (as opposed to leaflets) in different formats. For example, we were told that correspondence from the ophthalmology clinic would probably be sent to a partially sighted person in their preferred format, whereas the fracture clinic in the same trust would send an appointment letter in standard print even though the partially sighted person would not be able to read it.

Our work with patients, carers and voluntary organisations revealed similar experiences for people with learning difficulties and their carers. Good practice that may have been developed in one part of the healthcare organisation was not embedded in the information systems and practices throughout the whole organisation.

In our site visits, as in the RNIB report, we found that some PCTs were beginning to build measures into their contract tendering processes to test whether service providers had the awareness and systems to ensure that personal information was used to provide appropriate care. The NHS contract may include provisions under the clauses to support equalities and disability legislation, but healthcare staff, in a variety of roles, appeared to be unaware of such policies and PCTs did not seem to monitor whether provisions are made nor did they challenge service providers who provided inadequate services.

This section has addressed the issue of whether and how information about a patient, which may be non-clinical, is used to shape the delivery of healthcare for their individual needs or those of their family. Our site visits and the RNIB survey suggest that performance is generally poor, with notable exceptions in NHS and independent sector mental health service providers. Fundamentally this is an area of healthcare that is not viewed as a 'mainstream' part of the information governance agenda in most organisations. Yet it is an issue where deficiencies in the handling of personal information can result in poor care for patients, including delays in access to care, loss of privacy and independence.

Example of notable practice: South Essex Partnership University NHS Foundation Trust

This trust provides health and social care services for people with mental health problems and people with learning disabilities. Its electronic care record system includes fields in which to record physical and other disabilities, as well as factors that may affect the care provided for the patient. In addition, the system includes a free text box to enable staff to record information that may shape how care is delivered for the patient. Examples of information include whether the patient is overweight and uses a non-motorised wheelchair, or if they must be seen or treated by staff of a particular sex because of their medical history or cultural needs.

The information from the free text box and the disability fields is automatically downloaded when the patient is called for an outpatient appointment. The outpatient lists are prepared at least one week in advance and enable clinic staff, who are part of the information governance and data quality network, to prepare for the clinic. This includes ensuring that the patient has received notice of the appointment in the appropriate accessible format as well as to ensure that the clinic is prepared for any physical or sensory needs.

The appropriateness of care provided is monitored in several ways including a network of 'mystery shoppers' who test the trust's services, point of use patient surveys, complaints and concerns and other patient engagement and advocacy activities.

6. Overcoming the barriers to good practice

We identified some common barriers to managing personal information well, by combining the conclusions from the analysis of data, the effect of information governance on the quality of patient care, and what we learned from our site visits and our work with patients, carers and voluntary organisations.

The impact of organisational change in the NHS

In October 2006, there was a major reorganisation of PCTs and ambulance service trusts, which had a sustained impact on information governance.*

In the 2006/07 assessment year (the first assessment year following the major mergers) 55% of merged PCTs declared compliance with the core

standards relating to information governance, compared with 80% of the PCTs that had not been formed by a merger.

When we looked at the information governance toolkit (IGT) assessments, 24 of the 40 lowest average scores for trusts were for merged trusts and only one of the top 40 scoring trusts was a merged trust.

The average IGT scores of merged trusts were statistically significantly lower than those of the trusts that had not undergone a merger. This difference in IGT scores only ceased to be significantly different in 2008/09, two assessment years after the mergers occurred.

Example of notable practice: South Staffordshire PCT

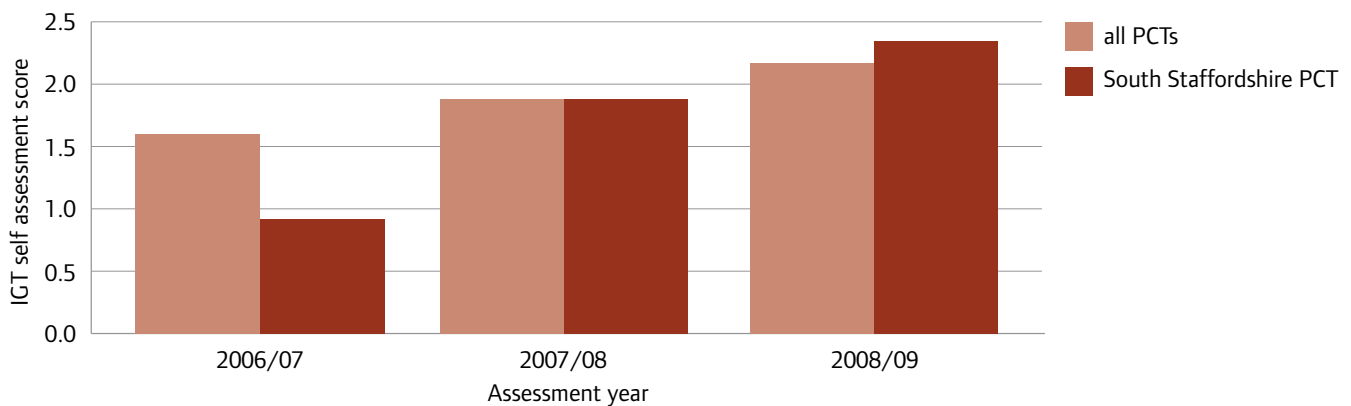
This trust was formed in late October 2006 by the merger of four primary care trusts. This substantial organisational change was used as an opportunity to review the trust's policies completely, to ensure that they fitted with national guidance and best practice and that they could be put into practice by staff working in a variety of community settings.

The trust uses an interactive IT network programme that alerts staff to consultations or the launch of new policies, provides links to the policy and specific training modules, tests their understanding and gathers formal acknowledgement of receipt and sign-up to policies by staff. The system is also used to provide interactive discussion between staff, enabling them to ask and answer queries, report near misses and share good practice.

This PCT uses NHS internal auditors to check a sample of its IGT self assessment scores. Figure 7 shows that the PCT's IGT average scores have improved substantially compared with the improvement in average IGT scores for all PCTs.

* There were also mergers of some acute trusts and mental health trusts, but these were not of the same scale. In the assessment year 2005/06, there were just over 300 PCTs. By 2006/07, there were 151 PCTs, 48% of which had been formed through a merger. The number of ambulance trusts decreased from 30 in 2005/06 to 11 in 2006/07. In the same period one acute trust out of 173 had been formed through a merger, and five of the 57 mental health trusts were formed through mergers.

Figure 7: Average IGT scores for each assessment year comparing South Staffordshire PCT with all PCTs



The conflict between good information governance and national guidance

During our site visits we found two examples of cases where national guidance and systems appear to contradict good practice. We were told that the wrist band automatically generated by the iPM patient administration system does not print out patients' date of birth in the preferred format of the National Patient Safety Agency (NPSA). The NPSA guidance also states that red wrist bands should be used for patients with allergies, but the black print generated by the iPM system is not clearly visible on a red wristband.

Guidance from the NHS Litigation Authority on standards in risk management states that stickers should not be placed on files containing patients' records. However, one organisation we visited identified a risk of confusing two patients with the same name and almost identical date of birth. Following a near miss incident, the organisation now places a red sticker on the files of patients with the same or similar names and dates of birth to alert staff to double check that the record selected matches the correct patient.

Those organisations we visited with good IGT capacity and capability were able to develop local systems and policies that safeguard patients and personal information despite conflicting with national guidance and systems.

Resources – investing in staff and technology

There have long been concerns about the capacity and capability of NHS organisations to make progress on all the elements of the national information governance agenda. An example is the role of the Caldicott Guardian (a senior person responsible for protecting the confidentiality of information on patients and services and enabling appropriate information-sharing, named after the 1997 report written by Dame Fiona Caldicott). In 2006, the Care Record Development Board found a general perception that Caldicott Guardians did not have adequate guidance and training, with insufficient emphasis on selecting the right person for this role. The report on information governance resourcing by the Digital and Health Information Policy Team during 2008 found that while organisations said that the role of the Caldicott Guardian was 'crucial' or a 'key role', most Caldicott Guardians could spend as little as one hour a week on the role.³⁰ When deficiencies were found in compliance with the basic patient confidentiality standard in NHS trusts (core standard C13c), performance was poor for those parts of the standard relevant to the role of the Caldicott Guardian.

The discussion at the national information governance conference in February 2009² demonstrated the confusion that is still apparent around who is best placed in an organisation to carry out the role of Caldicott Guardian. We also found

that a minority of organisations did not even have a designated Caldicott Guardian. In most organisations, the information governance team viewed the role of the Caldicott Guardian as being an advocate for patients and staff and a technical expert in information governance. There is a recognition that the information governance agenda is so varied and substantial that no single person could carry out both the advocacy role and have the information management technical expertise and responsibilities.

The resourcing report also found concerns about the recruitment and retention of information governance staff, particularly in London where the cost of living is high. It also reported variability in the grading of staff. We found in our site visits that organisations with relatively high average IGT scores had teams with experienced information governance staff who were well known for their expertise in the local health economy and belonged to professional networks for information governance staff. These staff often had direct access to, or were members of, the trust's board. Perhaps this also signalled the importance and priority that the organisation placed on information governance. These organisations had expertise embedded throughout the organisation by including information governance tasks in the network of clinical audit staff or carried out by administrative staff. Information governance expertise was seen as a development of the skills and knowledge of these staff, and enhanced their career prospects.

In our site visits, we found a mix of approaches to financing information governance. Some organisations had a dedicated budget, giving the information governance team autonomy to develop activities such as training. Others (in both the NHS and independent sector) signalled the importance of bidding or securing finance for specific information governance roles and projects through a business case route.

In summary, we found that good information governance does have a cost in terms of staff and technology. However, some organisations have maximised their investment in both these elements by embedding information governance throughout

the organisation or making it an activity integral to the delivery of healthcare services.

The responsiveness of national systems to local situations

The National Programme for Information Technology (NPfIT) will bring great benefits for patients and healthcare staff. Examples include better and faster clinical communication, a reduction in the number of errors, and wider access to specialist diagnosis and treatments through the transmission of medical images. Patients can also have more control of their own healthcare and their medical records. But there is a trade off between the efficiencies that a large scale initiative brings and its responsiveness to very local circumstances.

We noted in our site visits that the majority of organisations with high average IGT scores or particularly patient-centred systems had developed their own bespoke electronic patient record systems. These NHS and independent sector organisations had paid particular attention to tailoring the organisation's system using their knowledge of the patients they served and their staff who had to implement and use the system. All these organisations stressed the importance of ongoing engagement and involvement of clinicians in the development of the systems and the training programmes for staff using the system.

Organisations that did not have their own electronic patient record system were concerned about the cost, the efficiency and the responsiveness of national systems.

Some organisations we visited expressed mixed views about the Electronic Staff Record (ESR) which was implemented in March 2008. Some praised the system because limits could be set on the amounts of personal data about staff that were transferred between different parts of the organisation. Others were critical a year after implementation because:

- They had concerns about the security of the system because of the widespread use of the password to access the system.

- They found it difficult to alter fields in the system easily as it is a national system developed ‘outside the NHS’.
- The system still could not be used as the sole staff monitoring tool because of the lack of detail in some fields.
- It could not be used as a complete substitute for paper records.
- Not all staff have access to computers in order to book annual leave through the ESR.

It is important to recognise that an important factor in the development of IT systems is the level and quality of engagement between individual organisations and the systems’ developers. We did not set out to judge these aspects of the development and implementation of this system.

Local information governance networks

Our site visits highlighted the patchy nature of local information governance networks and sources of guidance. In line with the findings in the Digital and Health Information Policy team report,³⁰ we found some very active regional or local networks. These were fostered by experienced professionals who were well known to organisations in the local health economy. These networks were a source of expertise and advice for independent sector organisations such as hospices and independent practitioners such as GPs. However, in other parts of the country there was an absence of support and communication between trusts or independent sector organisations, even when the latter provided care for NHS patients. At one site, there was a contrast between (as they

Example of notable practice: Bradford and Airedale Teaching PCT

The trust was formed from a merger of four predecessor PCTs in October 2006. Key staff in the trust have been involved in local information governance for several years as part of the strategic health authority or in the predecessor PCTs. Staff stressed that the work carried out with GPs and other parts of the health economy was built on 15 years of investment in building IT and information governance capacity in the area. The trust recognised that dedicated extra resources would be needed to ensure that GPs and other independent contractors were compliant with good practice. It therefore bid for, and secured funding for a specific member of staff to work with independent contractors.

The trust assessed each of the 85 GP practices using a version of the IGT specific for GPs. GPs were already part of the PCT’s IT network and an audit of information security had also already been carried out in each practice. The member of staff recruited to the project visited all practices and presented briefings at local area and individual practice meetings. She also developed a resource pack for GPs and practice managers and was readily available to answer queries and support GPs and their staff. This resulted in a constructive and cooperative relationship between the PCT’s information governance team and the individual GPs.

The PCT developed specific training tools for staff, which included assessments of their knowledge and perceptions of information governance, and delivered training in imaginative and creative ways using practical examples and scenarios.

The PCT provided incentives for GP practices to achieve level 2 on the relevant standards in the IGT. For example, in order for a practice to be granted enhanced provider status, it had to achieve a level 2 score for the IGT themes relating data quality.

All GP practices contracted to provide care by the trust have achieved level 2 on the IGT, and work now continues with other groups of independent contractors such as dentists and optometrists. The feedback from GP practices has been positive and they recognise that good information governance practice improves the safeguarding of patients and staff.

saw it) the non-existent information governance network and the controlled drug local intelligence network. The latter was characterised as a valued and inclusive forum for organisations (NHS, independent sector and non-health organisations) across the locality.

Cultural and technical barriers to sharing information

One of the issues mentioned earlier in this report, which has been raised by organisations from regulatory bodies to patient representatives, is the variability in engagement and practice of independent practitioners such as GPs, independent sector organisations and non-health organisations such as social services.

We found a perception by some healthcare staff that some GPs did not have the capacity to develop secure information governance systems. Some of the independent sector organisations we visited expressed frustration that NHS trusts cited patient confidentiality as the justification for not sharing clinical information about patients. Healthcare organisations (NHS and independent sector) criticised the standards of practice in non-healthcare organisations such as nursing homes and social services departments.

Formal information-sharing agreements and protocols and participation in functioning information governance networks have the potential to break down these barriers. Some of the barriers are technical (lack of access to the NHS mail system and/or lack of a common patient identifier). However, there are cultural issues between health professionals in different healthcare settings and between health and social care professionals. If joined-up services are to be an everyday reality, these cultural barriers will need to be explored and broken down.

Our work with patients suggests that some healthcare staff appear to have a contradictory attitude to patient information. Patient confidentiality could be used as a reason for 'withholding' information about patients from carers or family members, yet at the same time, patients told us they had witnessed health professionals talking about patients in public places such as hospital corridors and lifts or at the reception desk in GP surgeries. As noted in the previous section, people of all age groups and social groups are much more inclined to consent to sharing their information if they know what level of information will be shared (is it demographic information such as date of birth and address or is it history of sexual or mental health?), and the purpose and benefits to the individual.

National priorities – security versus data quality

Our analysis of the IGT assessments showed that the elements of the IGT that relate to confidentiality and security of data had higher average scores than those for the quality of data. This is perhaps unsurprising given the raised awareness and priority, signalled through a series of letters relating to data security sent to NHS trust chief executives from the Department of Health since 2007. These letters have specified the policies and practices that must be in place to help ensure the security of person-identifiable information.

The focus of information governance now has to shift to improve the elements that deliver services that are responsive to, and supportive of, individual needs, and that improve patients' safety and provide the right clinical outcomes.

7. Moving forward

This study set out to look at how healthcare organisations manage personal information. We wanted to look beyond the personal data security stories that have hit the headlines over the last two years. In this chapter, we summarise the key findings and make recommendations for action to help improve information governance and the contribution that these systems make to the care of patients.

Improving performance in healthcare organisations

We found that most NHS healthcare organisations have improved their systems and processes for managing patients' information over the last three years. In general, the systems needed to manage patients' information adequately are in place, but some of the detailed elements that help to deliver safe, high quality care are missing.

There are sectors in the NHS, such as PCTs and ambulance trusts, where progress towards compliance with basic standards and the more detailed elements of information governance has been slow. A small number of organisations in these sectors have failed to meet one or more of the basic information governance standards over two consecutive years. In PCTs, this may have implications for their capacity to monitor and drive improvements in the performance of the organisations from which they commission care.

The deficiencies in the management of patient information in the NHS mainly relate to how patients' records are created, stored and disposed of properly and how staff are trained to fulfil these tasks. In the independent healthcare sector, poor performance

is focused on the detail of how patients' records, particularly multi-disciplinary records for patients using mental health services, are completed and filed. These elements of information governance are important because if medical records are incomplete or are not stored and disposed of properly, then patient care may be compromised because the right information may not be readily available to help inform the patient's treatment and care.

Most NHS and independent sector organisations ensure that they seek consent when they share personal information and they keep patients' information confidential. However, a small number of organisations fail to provide evidence of systems to review and justify the use of patient information and to monitor whether staff comply with the Data Protection Act 1998 and the NHS Code of Practice on Confidentiality. These are important parts of the role of the Caldicott Guardian.

When we looked at the performance of NHS trusts in more detail using the IGT, we found that average scores across all the information governance themes have improved over the last three years. As with the basic standards, trusts in the acute and mental health sector had higher average scores than PCTs and ambulance trusts. However, for all types of trust, there is still a large gap between trusts' own assessment of performance and the requirements of the NHS operating framework for 2009/10, which must be met by March 2010. This should mean that all trusts will focus on improving information governance during 2009/10. In the independent sector, the incentive to improve IGT scores is partly driven by the need to demonstrate compliance in order to gain access to the N3 network and to contracts to provide care for NHS patients.

Recommendations

1. Healthcare providers

- Senior managers, including members of the organisation's board, should include a wider range of performance indicators in their systems of assurance. These reports should include measures of the quality of data as well as whether the data are submitted on time. The board should treat the accuracy of patient data in a similar fashion to that of financial data.

Members of the board should signal the importance of high quality data by ensuring that adequate policies and guidance are in place to ensure consistency and improve overall awareness of the importance of data quality and assurance. The board should ensure that there are clearly defined responsibilities and accountability at board and managerial level for the quality of data, and that the board has the knowledge and expertise to understand and challenge issues on data quality. Boards could use the publication of benchmarks of data quality to provide incentives

for more accurate data collection, analysis and submission. For example, the Audit Commission's report *Figures you can trust* includes five questions that boards should ask themselves about quality of data.³¹

In addition, healthcare providers must ensure that they adopt and adhere to guidelines for good practice relating to record-keeping of patients' information for all registerable services that they provide.*

- Healthcare providers should review and develop their information governance systems, drawing on the expertise and views of patient and public groups. The information governance team (including the Caldicott Guardian) should join up their work with the staff responsible for working with patients in service user groups in the healthcare organisation. In this way, good information governance systems are more likely to be a means of delivering better care. The work of service user groups should include activities to ensure that good practice is

Examples of data quality indicators

- Discharge summaries. These must be submitted within the improving timescales set out in the NHS contract. However, the format of the summary is not set centrally. Examples include:
 - the percentage of summaries with the correct Hospital Resource Group code.
 - the percentage of summaries with complete and correct patient demographic data.
 - the percentage of summaries with the correct NHS number recorded.
- Mental Health Minimum Data Set.
 - the percentage of records with a complete primary diagnosis code in the quarterly submission to the Information Centre.
- Percentage of verified NHS numbers for patients/service users in electronic clinical care record systems.
- Percentage of patients with up-to-date clinical summaries.
- Develop an action plan to improve the quality of data submitted to the Information Centre and monitor progress through scrutiny of the Information Centre regular reports.

* From April 2010, all NHS trusts must be registered with the Care Quality Commission and from October 2010, all independent healthcare providers must register in order to be able to operate.

developed in a particular area of the organisation where patients have specific needs (including disabilities and cultural), and that this is then embedded throughout the service. Practical examples include ensuring that correspondence is automatically sent to patients in their preferred format from all parts of the organisation.

- All healthcare providers should ensure that training on information governance takes into account the perceptions and views of staff and patients on issues such as patient confidentiality. Providers need to pay particular attention to the 30% of staff (over 40% in ambulance trusts) who report that they have not had training, learning or development during the last two years in this important topic. Information governance and workforce development teams should work together to ensure that training and development is tailored to particular roles and that it addresses the different perceptions of risk associated with information governance. This should be provided to all relevant staff.

2. Commissioners of healthcare

- Organisations that commission healthcare have the potential, through World Class Commissioning*, to use the commissioning function as a lever to improve information governance in the organisations from which they commission care. They should build appropriate measures into the contract tendering process and in the subsequent monitoring activities to ensure that information governance systems are used to deliver care that is tailored to the personal needs of the patient and their families, and also to ensure that the data are accurate and held securely.
- Commissioning organisations should include scrutiny and assurance on confidentiality training and competence as part of the contract tendering and monitoring process. This should apply to contracts with voluntary organisations, who may

provide advocacy services, as well as NHS and independent healthcare providers.

3. Strategic health authorities (SHAs)

- SHAs should revitalise local information governance networks as a vehicle for spreading good practice. Such local networks could help to improve cooperation between health (NHS and independent sector) and non-health organisations. They may also help to improve the performance of trusts that are lagging behind in the delivery of the NHS Constitution pledge on sharing information with patients.

4. Local involvement networks (LINKs)

LINKs aim to give citizens a stronger voice in how their health and social care services are delivered. Run by local individuals and groups and independently supported, the role of LINKs is to find out what people want, monitor local services and to use their powers to hold them to account. Each local authority (that provides social services) should have a LINK in place. Although these organisations are relatively new, they build on the work of patient advocacy groups and representatives of patients and the public such as overview and scrutiny committees and patient groups and forums in individual healthcare organisations.

- LINKs and patient advocacy groups should monitor and campaign for the better use of information governance systems to ensure that personalised care is delivered throughout each healthcare organisation.

5. The National Information Governance Board for Health and Social Care (NIGB)

The remit of the newly-established NIGB covers both health and social care. It also has a strong focus on patients and has experience, credibility and expertise in how patients' information can be used, for example, in medical research.

* World Class Commissioning separates the commissioning of services from the provision or delivery of healthcare. It aims to provide a more strategic and long-term approach to commissioning services, with a clear focus on delivering improved health outcomes.

- The board should advise on the cultural and technological barriers to staff working together across health and social care sectors. It should explore the attitudes and concerns of patients about sharing information between these sectors. It should then develop practical models for implementing information sharing agreements throughout the wider health economy. Information sharing protocols are available, but it is the practical implementation of these agreements, taking into account the views of patients and carers, that is harder to achieve.
- The board should encourage all organisations that develop national systems and guidance that affect information governance to consult with them before a system or guidance is implemented. This would help to minimise the conflicts between national systems (such as the patient wristband system) or guidance and information governance practice. The board can also scrutinise the quality of engagement between people who develop national systems with those who have to put these systems into practice.
- The board should help to promote the efforts of the Information Centre and the Independent Healthcare Advisory Service to harmonise the data collected from NHS and independent sector providers, to ensure that patients have the data needed to make informed choices about their care.
- The board should be an advocate, on behalf of the health and social care sectors and for patients, by insisting on transparency and clear central national analysis and reporting of information governance-related SUIs. In this way, the number and effect of SUIs could be put into proper context, explaining where personally identifiable data really has been put at risk and the relative scale of the information lost to the amount of information handled.

6. Connecting for Health

- Connecting for Health should continue to develop the tools that support the performance assessment of organisations and management of information to reflect care pathways for patients (for example,

mental health services), and outcomes for patients such as the safety and quality of care. This would support a shift in the information governance agenda to include the use of information governance systems and processes to improve the personalisation of care, as well as maintaining the security of personal information.

- Connecting for Health should ensure that the external validation and audit (by NHS internal audit or external auditors) of healthcare organisations' IGT self-assessments are mandatory. The IGT will then be a performance assessment and management tool to help individual trusts to develop action plans to focus on those parts of information governance where the most improvement is needed.

7. The UK Council for Caldicott Guardians

- The council should encourage all health and social care organisations to have a designated Caldicott Guardian working as part of the wider information governance team. Caldicott Guardians should participate in work to understand the reasons why patients and staff view confidentiality of personal information differently. They should ensure that such insights inform the development of appropriate training for staff and contribute to a shared understanding with patients of the issue of confidentiality.

8. Regulators

Pathways of care for patients can be complex. They can involve care being delivered by staff working in different locations and for different organisations within the NHS or in the independent sector, or from social care organisations. A number of regulators assess and report on compliance with basic national information governance standards and the quality of data produced.

- Regulators should evaluate the quality of local information within their performance assessments. They should examine whether and how personal information is transferred across care pathways and the impact this has on the outcome and quality of care for patients.

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Appendix A: Summary of main data sources analysed in the study

Compliance with core standards		
<p>NHS trusts providing:</p> <ul style="list-style-type: none"> • Acute services (hospital based care). • Ambulance services. • Mental health services. • Primary care services. 	<p>Percentage of each type of trust compliant with core standards C9, C13b, C13c.</p> <p>Compliance figures include only those trusts declaring that they had met the standard for the whole of the assessment year.</p> <p>Non-compliant trusts are those organisations that declared 'insufficient assurance' or 'not met' or trusts which declared that they had 'met' the standard but this judgment was not supported at a core standards assessment visit.</p>	<p>Assessment period: (1 April to 31 March) 2006/07 2007/08</p>
<p>Independent sector organisations providing care predominately (equal to or over 50%) for NHS-funded patients:</p> <ul style="list-style-type: none"> • Acute services, including ISTCs. • Mental health services. • Hospices. 	<p>Percentage of organisations inspected against National Minimum Standards C29, C30, C31.</p> <p>Compliant organisations were judged to have met the standard. Non-compliant organisations were judged to have 'almost met' or 'not met' the standard.</p>	<p>Assessment period: 1 April 2007 to 31 March 2008</p>

Detailed requirements in the information governance toolkit (IGT)		
NHS trusts	<p>The average score was calculated using the trust's self-assessed score (0, 1, 2, or 3). Each question that applied to the trust was given the same weight when the average score was calculated for each information governance theme or for the overall IGT score.</p>	<p>Assessment period: (1 April to 31 March) 2006/07 2007/08 2008/09</p>

The views of patients		
Annual national NHS patient survey programme	Survey of adult inpatients in NHS hospitals in England, 2007. Respondents were 76,000 adult patients from 165 acute and specialist NHS trusts answering the survey between October and December 2007.	Summary data from 2002, 2005, 2006, 2007 are included in the report.
	Survey of patients' experiences of local health services in England 2008. Respondents were 69,000 people registered with a GP (in 152 PCTs) responding to the survey between January and April 2008.	Summary data from 2004, 2005 and 2008 are included in the report.
	Survey of community mental health service users in England 2008. 14,000 completed questionnaires received from service users aged 16 to 65 years from 68 trusts (including combined mental health and social care trusts and those foundation trusts and primary care trusts that provide mental health services).	Summary data from 2004, 2005, 2006, 2007, 2008 are included in the report.
Independent sector treatment centres (ISTCs)	1,973 responses to a questionnaire of patients receiving care in an ISTC between April and October 2006.	2006
Healthcare Commission patient and public engagement compendium	Commentaries from Patient, Public Involvement Forums (PPIFs) and Overview and Scrutiny Committees (OSCs) on the annual core standard declarations made by NHS trusts. Feedback from patient groups including PPIFs and OSCs to local assessors as part of local engagement activities. Workshops and meetings with voluntary organisations and patient groups as part of the Healthcare Commission patient and public engagement activities.	2005 to 2009
Information governance workshops	Two workshops addressing patient information issues with voluntary organisations and patient groups (including 'Seldom Heard' network).	January and February 2009

The views of NHS staff

Annual national NHS staff survey programme	Survey of staff in 391 NHS trusts in England. 155,922 questionnaires were returned in October 2007. GPs and their staff were not included in the sample.	Summary data from 2005, 2006, 2007 are quoted in the report. Data from the 2008 survey are also reported.
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Site visits

Visits took place in March 2009. Each visit lasted one day and comprised structured interviews with staff identified by the organisation as key to information governance. The interview questions explored a range of information governance issues raised by healthcare staff, healthcare organisations, patients, the public and voluntary organisations or were derived from the analysis of information governance performance on basic standards.

The organisations were chosen to provide:

- A mix of type of services and organisations providing care or services in the NHS and independent sector (hospital, mental health services, primary care, end-of-life/palliative care, strategic health authority and third party data processing).
- A mix of information governance performance including consistently high scores, consistently average or poor scores or markedly improving scores on the IGT.
- Organisations that had met the information governance-related basic standards in inspections in the independent healthcare sector.
- A geographical spread (South East, East of England, London, Midlands and North of England).
- A mix of large and small organisations, foundation and non-foundation NHS trusts.

Appendix B: Assessment of core standards

Standards for Better Health

The Department of Health published *Standards for Better Health* in 2004 and updated them in 2006. The standards describe the level of quality that NHS healthcare organisations are expected to meet and they represent the minimum level of service that patients and service users have a right to expect. NHS trusts in England are assessed against 24 core standards.

Compliance with these core standards is currently assessed as part of the annual health check. The assessment uses trusts' own declaration of whether they have met each standard. It combines this with an information-based checking process and assessment visits to trusts selected at risk of non-compliance with one or more core standards. Performance of these trusts is also compared with assessment visits to trusts selected at random.

The main core standards relevant to information governance are:

Governance domain:

Core standard C9 - Healthcare organisations have a systematic and planned approach to the management of records to ensure that, from the moment a record is created until its ultimate disposal, the organisation maintains information so that it serves the purpose it was collected for and disposes of the information appropriately when no longer required.

Patient focus domain:

Healthcare organisations have systems in place to ensure that:

C13b - appropriate consent is obtained when required, for all contacts with patients and for the use of any confidential patient information.

C13c - staff treat information confidentially, except where authorised by legislation to the contrary.

National Minimum Standards

Independent healthcare organisations have been subject to the Government's National Minimum Standards since 2000. These standards include 32 core standards with which all organisations must comply and standards that are specific to the type of services provided by the individual organisation, for example, acute hospital, mental health services, or hospices.

The main standards relevant to information governance are in the Records and Information Management domain:

C29: Records management

Records are created, maintained and stored to standards which meet legal and regulatory compliance and professional practice recommendations.

C30: Completion of health records

Patients are assured of appropriately completed health records.

C31: Information management

Patients are assured that all information is managed within the regulated body to ensure patient confidentiality.

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