Report of the National Information Governance Committee

July 2015

Summary and recommendations

1. In an interim report in September 2014\(^1\) the National Information Governance Committee (NIGC) made three recommendations, which were endorsed by the Care Quality Commission’s Board. They outlined improvements in the inspection system to help the Care Quality Commission (CQC) discharge its statutory duty to monitor and improve the information governance of health and social care providers.

The first recommendation called for the introduction of a mandatory element in inspections “to ensure that questions about the role of information and information governance in supporting good quality care are asked by inspectors on every inspection and assessed without fail.” Access to reliable and accurate information is a crucial underpinning to all of CQC’s regulatory activities including inspections, and demonstrates the overlap between information governance issues and clinical governance failings\(^2\). After advice from the NIGC, the CQC Executive Team was already considering the introduction of an Information Governance (IG) - specific Key Line of Enquiry (KLOE) for healthcare inspections. The CQC board agreed at its meeting on 17\(^{th}\) September 2014 that the IG KLOE should be structured into all the CQC provider handbooks\(^3\) for hospital and general practice inspections. The NIGC welcomed this positive response, which meant that no healthcare inspection could be regarded as complete without questions being asked about information governance.

As a result, CQC inspection teams have learned more than before about providers’ ability to manage information governance to improve the quality of care given to patients, service users and their carers. Unsurprisingly they have found that standards are variable. There is much good practice, but inspectors also identified lapses that put people at risk, including failure to maintain up-to-date care records that are accurate and securely held. There is plenty of positive evidence that providers are sharing information well within the direct care team, but there are also many examples in hospitals and adult social care of poor handover arrangements that could prejudice the continuity of care and contributes to death in some cases\(^4\).

Recommendation 1: We recommend that the CQC should ask providers to learn from the evidence of inspections. In particular we urge providers that failed to uphold the highest standards of information governance to learn from the good practice of others.

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\(^1\) Link to Interim Report of the National Information Governance Committee

\(^2\) NPSA: http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=134790&type=full&servicetype=Attachment

\(^3\) CQC Provider Handbooks are published on the CQC website and describe CQC’s approach to regulating, inspecting and rating organisations that provide care which CQC regulate

\(^4\) http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=60046&type=full&servicetype=Attachment
2. Other aspects of the NIGC’s interim recommendations have not yet been fully implemented. The interim report called for procedures to ensure that findings about providers’ information governance are included in all inspection reports. It said: “To discharge its responsibility to monitor information governance, the CQC must not only ask the right questions; it must also capture the answers.” This objective has not yet been consistently achieved in all reports. Analysis on pages 12-22 of this report shows that it is not possible to look consistently across the field of recent inspections to draw conclusions about the state of information governance among providers. Although inspectors must report on each domain of inspection, they do not have to comment on each KLOE within each domain in the published inspection report. As a result, reporting on information governance is patchy. All reports do mention it but they deal with it in different ways. The CQC should be able to look across all its inspection reports to draw national conclusions about information governance performance. As things stand, it cannot do so. This is a general consequence of the system for reporting and there is no reason to believe that information governance is particularly disadvantaged. However, the CQC board should consider how it can effectively carry out its statutory duty to monitor information governance if the evidence is not contained in inspection reports and available for national analysis.

Other points in the NIGC’s interim report recommendations in 2014 included:

- Having made the role of care and treatment information a mandatory part of the inspection framework, it will also be important to ensure that inspectors use this evidence to draw relevant conclusions in inspection reports. To discharge its responsibility to monitor information governance, the CQC must not only ask the questions; it must also capture the answers. The NIGC therefore recommends a clear closure procedure for reporting on the IG KLOE and IG-relevant prompts.
- The NIGC agree that capacity and capability throughout the inspection process is crucial. There should be information and IG capability within the inspection teams themselves. The final part of the information governance assurance process is that it is particularly important that the CQC ensures there is sufficient analytic capacity and capability for this important area of work. Having asked the right questions (recommendation 1) and captured the answers (recommendation 2), it will be important to spot trends and identify areas for improvement. An evidence management system enabling CQC to drill down into its inspection evidence would also be of great benefit, but clearly not just in the realm of IG.

These points also represent unfinished business for the CQC.

The CQC should ensure that each inspection team has the expertise to deal with any IG issues highlighted within their inspection. To achieve this, the CQC should carry out a training needs analysis to assess the need for initial and continuing training. Based upon this analysis, the CQC should put in place an appropriate training programme to meet the identified needs, and ensure that all inspectors have adequate and appropriate IG training.

**Recommendation 2:** We recommend that the CQC Board completes the task of implementing all the recommendations in the NIGC interim report.
3. The CQC should also do more to monitor and improve information governance among providers by giving greater attention to IG at the pre-inspection stage. Dame Fiona Caldicott, the National Data Guardian, said in the Independent Information Governance Oversight Panel report in December 2014: “Action in every health and social care organisation should be monitored using a new version of the Information Governance Toolkit\(^5\), which should measure how well the organisation is implementing the Caldicott\(^2\) recommendations and, in particular, how well it performs in sharing information for direct care.” The CQC should contribute by using the results from this Toolkit in its pre-inspection assessment of each provider, to identify useful avenues of inquiry during inspection. Systematic use of the Toolkit would improve monitoring and also act directly to improve performance. The CQC should use feedback from the Information Commissioner’s Office (ICO), the public, patients and service users on their experiences to guide this pre-inspection work, together with intelligence about information security among providers gathered from a security assessment framework offered by the Health and Social Care Information Centre (HSCIC).

**Recommendation 3:** We recommend that the CQC enhances its pre-inspection procedures to pay more attention to information governance including the views of people who use services, the public, and the IG Toolkit.

4. Looking ahead, we expect issues of information governance to gain increased significance as organisations adopt the new provider models envisaged in the NHS Five Year Forward View. Also, the drive to integrate health and adult social care cannot succeed without an improved flow of information across traditional organisational boundaries. Procedures adopted by providers to help this happen – to improve services for people without endangering their confidentiality and trust – will depend on effective information governance. We noted an important proposal in the CQC’s report in April 2015, “Shaping the Future\(^6\)”, which looked ahead to possible changes in the regulatory model. This report set out how CQC would do this by regulating new care models, looking at the quality of care pathways, and looking at quality of care in localities. The board committed to two “place-based” pilots, which will seek to inspect every aspect of health and adult social care provision in two geographic areas. This “placed based” work will provide a golden opportunity to inspect across sectoral boundaries to establish how information is being shared among hospitals, primary care, mental health and social care, particularly at discharge and handover points.

**Recommendation 4:** We recommend that information sharing and other aspects of information governance should be a key focus of the CQC’s “place-based” work.

5. To facilitate this we believe the CQC board should reconsider the lack of an Information Governance -specific KLOE for adult social care. Although the board decided to avoid further

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\(^5\) The Information Governance Toolkit is an online system which allows NHS organisations and partners to assess themselves against Department of Health Information Governance policies and standards.

changes to the inspection handbooks before September 2016, we would expect there to be a review at that point. The board should examine the evidence about how well the Information Governance prompts have worked in adult social care and whether Information Governance features adequately in adult social care inspection reports. The CQC’s report “Cracks in the Pathway”, which looked at problems in dementia care, drew attention to poor information sharing between hospitals and adult social care. It seems odd that information sharing should be an important focus of that review, but not a necessary part of adult social care inspections.

**Recommendation 5:** We recommend that the CQC board acts to ensure that its monitoring of Information Governance is at least as effective in adult social care as in other areas of inspection.

6. In addition to improving its monitoring of information governance, the CQC has a responsibility to improve the Information Governance practice of health and social care providers. We note that in early 2015 the CQC produced a publication “Celebrating good care, championing outstanding care”, which focuses on good or outstanding performance. It would be extremely helpful if this or another publication would highlight good and excellent practices in information governance, such as sharing information well across organisational boundaries for the direct care of patients and service users. Communication materials, such as posters and information leaflets, should be used by inspection teams and providers, so that everyone knows “what good looks like” and what impact “good” Information Governance has on safe care.

**Recommendation 6:** We recommend that the CQC does more proactively to encourage safer and more effective care by promoting good information governance practices.

7. The CQC should also work with other national organisations with expertise in areas such as information security, to develop frameworks for assessing Information Governance competency that could be used at the pre-inspection evidence analysis stage. This work has already commenced, with the Memorandum of Understanding (MOU) with the ICO is a good example that we hope will be further developed, and replicated to participate fully in an integrated approach to information governance.

Furthermore, the work of other key players in the Information Governance arena is becoming more significant and should be assessed against the work of CQC on an on-going basis. A key contribution is likely to emerge from the National Information Board’s Framework for Action, specifically work stream 4, which focuses on building and sustaining public trust.

**Recommendation 7:** We recommend that the CQC ensures that it has processes in place to liaise more effectively with other organisations in this complex landscape.

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8http://www.cqc.org.uk/content/celebrating-good-care-championing-outstanding-care-1]
8. The terms of reference of the NIGC said it must be in place until 31st March 2015, at which time the CQC board would review its role and determine if it is still required. The board deferred that review to give the NIGC time to complete this report, including analysis of the Information Governance content of the new wave inspections. The NIGC does not expect to exist in perpetuity, but its members stand ready to continue to offer advice, if the CQC board wants it. Our sense is that the CQC, as an organisation, is still in the process of learning how to discharge its responsibilities for information governance. It needs help and advice of some sort.

The CQC must understand and accept the increasing risk that a lack of advice on the monitoring and improvement of information governance presents. The digital revolution is upon us and to help providers deliver safe care in this environment the CQC must ensure that the security and Information Governance underpinning the pervasive technology is continually improved in a rapidly changing environment. As the NIGC has not yet finished the job it started, there is a risk that the CQC is seen to be minimising the importance of Information Governance at a time when Information Governance risks are increasing and that the CQC is failing to lead by example, by discontinuing the Information Governance leadership the NIGC has brought about. Most importantly, the CQC must ensure that provisions are in place to ensure the public feel reassured that the services they use are safe and secure.

**Recommendation 8:** We recommend that the CQC Board continues to make arrangements to take advice on Information Governance.

**Recommendation 9:** We recommend that the CQC clarifies how it will take corporate responsibility for ensuring that the organisation fulfils its responsibility to monitor and seek to encourage improvement in the Information Governance practice of health and social care providers.

**Recommendation 10:** We recommend that the CQC board should commit to reporting annually in both the State of Care report and the CQC Annual report on how it has discharged its statutory responsibility to monitor and seek to improve the Information Governance practice of health and social care providers.

**Main report**

1. This is the first formal full report written by the National Information Governance Committee (NIGC) for the Board of the Care Quality Commission (CQC). The report has main two purposes: to present the main findings from CQC inspections on information governance issues since the publication of its interim report; and to consider the main options open to the CQC Board to address these issues in the future. Also the report should be useful to the public and those who lead information governance work within organisations providing care, including Caldicott Guardians, as it contains examples of good practices of information governance found from CQC inspections that others can follow.
The role of the National Information Governance Committee

2. The Health and Social Care Act 2012 gave CQC new legal responsibilities from 1 April 2013 for monitoring and seeking to improve registered providers information governance practices. It did not give CQC any new powers in relation to these functions. CQC was required to set up a National Information Governance Committee (NIGC) to provide this advice, which was established in June 2013. NIGC’s role is to provide independent and objective advice on development and delivery of CQC’s information governance monitoring functions. The monitoring of registered providers can be undertaken in a number of ways as the duty is broadly drawn and it is not specific on the extent or method of monitoring.

3. The NIGC has two main objectives (more details of its role and activities is in Appendix A):
   - To provide advice and support to CQC so that it establishes a confident and meaningful approach to monitoring information practices among registered health and social care organisations which can be effective on an on-going basis; and
   - To use learning from CQC’s activities alongside the committee’s expertise in the field to highlight good practice and identify main areas for learning and improvement in the way that information is used to support good quality care for all people who use health and social care services and to share these appropriately.

4. The Committee has met quarterly, with an update provided to the CQC Board after each meeting. A key achievement has been the advice to the CQC Board that has resulted in specific questions for inspectors to ask in the Key Lines of Enquiry in every new style acute and PMS sector CQC inspections to test a provider’s approach to information governance.

5. This report makes a number of recommendations to the CQC Board based on considering the following:
   - The introduction looks at the importance of information governance to people’s experience of care and how the work of the NIGC fits into CQC’s new approach to inspection and regulation.
   - Part 1 contains an analysis of the main findings on information governance from CQC inspections based on a recent sample of 27 inspection reports that have used the new Key Lines of Enquiry for Information Governance and considers five main themes that have emerged that providers need to manage. Also there are examples of good practices found from inspections.
   - Part 2 considers how CQC needs to take its work on information governance forwards including consideration of the likely strategic challenges in the next five years, the role of strategic partners and the unique contribution that CQC can make.
   - Part 3 contains the recommendations from NIGC to enable CQC to be effective in discharging its statutory duty.
   - Appendices which provide more details on specific issues.

Introduction

Why is Information Governance important?
6. Information governance is important to the public, people using services and staff working in services because:

- The promise of confidentiality has been the cornerstone of medical practice for centuries and the relationship of trust between a doctor and patient depends upon it. The patient needs to be able to tell the truth about intimate matters, knowing that this information will not be improperly disclosed. This is equally important in social care, for example when a social worker is making arrangements for an individual’s care and well-being.
- Also individuals need to know that the team of people who are responsible for their care share information reliably and effectively. Confidential information about an individual must not leak outside the care team, but must be shared within the team in order to provide a seamless, integrated service. Indeed lives may be lost if information is not shared as it should be.
- Across England, more than a million people a day make contact with health and social care services, expecting they can trust the professionals looking after them with confidential information.

7. Information governance is concerned with promoting how information is used to support the care of patients and people using services. It has an important legal framework and there is a wide range of guidance from a number of authorities concerning how it should be used for the benefit of patients and service users. Information governance includes:

- data protection, confidentiality and privacy
- freedom of information and open data
- management of information and records
- information that is accurate and up-to-date
- information security; and
- governance, management and oversight.

8. It is an integral part of corporate governance. All people who use patient and service user information have a personal responsibility to use it responsibly and within the legal and advisory guidelines. All health and adult social care providers are required to demonstrate that they have achieved the standard of information governance required by the Department of Health which are set out within the Information Governance Toolkit. Service providers self-assess their scores, and these are published in full on the Health and Social Care Information Centre website, for the public to see. There is a documented body of knowledge that this is an issue that impacts upon good quality care. [link to add]
9. The main objective in establishing these standards is to ensure that ‘the right information is in the right place at the right time’ for the support of patient and service user care. Such information is an integral part of good quality care. Without it, there can be problems such as missed appointments, missed procedures, ‘never’ events and other mistakes which have led in some cases to very poor care, which has been detrimental and damaging to the individuals concerned, or even to the death of individuals.

10. The importance of information governance may be shown in the contrast between good information governance (Figure 1) and bad information governance (Figure 2). The importance of good information governance cannot be overstated. Examples of similar material could be used by CQC inspectors and providers as communication materials, such as posters and information leaflets, so that everyone knows “what good looks like” and what impact “good” Information Governance has on safe care.
Figure 1: What good information governance looks like

The right information in the right place at the right time

A. Miss Green sees her GP about her stomach pain. The practice manager has already given her a leaflet about how patient information is used.

B. The GP explains that he will use her information to make a referral to a consultant at the hospital. He records her allergies. He shows her a copy of the record.

E. The GP can see straight away what has been diagnosed, by looking at the note on the shared record. So when Miss Green asks him about her treatment, he can answer, without having to wait for a letter from the consultant.

D. The consultant thinks that she could have a kidney infection. But he can see from the shared record what her allergies are, so when heprescribes some medication, he can take this into account.

C. The consultant, whom Miss Green has never met, wants to access her shared electronic record and asks her consent. She agrees. This means she doesn’t have to repeat her story again.
11. It is essential to have good information as it is a key component of delivering good care. By having the right information in the right place at the right time, patients can be assured that clinicians have the facts that they need, in front of them, to ensure that the appointment or procedure won’t be cancelled. Patients won’t have to repeat all aspects of their history, which can be very frustrating for them. Good information governance ensures that allergies and other important medical facts are recorded accurately and can be taken into account.
12. Improved sharing of patient or service user information can speed up processes, prevent duplication of effort, reduce hospital admissions and save professional time, as for example, in the Bristol-based multi-agency sharing approach 'Connecting Care'.

13. Appropriate information sharing can prevent serious harm or death, particularly when it concerns vulnerable people. There are many enquiry reports into such deaths and where information has not been shared is cited as a causal factor.

14. It is important that lapses in the protection of personal information are not seen as an excuse for not sharing information appropriately when it is needed to provide good care and prevent serious adverse events. As the ICO told the Information Governance Review in 2013 (Caldicott 2) ‘No civil monetary penalties have been served for a breach of the Data Protection Act due to data sharing which has been appropriately shared and which has a legitimate data sharing agreement’

15. As the Caldicott principles set out (see Appendix E), good information governance is about protecting sensitive information from inappropriate disclosure and ensuring that timely accurate and sufficient information is available to support care when required. It provides assurance to patients that their information is being used respectfully, confidentially and in their best interests. It includes informing patients about how their information is used, being clear who sees it, and when the patient’s consent will be sought. It ensures that the duty of candour is understood and that this includes explaining patient’s rights to them. The NIGC would like to affirm its support of the Caldicott principles. We expect that all organisations registered with the CQC should comply with them.

Part 1: Analysis of what CQC has found on information governance during its inspections


19 https://www.gov.uk/government/publications/the-information-governance-review
CQC’s new approach to regulation

16. In 2013, as the NIGC was being set up, CQC published a new three year strategy, rolling out a fundamental reform of the model of inspection. The purpose of the new model is to make sure health and social care services provide people with safe, effective, compassionate and high-quality care, and to encourage services to improve. The CQC aims to put people who use services at the heart of its work. CQC has five key questions that it believes matters to people that are always asked in its new approach to inspections:
   - Are services safe?
   - Are services effective?
   - Are services caring?
   - Are services well led?
   - Are services responsive to people’s needs?

17. This new approach is intended to allow far deeper insight and that allow services to be rated on the five key questions as either outstanding, good, in need of improvement or poor. This process better allows CQC to highlight and share good and outstanding practice.

18. Understanding the quality of care is complex – it is about how people experience services, it is about the outcomes of the services (for example the clinical effectiveness of hospital care or the dignity of end of life care) and about how safe they feel. These dimensions of quality are underpinned and influenced by the quality of the leadership and the culture it creates within a provider. And information governance is a key ingredient for creating all these attributes of quality.

19. The NIGC advised the CQC to take advantage of this new approach by ‘hardwiring’ the monitoring of information governance into every inspection of health and social care providers required to register with CQC. This is achieved by inspectors asking questions about information governance as part of their Key Lines of Enquiry.

20. CQC is now starting to develop its next strategy to cover the period from 2016 to 2021 and this provides an opportunity to learn from CQC’s regulatory approach so far to establish how well it assesses information governance in providers, as well as what improvements should be made in the approach going forwards.

21. Analysis of recent inspection reports

22. NIGC asked the CQC to conduct an analysis of recent inspection reports to assess how CQC has built information governance into its inspections. The CQC team analysed a recent sample of 27 inspection reports to gain a flavour of the evidence included in reports on the assessment of information governance. The analysis was carried out during June 2015 and included 6 acute reports, 2 mental health service reports, 11 adult social care reports, and 8 primary health care reports. As a qualitative study the sample is not intended to be statistically representative of all inspections, but the reports were chosen using a sampling framework to ensure broad coverage across sector, geographical area and overall ratings.
23. Due to limitations in CQC’s information systems the CQC team was unable to extract and analyse information for specific KLOEs, therefore they had to read the inspection reports to identify the most relevant findings. All the reports analysed contained information about information governance related issues, however, whilst the NIGC requested it, the CQC team could not give results of individual KLOEs as CQC does not hold this detailed information centrally.

24. The approach taken to assessing information governance in providers has differed by care sector so the CQC team has reported the analysis separately for each care sector – hospitals, primary medical services and adult social care. For each sector the CQC team has assessed the results against five themes that were identified in the interim report:
   - use of care records that are up-to-date, accurate and are securely held;
   - ensure that confidential personal information is protected;
   - share information to support team working internally and externally;
   - use of information to monitor the quality of a person’s care; and
   - development of effective governance and oversight structures on information governance.

25. The CQC team has included comments from the public on information governance issues from engagement events held as part of inspections. Also they have included examples of good practices found from sampling approximately 75 reports where CQC has published a rating under the new system of inspection. These examples have been selected on the basis that they provide evidence of good or outstanding practice and have sufficient detail that others can learn from and hopefully emulate. We recommend that the CQC does more to encourage safer and more effective care by promoting good information governance practices (Recommendation 6).

The CQC model of inspection and Key Lines of Enquiry in hospitals and primary medical care services

26. There are mandatory KLOE questions on information governance under the Effectiveness Domain for the inspection of hospitals (which includes acute care, community health services and mental health services) and primary medical services which ask:
   - Do staff have all the information they need to deliver effective care and treatment to people who use services?
     i. Is all the information needed to deliver effective care and treatment available to relevant staff in a timely and accessible way? (This includes test and imaging results, care and risk assessments, care plans and case notes.)
     ii. When people move between teams and services, including at referral, discharge, transfer and transition, is all the information needed for on-going care shared appropriately, in a timely way and in line with relevant protocols?
     iii. How well do the systems that manage information about people who use services support staff to deliver effective care and treatment? (This includes coordination between different electronic and paper-based systems and appropriate access for staff to records.)
27. The rest of this part of the report considers:
- Comments from people who have attended CQC engagement events before inspections take place that illustrates the often profoundly negative consequences of when privacy is not respected, information not shared between professionals or people are not told what is going on.
- The findings of from the sample of 27 inspections on information governance and good practice examples firstly from hospitals, then primary medical services and finally adult social care services.

Public comments on how care has been impacted by poor information

28. NIGC is aware that CQC has been increasing the amount of engagement with patients and service users prior to inspections to suggest areas for the inspection teams to follow up. This is a rich source of information for CQC, as highlighted by the quotes below in each sector. The examples below illustrate that poor quality care can often be due to basic errors relating to information sharing and poor communication. People attending pre-inspection engagement activity are more likely to bring stories of poor experiences, however the examples below demonstrate the breadth of information issues.

Examples of Poor care in hospitals

1. My father had a walking stick which had been arranged at his surgery. Unfortunately he became ill with pneumonia and couldn’t go in person to collect it and they wouldn’t give it to me. When he came out of hospital he went to the surgery to pick it up and they told him that he had been discharged and that he would have to go back to his own GP to get referred again. The whole process took 6 months and he was without a walking stick for 6 weeks and was struggling to move around. He is 80 years old. This is bureaucracy gone mad!”

2. “I know another lady who is Ghanaian. She isn’t fluent in English either. She was working as a domiciliary care worker and injured her right hand at work. Because of her injury she had to take time off work and eventually had to give up work. She was in continuous pain and went to her GP who referred her to the Orthopaedic Department at this hospital. They operated on her hand but it wasn’t successful and she continued to remain in a lot of pain. She went back to her GP to ask for a second opinion. Her GP sent her to another Hospital – there she was told that she would need another operation. She was very distressed and scared of having to go through the procedure again. She felt that although she had agreed to the operation but because of her lack of English she didn’t understand her treatment or what the risks may have been. The injury and subsequent ‘failed’ operation have had a major impact on her life. She can’t do many of the things she used to and is in constant pain. She feels he hasn’t received good care or aftercare (discharge). She’s now come to our service for counselling.”

3. “My son has Sickle Cell Thalassemia and has been in and out of the hospital since he was born. After a long struggle I now have open access to the hospital which means I can ring and get access to help promptly. This hasn’t been easy. The majority of clinical staff don’t know anything about Sickle Cell Thalassemia. They don’t know the seriousness of the illness – and don’t have authority to take action. We are trying to raise awareness of the illness - and although the Haematology doctors and community nurses are much more supportive but we’ve got a long way to go. When my son was having his stroke he was going through a ‘Sickle Cell Crisis’ but the staff didn’t know how to respond. They

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should have tested his blood for sickle cell percentage – but they didn’t - which eventually resulted in him losing 90% of his small intestines (they were removed). The diagnosis and monitoring is very poor.”

4. “We went to A&E at 2pm and by 7pm were still waiting for them to see him. By 10pm I was so tired that I went home and during the night they transferred him to another hospital but didn’t inform me. When I rang they said he had been transferred but when I contacted they couldn’t locate him. I was very worried. From 9am till 4pm I contacted reception; admissions; services on numerous occasions but no one could tell me where he was. I sounded so distressed that in the end one of the receptionists took pity and gave me his hospital bed number and I managed to trace him. This woman told me she wasn’t meant to give me this info. I think she felt sorry for me. I was so distressed by this experience. I feel that they should have informed me that he had been admitted and ward details.”

5. “I had a very negative experience over Christmas. I was quite ill and had to go to A&E. After they checked me out they sent me to the unit. I was transported by wheelchair across the hospital. They gave me a separate room. When the healthcare assistant came in she was wearing a mask, gloves and protective clothing. I was alarmed when I saw her - but they didn’t give me any explanation as to what was going on. When my friends visited me they were also wearing protective clothing. Again, I asked the staff what was going on and why I was in isolation but didn’t get a satisfactory answer. I got very annoyed and kicked up a fuss - wanting to know what was going on. Only after I demanded that they told me I’d got influenza A. I felt very intimidated by the whole experience – I use I thought I’d got Ebola. A nurse or doctor should have explained to me what was going on. Since then I have complained to the CEO. It was ironic that they transported me across the hospital in a wheelchair yet put me in isolation– there was no consistency. I was in the unit for 4 days. I noticed that after 7pm no one came to check up on me during the night. I could have died in the night and they wouldn’t have known! It was terrible.”

Examples of Poor care in primary care

1. “I struggle getting appointments. I can never see my doctor - it’s always locums! So each time you have to go through your history with a new doctor – they always ask what medication I’m taking. I feel like saying ‘you’re the doctors why don’t you reading my notes.’ It’s very frustrating! ... I want to flag up the Reception Desk. The design of the building is such that it’s in the middle of an open space. There’s no sign marking it ‘private’. Everyone can hear your business. It’s not ideal at all! Same with the Pharmacy Area it’s not a good design.”

2. “I’m showing signs of diabetes and went for a blood test. The results came back and my doctor put me on a programme of medication. I was told that my medication upgrade would automatically be picked up by foot care but foot care didn’t have any information about this – yet they are all in the same building. I feel there is some internal politics going on between foot care and the surgery. They don’t seem to be talking to each other and the patients are getting caught up in the cross fire. ‘Another problem is repeat prescriptions – they are always late. Sometimes the delivery person doesn’t even knock on the door and takes the medicine back to the pharmacy.’

“We feel language can be a barrier. Most GP practise don’t offer interpreting services. So patients either have to take a family member to translate or just make do with broken communication. My mum didn’t have an interpreter so she kept on taking medicine which she shouldn’t have - and the doctor never reviewed it.”
“I’ve got high blood pressure and am on medication. But the GP changed my prescription without telling me – and the new medicine didn’t suit me. I had a really bad reaction. When I went to my doctor to ask him for information he didn’t explain anything to me – In fact he dismissed me. He didn’t care! I felt I was just a number to him. I’ve also got a language barrier and can’t explain myself properly but they’ve never arranged for an interpreter. The doctors think they know best – I feel they don’t take on board patient’s views.”

Examples of Poor care in Community Services

“I’ve had challenges at this sexual health clinic. I have more than one partner and go regularly for tests. When you say you’re not on any contraception they get taken aback and then you have to explain why you’re not on any contraception. Each time you feel you’re having to ‘come out’ - and have to decide if you want to ‘come out’ to the next person. Its hit and miss.

29. We recommend that the CQC enhances its pre-inspection procedures to pay more attention to information governance when gathering peoples experiences of services (recommendation 3)

Inspection Findings on Information Governance in Hospitals

30. Use of care records that are up-to-date, accurate and are securely held

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<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge letters in the care record noting that policies for safe discharge had been followed and evidence in care records that people had been involved in decisions about their care.</td>
<td>Errors in care records including missing signatures; in mental health services post-seclusion reviews were not systematically documented as required by the Mental Health Act Code of Practice</td>
</tr>
</tbody>
</table>

31. Ensure that confidential personal information is protected

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
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</thead>
<tbody>
<tr>
<td>Secure storage and suitable facilities for shredding, using symbols on patient records (such as a blue butterfly) which kept the medical issues known only to the clinical staff involved.</td>
<td>CQC inspectors found an instance where they (and therefore anyone else) were able to access a restricted area with no swipe card, instances of children’s names being displayed around a paediatric ward, and nurses complaining about missing records of child patients.</td>
</tr>
</tbody>
</table>

32. Share information to support team working internally and externally

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Innovative ways to disseminate key information and learning from incidents by using folders of information on lessons</td>
<td>Handovers between clinical teams were not recorded so could undermine the continuity of care or the handling of serious incidents,</td>
</tr>
</tbody>
</table>
learnt on the wards, including briefings attached to wage slips. Also regular multidisciplinary team meetings to share information and learning.

not all staff having access to reporting incidents electronically to the hospitals central safety incident information system.

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
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<tbody>
<tr>
<td>Clinical governance newsletters containing updates on guidance, learning from incidents such as pressure ulcers and complaints; robust clinical audits used such as the Intensive Care National Audit (ICNARC), and the Myocardial Ischaemia National Audit Project (MINAP), and completion of the NHS Safety Thermometer to monitor and assess the quality of care being delivered.</td>
<td>No robust systems in place to feed back to people and learn from formal complaints. Also inspectors found a lack of performance information in some areas, such as management of appointment letters, waiting times in clinics, and communication with GPs following an outpatient consultation. Also instances where issues were identified but no actions were put in place to remedy them</td>
</tr>
</tbody>
</table>

33. **Use of information to monitor the quality of a person’s care**

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff were trained in information governance alongside their training in safety and safeguarding.</td>
<td>A lack of assurance that consent processes are in line with the Mental Capacity Act 2005.</td>
</tr>
</tbody>
</table>

34. **Development of effective governance and oversight structures on information governance**

35. Below are some examples of good practices found from inspections of hospitals that we urge providers to learn from (see recommendations 1 and 5).

### Examples of Good care

**University Hospital, Birmingham** – The Trust had an IT interface available on a tablet device for use by the staff whilst interacting with the patient. This allowed staff to see immediately which interventions were due and record observations. This device would, for example, restrict prescribing of medication that patients were allergic to, and alert staff of missed medication doses.

Staff told us how the trust IT system encouraged multidisciplinary working. Single Systems encouraged all staff to share and discuss information on patients. They said it helped them to create a single plan of care for each patient.

Staff praised the IT services for the provision of real-time information. The PICs system provided patient and Human Resource dashboards. Staff said they were both engaged in its development and that it helped suggest new models of working.

**Resolve (Care Northern) Limited**

Resolve -

Where people were at risk of self-injury, harm and challenging behaviour, we saw there
were very robust systems in place to record their behaviour, including the use of positive
behaviour. These behaviour records could
be accessed remotely by other clinical staff, for example, the forensic psychiatrist and
psychologist, who supported staff at the service to manage and monitor people’s well-being
and their behaviour. Care records included
information for staff on how to respond to people’s behaviour. For example, we saw a
behaviour support plan that provided very detailed information about one person’s
behaviour, the triggers that might result in challenging behaviour and steps to take to
minimise or prevent this.
There were clear risk management assessment plans in place that illustrated strategies to
be followed. For example, how verbal or physical aggression towards other people or
objects should be handled to keep other people and themselves safe.
The service used imaginative ways to manage risk and keep people safe, everyone who used
the service received one to one support and they had been involved in all risk taking
decisions, while still making sure that they had a full and meaningful life through work
placements, education and community involvement. The service actively sought out new
technology and solutions to make sure people remained safe and that practices were as
free from restrictions as possible, for example, external doors could
only be opened by fingertip scan technology. This was activated in the event of a fire alarm
sounding.

**Inspection Findings on Information Governance in Primary Medical Services**

36. *Use of care records that are up-to-date, accurate and are securely held*

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
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</thead>
<tbody>
<tr>
<td>Care records being kept up-to-date and including key details, recording of (action taken) on medical alerts from the MHRA, noting when patients were involved in the development of their care plan and to identify people including carers who may need on-going support.</td>
<td>We could find no examples mentioned in the sample of inspection reports on poor practices in primary medical services which might indicate the need for better reporting of this issue in inspection reports.</td>
</tr>
</tbody>
</table>

37. *Ensure that confidential personal information is protected*

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protecting personal information including in primary medical services where practice switchboards were located away from the reception desk, and a separate room made available if patients wished to discuss matters with a receptionist in private; patient records being stored electronically and with password protection; and touchscreen booking that avoided patients needing to say their name out loud in reception within the hearing of other patients waiting</td>
<td>Some of the primary medical services inspections highlighted a lack of assurance of how the information on patients that is collected by practices is treated confidentially and with respect by staff.</td>
</tr>
</tbody>
</table>
38. **Share information to support team working internally and externally**

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
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</thead>
<tbody>
<tr>
<td>Electronic sharing of test results between pathology departments and practices, patient information being available electronically to the out of hours service and evidence of GPs reviewing notes for all patients discharged from hospital.</td>
<td>Little evidence of whether information about on-going care is available and shared when patients move between teams and services.</td>
</tr>
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</table>

39. **Use of information to monitor the quality of a person’s care**

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
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<tbody>
<tr>
<td>Use of the Quality and Outcomes Framework and clinical audits to monitor performance and compare against others practice; use of an electronic patient record to co-ordinate, document and manage each patient’s care; and annual reviews of complaints to detect learning from themes and trends.</td>
<td>Not all complaints and concerns being recorded; no analysis of events and therefore no lessons learnt; patchy implementation of systems for assessing, monitoring and managing risks relating to medicines, emergency procedures, health and safety and complaints.</td>
</tr>
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</table>

40. **Development of effective governance and oversight structures on information governance**

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
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</thead>
<tbody>
<tr>
<td>Governance and oversight in primary medical services including information governance being included as part of mandatory training</td>
<td>Policies on information governance that did not contain enough information or guidance.</td>
</tr>
</tbody>
</table>

41. Below are some examples of good practices found from inspections of primary medical services that we urge providers to learn from (see recommendations 1 and 5).

### Examples of Good care

**Heaton Road Surgery** – Phone calls from patients were taken by staff in areas where confidentiality could be maintained... People’s privacy dignity and right to confidentiality were maintained. For example, the practice offered a chaperone service for patients who wanted to be accompanied during their consultation or examination. A private room or area was also made available when people wanted to talk in confidence with the reception staff. This reduced the risk of personal conversations being overheard.

**Stowheath Surgery, Stowmarket** - The practice had systems to provide staff with the information they needed. Staff used an electronic patient record to coordinate, document and manage patients’ care. All staff were fully trained on the system, and commented positively about the system’s safety and ease of use. This software enabled scanned paper communications, such as those from hospital, to be saved in the system for future reference. We saw evidence that audits had been carried out to assess the
completeness of these records and that action had been taken to address any shortcomings identified.

**Parish Fields practice** - The practice used information received to ensure patient care was being planned effectively. For example, the practice received hospital data on admissions and A&E attendances daily. This information was disseminated to the patient’s named GP via email by an administrator within the practice. If a patient remained in hospital for more than seven days, the named GP rang the hospital to discuss the admission and to attempt to facilitate discharge. Patients were contacted by their named GP within 48 hours following discharge from hospital.

**East Lancashire Medical Services Limited** - Primary Care Out Of Hours (Genitourinary medicine site) - The use of the electronic system to allow GPs at the service to access the front page of patients records held at their usual GP practice. This allowed GPs at the service to have read only access to patients allergies, medication and any recent tests carried out by their GP. This was only available once patients had given their consent.

The CQC model of inspection and Key Lines of Enquiry in adult social care services

42. While inspections of hospitals and primary medical care have a single set of questions to assess information governance issues, inspections of adult social care CQC look at three mandatory Key Lines of Enquiry that might relate to information governance. These are:

1. **Caring** - How is people’s privacy and dignity respected and promoted? (Prompt: How are people assured that information about them is treated confidentially and respected by staff?)
2. **Effective** - Is consent to care and treatment always sought in line with legislation and guidance? (Prompt: How does the service monitor and improve the way staff seek people’s consent to their care and treatment to make sure it is acting within legislation?)
3. **Well-led** - How does the service deliver high quality care? There are two key prompts:
   a. Are quality assurance and (where appropriate) governance and clinical governance systems effective, and are they used to drive continuous improvement?
   b. How does the service make sure they have robust records and data management systems?

43. This approach was agreed with the aim of reflecting how information governance can influence these different components of care that affect a person’s life over the longer term.

44. **Use of care records that are up-to-date, accurate and are securely held**

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
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</thead>
<tbody>
<tr>
<td>Records which included details about when consent had been obtained, recording when people and their families had been involved in developing the care plans and when risk assessments made and care reviewed</td>
<td>Poor practices around incomplete, out-of-date or missing records that made it difficult for staff to access care data, presenting higher risks where staff turnover was high and important issues could be missed. Examples of missing data included no signatures in medication administration</td>
</tr>
</tbody>
</table>
45. **Ensure that confidential personal information is protected**

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
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</thead>
<tbody>
<tr>
<td>Patient records being locked securely, and policies adhered to on key safes and identity badges for staff</td>
<td>Little evidence within sample</td>
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</table>

46. In order to report back on whether confidentiality in Adult Social care is protected, **we recommend that in future adult social care inspections should have a stronger focus on handling confidential personal information in adult social care inspection reports (see recommendation 4).**

47. **Share information to support team working internally and externally**

<table>
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<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
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<tbody>
<tr>
<td>Formal handover meetings held between staff at the end of each shift, dietary needs and preferences shared with kitchen staff and agency workers given a summary of the care record before meeting a service user.</td>
<td>Handover meetings being rushed, dietary information not available to kitchen staff at weekends and a lack of clarity about how the service works in partnership and shares information with key organisations, including the local authority, safeguarding teams and clinical commissioning groups.</td>
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48. **Use of information to monitor the quality of a person’s care**

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<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
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<tbody>
<tr>
<td>Recordings of lessons learned in terms of improved outcomes, for example in response to incidents or complaints; complaints investigated and used as a learning tool at team meetings and staff supervision sessions; audits carried out with feedback to staff to support changes in practice (for example on infection control practices); audits action plans signed off with clear accountability for implementation; resident meetings held to gain feedback which is valued and acted on; regular</td>
<td>We could find no examples mentioned in the sample of inspection reports on poor practices in adult social care services which might indicate the need for better reporting of this issue in inspection reports (see recommendation 4).</td>
</tr>
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</table>
meetings, surveys and internal audits designed to ensure compliance with regulations; and unannounced spot checks by managers and directors on the quality of front-line services being delivered

49. Development of effective governance and oversight structures on information governance

<table>
<thead>
<tr>
<th>Good Practice</th>
<th>Poor Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training records, including information governance, kept up-to-date and reviewed periodically.</td>
<td>Some staff not having a good understanding of the Mental Capacity Act 2005, and, in one case, training records demonstrating the majority of staff had not received formal training in information governance.</td>
</tr>
</tbody>
</table>

50. Below are some examples of good practice found from inspections of adult social care services that we urge providers to learn from (see recommendations 1 and 5). Hospice services are included within this directorate’s work, which is why they are included here.

**Good practice examples in adult social care**

**Ashcroft** - With people’s consent, most relatives opted to receive weekly reports on their family member’s activities and progress. Staff consulted people about their daily routines and activities and no one was made to do anything they did not want to. The service ethos was centred around each person’s wishes and needs rather than the routines of the home. Each person kept a daily diary of their activities and the things they enjoyed or disliked. Some people were able to write their own daily notes with prompting from staff; others relied on staff to record their daily activities for them. People’s needs and preferences were then recorded in a weekly key worker report. The key worker was responsible for ensuring the person’s needs and preferences were known and respected by all staff. Each person had a designated key worker and a dedicated team of care staff.

**The Grange** - We saw that pre admission assessments recorded individual’s personal details, details of healthcare professionals such as GP, psychiatrist, care manager, information about any specific eating conditions, past and current usage of substances or alcohol, medication, allergies, physical and mental health and any potential risk to self or others. All information regarding people’s medicines were verified with their doctors. This information was reviewed prior to any treatment given. This meant that staff had the most up to date medical information that related to the person.

**Forget me Not Hospice** – Children’s choices, wishes and preferences were reflected throughout the care planning process. These contained very detailed and thorough information. We saw child-centred plans for care and detailed risk assessments to ensure children’s welfare.
Communication records were highly detailed and there was extensive evidence of multi-agency working with other professionals to provide the most effective care. Within each child’s care plan, we saw an individual ‘play passport’ showing their personal play preferences and this illustrated excellent attention to detail and care that was taken.

**Greenhive House** - People were involved in discussions about their care and care plans had been signed by people or their representatives. A social worker involved with the home said staff “consulted residents regarding care provision and choices whenever possible.” Assessments identified people’s care and support needs and care plans were developed to address them. The plans identified the areas in which people wished to be independent and those where they needed support from staff. Plans were sufficiently detailed to provide care as the person preferred. For example a night time plan stated the person wanted to sleep in the dark and have two pillows.

**St Cuthberts Hospice** - Annual quality accounts were produced and measured against key aspirations the hospice had chosen for the previous twelve months. People who used the service, staff and volunteers are consulted about these before they are chosen. The hospice regularly reviewed complaints and incidents that had been recorded with an audit of all of these, including actions taken and lessons learned being published in the providers annual quality account.

Staff we spoke with told us they felt supported and enjoyed their work. We spoke with three members of staff. One person told us “This is one of the best places I have ever worked in. I believe the care here is first class.” Another staff member said “I really appreciate the time I am allowed to spend time with People and their families.”

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**Thematic reviews and information governance**

51. The committee has contributed to the development of two specific thematic reviews in terms of identifying information governance themes that need to be included. “Right Here, Right Now” was published in June 2015, and reviewed of experience of people having a mental health crisis. CQC also published “Cracks in the Pathway” in October 2014 which looked at people’s experiences of dementia care as they move between care homes and hospitals. It found that poor information sharing between hospitals and adult social in around a quarter of care homes and hospitals visited that were detrimental to people’s care (inset reference). There are a

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number of other thematic reviews that have included issues related to information governance including:

- The Review of services for people with a learning disability\textsuperscript{22} (published June 2012 – which included themes such as whether people were provided with accessible information about the service before and during admission.
- From the Pond to the Sea; Transition arrangements for young people with complex health needs from children to adult services\textsuperscript{23} (June 2014) where there were findings of poor arrangements around consent and assessing capacity which meant it was unclear whether the interest of vulnerable people were being recorded or that their voices were being heard.
- Complaints Matter\textsuperscript{24} (December 2014) which included findings on information recording, information sharing and poor use of feedback information to improve services.

52. Given the prevalence of information governance related issues in past thematic reviews, as well as in the future the likelihood that organisations will increasingly adopt new provider models that integrate health and adult social care, we recommend that when future thematic reviews are being designed consideration be given to including information governance issues in the proposals (see recommendations 3 and 4).

Conclusions from the analysis of the inspection reports for providers

53. The analysis of this sample provides only a partial picture of the state of information management amongst health and social care organisations regulated by CQC. In terms of conclusions for providers:

- There is wide variation in how information governance issues are managed in different providers, including those in the same care sector.
- There is a common set of issues that are important across all sectors - such as completeness of records, protection of personal information, sharing information amongst teams caring for patients and/or service users, using information to monitor and improve care, having effective systems to oversee information governance across the organisation – that all providers need to make sure they are managing well.

\textsuperscript{22} http://www.cqc.org.uk/content/national-report-finds-half-learning-disability-services-did-not-meet-standards


\textsuperscript{24} http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=1&cad=rja&uact=8&ved=0CCEQFjAAahUKEwicwqjggNgAhXbiXb8KHwxcAPM&url=http%3A%2F%2Fwww.cqc.org.uk%2Fcontent%2Fcomplaints-matter&ei=9DOlVz4f4M3j7QbsulGYDw&usg=AFQjCNvGwzAAdEKhCoOh8fKYOeGDiQMjQ&bvm=bv.97653015,d.ZGU
• There are some sector specific issues that providers in those sectors need to be given particular attention to ensure they are addressed:
  o Hospital care – information when patients are discharged as well as sharing and recording information when handovers take place between teams
  o Primary medical services – protecting the confidentiality of personal information of patients, sharing information when patients move between services, ensuring learning takes place from concerns and complaints
  o Adult social care - consent in setting such as care homes where people are often vulnerable due to their circumstances and the setting is their home in the long term, sharing information with partner organisations, sharing and recording information when handovers take place between teams.

54. Examples of good practices were found by inspectors that give organisations opportunities to learn from others. **We recommend that the CQC board should commit to reporting annually in both the State of Care report and the CQC Annual report on how it has discharged its statutory responsibility to monitor and seek to improve the Information Governance practice of health and social care providers.**

55. Where providers currently have multiple approaches then they should consider whether there are advantages to taking a single co-ordinated organisation-wide approach to information governance.

**Conclusions on methods used by inspection teams to assess issues relating to information governance**

56. This review of this relatively small sample of CQC’s ‘new approach’ inspections suggests that in many cases inspectors are asking the questions required to uncover evidence of both good and bad practice in information governance and making clear links to how this has an impact on the experience of people who use services. We note however that this is not universal, and recommend that it may be necessary to ensure that inspectors more explicitly seek out the evidence supporting the key lines of enquiry on information governance on every inspection. This may require further training and support for CQC staff to understand what issues to look out for and test during an inspection). The CQC should ensure that each inspection team has the expertise to deal with any IG issues highlighted within their inspection. To achieve this, the CQC should carry out a training needs analysis to assess the need for initial and continuing training. Based upon this analysis, the CQC should put in place an appropriate training programme to meet the identified needs, and ensure that all inspectors have adequate IG training (**see recommendation 2**)

57. The structure of the KLOEs means there is some overlap of inspection findings between information governance and other KLOEs that need to be managed during inspections. For example:
  • the information governance findings on the theme of “use of care records that are up-to-date, accurate and are securely held” overlaps with safety KLOE S3 prompt 11 ‘Are people’s individual care records written and managed in a way that keeps people safe?’
the information governance findings on the theme of “the use of information to monitor the quality of a person’s care” has findings on learning from complaints and concerns (KLOE Responsive 4 prompt 5 ‘How are lessons learned from concerns and complaints and is action taken as a result to improve the quality of care? Are lessons shared with others?’).

Part 2 CQC future role in information governance

58. This section considers the recommendations for taking forward information governance issues in CQC’s regulatory and inspection activities. This final section considers:

- the main strategic challenges in the next five years from developments in the health and adult social care sectors
- the role of strategic partners and their relationship to CQC
- the unique contribution that CQC can make to information governance
- the recommendations of the NIGC on CQC’s future activities on information governance

The main strategic challenges in the next five years affecting information governance

59. There are a number of likely challenges and opportunities in the next five years from developments in the health and adult social care sectors that will ensure that information governance continues to be an important issue that CQC needs to address.

- Delivering more integrated models of care – where information on service users is shared increasing by services with implications for protecting confidentiality of information whilst also ensuring the effective sharing of information to support team working between those providing care
- More use of the internet – and the ability to share information more easily could threaten keeping information confidential
- More information on performance that improves transparency through more public reporting on care services to compare performance and learn from the good practices of others
- Expanding the set of NHS authorised apps for people to use to support their care and improving the digital inclusion of more people to access and use this information to support their care
- Electronic patient records that can be accessed by patients and service users and can be shared
- Family doctor appointments and electronic and repeat prescribing available routinely on-line everywhere
- Bringing together hospital, GP, administrative and audit data to support the quality improvement, research, and the identification of patients who most need health and social care support. Enabling individuals to opt out from their data being used in this way.
- Technology – including smartphones - can be a great leveller and, contrary to some perceptions, many older people use the internet. However, the need to take steps to ensure
that the capacity of all citizens to access information is built, and to train our staff so that they are able to support those who are unable or unwilling to use new technologies.

[Reference: Five Year Forward Review NHS England 23 October 2014]
The role of strategic partners and their relationship with CQC

60. There are a number of other organisations which provide support, guidance and oversight on information governance that CQC needs to work with. They include the Information Commissioner’s Office, the Health and Social Care Information Centre, the National Information Board and NHS England (see Appendix D for more details). In carrying out its work the NIGC has needed to develop an understanding of the roles of these different organisations, any potential overlaps, opportunities to work alongside these organisations to pursue common objectives.

61. In addition, since the establishment of the NIGC, there have been some new additions to the playing field:

- **The National Data Guardian**: in November 2014, the Secretary of State for Health appointed Dame Fiona Caldicott to a new role as National Data Guardian for health and care. The National Data Guardian will become the patients’ champion on security of personal medical information, supported by her panel, the Independent Information Governance Oversight Panel. They provide advice to the government on healthcare information sharing, and can intervene if she is concerned by how an organisation is sharing data. She can refer concerns directly to the Information Commissioner’s Office (ICO) and the Care Quality Commission (CQC) to investigate and sanction where necessary. Organisations that fail to act on recommendations may face sanctions such as fines and the removal of the right to share personal data.

- **The IG Alliance**: The Information Governance Alliance (IGA) is a group of national health and care organisations that are working together to provide a joined up and consistent approach to information governance. It is hosted by the Health and Social Care Information Centre.

CQC needs to have clear leadership on information governance so it can develop relationships with strategic partners to share expertise and good practices. **We recommend that the CQC ensures that it has processes in place to liaise effectively with other organisations in this complex landscape. (Recommendation 7)**

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**Figure 4: The roles of different strategic partners on information governance**

CQC sits within a wide information governance landscape, which includes the following organisations. This table reflects the fact that there are less bodies looking at social care information.

<table>
<thead>
<tr>
<th>Department of Health</th>
<th>Develop and maintain information governance assurance framework for health and social care, including the National Information Board</th>
</tr>
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</table>
| **NHS England**      | Sets IG standards for whole system and publishes guidance on processing information  
|                      | Coordinates guidance and standards on using NHS data  
<p>|                      | Coordinates collaborative working through the Information Services |</p>
<table>
<thead>
<tr>
<th><strong>Agenda item 9</strong></th>
<th><strong>Paper No: CM/07/15/09 Appendix 1</strong></th>
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<thead>
<tr>
<th><strong>Commissioning Group</strong></th>
<th>Publishes Code of Practice on Confidential Information</th>
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<tr>
<td></td>
<td>Provides other advice and guidance on data collection and use</td>
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<td></td>
<td>Maintains and oversees the Information Governance Toolkit</td>
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<thead>
<tr>
<th><strong>Health and Social Care Information Centre</strong></th>
<th>Regulator of quality in health and social care</th>
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<tbody>
<tr>
<td></td>
<td>Responsibility to monitor and seek to improve registered providers’ information governance practices</td>
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<tr>
<th><strong>Care Quality Commission</strong></th>
<th>Independent regulator of the Data Protection Act and the Freedom of Information Act.</th>
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<tbody>
<tr>
<td></td>
<td>Carries out data processing audits of public bodies</td>
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<table>
<thead>
<tr>
<th><strong>Information Commissioner’s Office</strong></th>
<th>Approvals role regarding access to confidential patient information for health research purposes under S(251) through their Confidentiality Advisory Group</th>
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<tr>
<th><strong>Health Research Authority</strong></th>
<th>Licencing and regulation</th>
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<tbody>
<tr>
<td></td>
<td>Encourage professional responsibility</td>
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<table>
<thead>
<tr>
<th><strong>Professional regulators</strong></th>
<th>Required to support integration and cooperation between services. In the process of merging with the Trust Development Authority to become the NHS Improvement Agency.</th>
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<table>
<thead>
<tr>
<th><strong>Monitor</strong></th>
<th>Assurance of information governance and risk in NHS Trusts as part of their accountability framework. In the process of merging with Monitor to become the NHS Improvement Agency.</th>
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<table>
<thead>
<tr>
<th><strong>Trust Development Authority</strong></th>
<th>Provide information, guidance and share good practice</th>
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<tr>
<th><strong>Social Care Institute for Excellence</strong></th>
<th>Accreditation system for research and similar projects</th>
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<th><strong>Local Government Association</strong></th>
<th>Produce standards for providers to drive improvement, and practical tools</th>
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<tr>
<th><strong>National Institute for Health and Care Excellence</strong></th>
<th>Publishes Code of Practice on Confidential Information</th>
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<td>Provides other advice and guidance on data collection and use</td>
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<th><strong>Commissioning Group</strong></th>
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<th>Regulator of quality in health and social care</th>
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<td></td>
<td>Responsibility to monitor and seek to improve registered providers’ information governance practices</td>
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<tr>
<th><strong>Care Quality Commission</strong></th>
<th>Independent regulator of the Data Protection Act and the Freedom of Information Act.</th>
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<td>Carries out data processing audits of public bodies</td>
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<tr>
<th><strong>Information Commissioner’s Office</strong></th>
<th>Approvals role regarding access to confidential patient information for health research purposes under S(251) through their Confidentiality Advisory Group</th>
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<th><strong>Health Research Authority</strong></th>
<th>Licencing and regulation</th>
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<td></td>
<td>Encourage professional responsibility</td>
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<th><strong>Professional regulators</strong></th>
<th>Required to support integration and cooperation between services. In the process of merging with the Trust Development Authority to become the NHS Improvement Agency.</th>
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<tr>
<th><strong>Monitor</strong></th>
<th>Assurance of information governance and risk in NHS Trusts as part of their accountability framework. In the process of merging with Monitor to become the NHS Improvement Agency.</th>
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<tr>
<th><strong>Trust Development Authority</strong></th>
<th>Provide information, guidance and share good practice</th>
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<th><strong>Social Care Institute for Excellence</strong></th>
<th>Accreditation system for research and similar projects</th>
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The unique contribution that CQC can make to information governance

62. CQC can provide a unique contribution to developing information governance practice through:
   • Inspection that allows access to front-line care in every organisation that CQC regulates.
   • CQC assessing the broader quality of care through its five CQC key questions on care - safety, effectiveness, caring, responsive and well-led – and make the links to information governance practices.
   • The increasing capability to look at particular types of care that people experience such as people with dementia and the care they receive from different providers, as well as developing the capacity to inspect health and social care provision in a particular geographic area or place and highlight issues such as information sharing (see recommendation 3).
   • Enforcement powers that provides leverage for information governance problems to be addressed and followed up to check on progress made.

63. Parliament showed great foresight when it included in the Health and Social Care Act 2012 a mandatory requirement on the CQC to establish the National Information Governance Committee. The CQC needed advice on how it should fulfil its new statutory responsibility to monitor and seek to improve the IG practice of providers and the NIGC has provided it.

64. The CQC’s need for advice has not diminished over the past three years. Indeed it has increased. The digital revolution opens up exciting opportunities for providers to improve services by making accurate information available in the right place at the right time. But the opportunities also carry greater risks to confidentiality and security.

65. The 2012 Act required the CQC to establish the NIGC until the end of March 2015, after which the CQC had discretion to continue with it or disband it. A question the CQC Board must consider is who will continue to provide advice if the NIGC is disbanded. We believe the need for advice has increased, as outlined above. We are still the only statutory IG advisory body for the CQC and are committed to our function, keen to continue in this role. We recognise that the CQC may decide to seek advice through another route, but seek reassurance that this is appropriate.

66. In our view it would be premature to disband the NIGC before putting alternative arrangements in place. NIGC recognises that the function needs to be addressed, and from that the ‘form’ of the function will follow. Members of the NIGC would also appreciate the opportunity to receive and discuss the CQC Board’s substantive response to our recommendations. We recommend that the CQC Board continues to make arrangements to take on-going advice on Information Governance (recommendation 8).

67. Without advice, the CQC’s monitoring and improving remit is not likely to be fulfilled. It is only part way through a process of learning how to fulfil its statutory responsibilities for IG. Embarrassing and dangerous fatal incidents and poor practices can be avoided by continuing down the path of embedding the IG KLOE and identifying and promulgating good practice. We recommend that the CQC clarifies how it will take corporate responsibility for ensuring that the organisation fulfils its responsibility to monitor and seek to encourage
improvement in the Information Governance practice of health and social care providers (recommendation 9).

68. The CQC must understand the increasing risk that inadequate monitoring and improvement of information governance presents. As the NIGC has not yet finished the job it started, there is a risk that the CQC is seen to be minimising IG at a time when IG risks are maximised and that the CQC is failing to lead by example, by discontinuing the IG leadership the NIGC has brought about. Public perceptions are critical, as patients, service users and carers are the ultimate customers benefitting from the safer care brought about by better information governance.
Part 3: NIGC’s recommendations to CQC’s Board to enable it to make best use of its unique contribution

69. The NIGC makes the following recommendations to the CQC Board in order to maximise its contribution to developing good practices in information governance in services that it regulates.

1. We recommend that the CQC should ask providers to learn from the evidence of inspections. In particular we urge providers that failed to uphold the highest standards of information governance to learn from the good practice of others.
2. We recommend that the CQC Board completes the task of implementing all the recommendations in the NIGC interim report.
3. We recommend that the CQC enhances its pre-inspection procedures to pay more attention to information governance including the views of people who use services, the public and the IG toolkit.
4. We recommend that information sharing and other aspects of information governance should be a key focus of the CQC’s “place-based” work.
5. We recommend that the CQC board acts to ensure that its monitoring of Information Governance is at least as effective in adult social care as in other areas of inspection.
6. We recommend that the CQC does more proactively to encourage safer and more effective care by promoting good information governance practices.
7. We recommend that the CQC ensures that it has processes in place to liaise more effectively with other organisations in this complex landscape
8. We recommend that the CQC Board continues to make arrangements to take advice on Information Governance.
9. We recommend that the CQC clarifies how it will take corporate responsibility for ensuring that the organisation fulfils its responsibility to monitor and seek to encourage improvement in the Information Governance practice of health and social care providers.
10. We recommend that the CQC board should commit to reporting annually in both the State of Care report and the CQC Annual report on how it has discharged its statutory responsibility to monitor and seek to improve the Information Governance practice of health and social care providers.
Appendices

A. The role and activities of the National Information Governance Committee

B. Links to key documents on Information Governance (via link to HSCIC Confidentiality Guide)

C. Detailed roles of strategic partners in information governance

D. Glossary of terms

E. Caldicott Principles

Appendix A: Role and activities of the National Information Governance Committee

The Health and Social Care Act 2012 gave CQC new legal responsibilities from 1 April 2013 for monitoring and seeking to improve registered providers information governance practices but did not give CQC any new powers in relation to these functions. CQC was required to set up a National Information Governance Committee (NIGC) to provide this advice, which was established June 2013. NIGC’s role is to provide independent and objective advice on development and delivery of CQC’s information governance monitoring functions.

The NIGC has two main objectives:

- To provide advice and support to CQC so that it establishes a confident and meaningful approach to monitoring information practices among registered health and social care organisations which can be effective on an on-going basis; and
- To use learning from CQC’s activities alongside the committee’s expertise in the field to highlight good practice and identify main areas for learning and improvement in the way that information is used to support good quality care for all people who use health and social care services and to share these appropriately.

Four independent members were recruited - Christopher Fincken, Alan Gillies, Christina Munns and Dilys Jones. Also there are members who represent the views of organisations with an interest in promoting good practice in information governance - Karen Thomson (NHS England), Clare Sanderson then Peter Hall (Health and Social Care Information Centre) and John Carvel (Healthwatch England). In addition, Dawn Monaghan, of the Information Commissioner’s Office, attends as an observer. The NIGC was chaired by CQC Board member Stephen Hitchens until December 2013, then by Dr Paul Bate, CQC’s Executive Director of Strategy and Intelligence.

The Committee has met quarterly, with an update provided to the CQC Board after each meeting. The NIGC provided CQC with advice regarding:

- Detailed consideration of the new inspection methodology where members suggested specific questions to ask in the Key Lines of Enquiry to demonstrate a trust’s approach to information governance.
- Analysis of evidence held by CQC, together with some other publically available information, on the quality of information governance within the health and social care sectors.
- Development of the information pathway which describes a user’s experience of care if information is used effectively.
The Memorandum of Understanding between CQC and the Information Commissioner’s Office.

The Caldicott Review and how CQC should implement relevant recommendations.

Contributed to two specific thematic reviews: ‘experience and outcomes for people experiencing a mental health crisis’ and ‘quality of dementia care’.

Terms of reference for the National Information Governance Committee (NIGC)

1. INTRODUCTION

1.1. The Health and Social Care Act 2012 (the Act) gives the Care Quality Commission (CQC) new functions to:

- monitor and seek to improve information governance (IG) practices of registered health and social care providers; and
- keep the NHS Commissioning Board and Monitor informed about this practice.

1.2. The Act does not describe how CQC will fulfil these new functions. It does not extend CQC’s remit or give CQC any new powers in relation to these functions.

1.3. Under the Act CQC must set up a National Information Governance Committee (NIGC) to provide advice and assistance in relation exercising the above functions.

1.4. The NIGC has no executive powers; it will provide independent and objective advice to the Commission. Each member should have relevant expertise; have a good understanding of CQC’s role, and of their role as an NIGC member.

1.5. The NIGC must be in place until 31st March 2015 (this original review date was extended to end July 2015 by the CQC Board at its March 2015 meeting); at this time the CQC Board will review its role and purpose, and determine if it is still required.

2. RESPONSIBILITIES

2.1. The role of NIGC is to provide advice and assistance to CQC in relation to exercising its functions to monitor and seek to improve registered providers’ IG practices.

2.2. The CQC board has agreed that these monitoring functions should:
• add something beyond our regulation of the essential standards, including identifying examples of good practice;
• generate an overview picture of quality in IG practice, through use of sampling and a focus on priority topics;
• focus on the impact of IG on the quality of care people receive, including the importance of sharing information between services;
• not be limited to direct observation, they are likely to include review of governance systems and analysis of available intelligence; and
• be informed by specialist expertise.

2.3. A small specialist monitoring team will undertake a planned programme of monitoring reviews focusing on priority IG issues across representative samples of providers. The NIGC will provide advice and assistance to inform the work of this team.

2.4. The main areas that the NIGC will be asked to provide specialist advice will include:
• identifying priorities, themes and standards to be covered by the monitoring activity, including taking account of any specific recommendation from the Caldicott Review;
• development of monitoring methods, including how to identify risks and good practice examples;
• how CQC can monitor information sharing and how health and social care information is used in local commissioning and needs assessments;
• evaluating intelligence and findings;
• publishing reports of findings;
• sharing good practice and promoting improvement;
• links with stakeholders and other IG oversight mechanisms; and
• evaluating implications of relevant external reports, such as the Caldicott Review and the Francis Inquiry.

2.5. The advice and assistance from the NIGC will mainly be requested by the IG monitoring team; the CQC Board may also ask the committee directly for advice on specific topics. The CQC Board will “have regard to relevant advice and information,” given by this Committee in line with the Act.

3. MEMBERSHIP

3.1. The NIGC will be established by the CQC Board. Schedule 1 of the Health and Social Care Act 2008 states that any advisory committee must include persons of a prescribed description. Membership criteria are agreed by the CQC Board and the committee is covered by the Board standing orders.

3.2. A representative from the NHS England, the Health and Social Care Information Centre, and Healthwatch England are invited to be members. The Information Commissioner’s Office (ICO) will be invited as an observer. These members will bring relevant expertise from key stakeholder organisations; they are expected to have the authority to speak on behalf of the body they represent.
3.3. Up to five independent members will be recruited. Members will be chosen to ensure the widest range of specialist experience relating to the role of information governance in health and social care.

3.4. Independent members of the NIGC will be appointed for an initial two year term or until 31 March 2015 if appointed after 1 April 2013. The Board will approve further terms of appointment.

3.5. The NIGC Chair will be a non-executive member of the CQC Board. The NIGC will appoint one of its members as Deputy to act as Chair in their absence.

3.6. The Chair has responsibility for ensuring that the NIGC is appropriately resourced and supported, and that it maintains effective internal and external communication.

3.7. A member of the CQC Secretariat will act as the Secretary to the Committee. Relevant policy support will be provided by the information governance monitoring team.

4. REMUNERATION

4.1. Members of the NIGC will be paid at the standard day rate of a CQC Board member, with travel and subsistence expenses covered. Organisational representatives will not be reimbursed.

4.2. Meetings will be arranged to avoid overnight stays. Travel is expected to be second class, in line with CQC policy. Claims must be submitted to [insert email address here] using the prescribed form within one month of the meeting. CQC will publish on the website the expenses paid to members.

5. MEETINGS

5.1. Frequency and organisation of meetings

5.1.1. The NIGC will meet at least four times a year. Additional meetings, or task and finish groups, shall be arranged if required. The Chair will agree the agenda of each NIGC meeting.

5.1.2. The expected maximum annual requirement for committee members is up to 10 days.

5.1.3. Unless otherwise agreed, notice of each meeting will be confirmed, and the agenda and supporting papers will be sent to each member no later than five working days before the meeting. The notice will also be sent to all CQC Board Members.

5.2. Attendance at meetings
5.2.1. All Board Members may request to attend NIGC meetings as observers: requests should be made to the NIGC Chair. Only NIGC members have the right to vote.

5.2.2. A minimum of 50% of the NIGC must be present for the meeting to be deemed quorate. Either the NIGC Chair or the Deputy Chair must be present at each meeting.

5.3. Minutes of the Meeting

5.3.1. The NIGC Secretary will write minutes of each meeting, including the key points of advice. The minutes of the previous meeting must be approved and signed off by the Chair as a true record at each meeting.

5.3.2. The Chair will establish, at the beginning of each meeting, the existence of any conflicts of interest and they should be minuted accordingly.

5.3.3. The minutes of meetings will be circulated promptly to all NIGC members for agreement and published as draft on the CQC website until formally signed off.

6. REPORTING

6.1. The Committee will provide a written update to the CQC Board after each meeting summarising advice given; this may be in the form of the minutes of the meeting.

6.2. The Committee will contribute to the CQC annual report. It will also review and contribute to a report of the monitoring activity and findings in early 2015 to reflect conclusions over the two year period.

7. STANDARD OPERATING PROCEDURES

7.1. The Committee will aim to provide advice based on consensus. Should a vote be required this will be via a show of hands, with the vote of each member noted in the minutes. If it is required, the Committee Chair will have a casting vote.
Appendix B: Links to key documents on Information Governance
(via link to HSCIC Confidentiality Guide)

‘A Guide to Confidentiality in health and social care: references’ published by the Health and Social care Information Centre provides a summary of some important legal and other documents as well as good practices including:

- the Caldicott Review of Information Governance and its principles (Section 1);
- the common law of confidentiality and consent (Section 2);
- the Data Protection Act 1998 (Section 3);
- Human Rights Act provisions (Section 4);
- Professional regulators’ guidance (Section 5);
- record-keeping best practice (Section 6);
- quality statements on sharing information for direct care (Section 7);
- sharing information with carers, family members and friends (Section 8);
- safeguarding of children and vulnerable adults (Section 9);
- using health and social care information for direct and indirect care purposes (Section 10);
- privacy impact assessments (Section 11);
- anonymisation guidance (Section 12);
- accredited safe havens (Section 13);
- data sharing contracts and agreements (Section 14);
- The Health and Social Care Information Centre’s powers (Section 15);
- Legislation that controls confidential information disclosures (Section 16);
- rights to object to information being shared (Section 18);
- List of key documents underpinning this guidance;
- glossary of terms.


8th July 2015
Appendix C. Detailed roles of strategic partners in information governance

Still to come – NHS England

1. Health and Social Care Information Centre

Over the last couple of years the HSCIC has been reacting to the Health and Social Care Act, ensuring that it fulfils its statutory duty for IG in its two core roles; assuring the secure delivery of IT systems that hold patient data and ‘handling’ (collecting, analysing, publishing and disseminating) information.

The focus has been and continues to be on the following key areas:

1. IG toolkit re-launch. There are opportunities for the CQC to influence this, particularly to facilitate their pre-inspection evidence gathering phase,
2. HSCIC as host to the IGA and its role in promulgating good practice. There is an opportunity for the CQC to become a member and/or to share good practice examples,
3. HSCIC’s Code of Practice, applicable to every organisation that collects, publishes, analyses and disseminates health and social care data. This could be embedded within the CQC’s inspection regime and best practice promulgated,
4. Cyber security programme of work, including the development of CareCERT (providing a proactive service to enable rapid, controlled dissemination of information about, and fixes to, cyber threats). There is an offer from the HSCIC, of input into the security framework to support the pre-inspection information gathering process.

Looking forward it aims to become more proactive in the area of IG and is developing an IG Strategy to ensure good IG is embedded throughout the organisation, for the benefit of its customers, the public and its staff.

2. The Information Commissioner’s Office

As the regulator of the Data Protection Act, the Freedom of Information Act and the Environmental Information Regulations the ICO are responsible for ensuring organisations meet their legal obligations and assist citizens in understanding and exercising their information rights.

Since 2012 the Information Commissioners Office (ICO) has committed key resources to ensure that those with responsibilities for the implementation of the Health and Social Care Act 2012 fully recognised the need to take into account the importance of organisational information governance in this arena.

To do this they have engaged with both established and new regulatory health bodies to raise awareness and aid improvements of information governance compliance across the health sector.
The responsibility of the Care Quality Commission to monitor information governance complements ICO efforts to identifying key issues and areas for improvement within health and social care.

In 2014 the ICO and Care Quality Commission entered into a Memorandum of Understanding (MoU). Whilst both organisations must adhere to restrictions upon the sorts of information they are allowed to share; the agreement allows general trends and key issues to be identified. Working together they can take appropriate action in a coordinated manner.

3. Healthwatch England

Information sharing and information security are important issues for the public. Over the past year, Healthwatch England has heard some significant concerns that have been raised by the public through their local Healthwatch. The key issues and actions we have subsequently taken are highlighted below.

Following issues raised by the public and a number of local Healthwatch organisations we contacted NHS Choices to alert them to the fact that some GP and practice information on the Choices website was inaccurate and out of date. We agreed a process for Local Healthwatch to raise any errors direct with Choices and get them corrected quickly, thus ensuring the information provided is accurate, up to date and quality assured. We also raised concerns with Choices around the accuracy of information on dentistry and Choices are reviewing this and will share their findings with us.

In September we responded to the Department of Health consultation on Accredited Safe Havens for data and made the point that there should be a single regulatory regime for all the different big data programmes, with consistent penalties for breaches in information security.

We continue to monitor the progress with various government ‘Big Data’ programmes. We are members of the independent Care.Data advisory group and continue to hold the programme to account. In June 2015 we published our ten principles for data security and information sharing by which we will judge our position on Care.Data and similar programmes. Significantly it is our view that professionals in the health and care system should treat people’s personal data as if it was their own. The principles include:

- People can access their own health and social care data and records to see what the system has collected and who they are sharing it with.
- Data is collected and shared in a manner that does not unjustifiably compromise people’s anonymity, safety or treatment.
• Collecting and sharing data cannot be used to justify treating people on an unequal basis with others.
• Data collection and sharing will not have impact on a person's wellbeing by, for example, causing them additional anxiety or distress.

We know that information sharing and security are important issues for consumers and are getting increasing numbers of alerts from members of the public concerning accuracy of the medical records held by GPs or hospitals about them and also querying their ability to correct that information. This could be a growing issue in the light of NHSE programmes such as Patient Online which is being rolled out nationally this year and should offer the opportunity for people to access their summary care records held by GPs. We have had a handful of enquiries from consumers who have stated that getting registered with their practice so they can make online bookings is onerous. This is something we will be keeping a close eye on in the coming year and we are linked into the Patient Online stakeholder group.

Information pathways and communications are increasingly emerging from our special inquiry as areas of breakdown in people's discharge from hospital, care homes and secure mental health settings. Results of our Special Inquiry on Unsafe Discharge were due for publication in July 2015. The findings that were previewed to the NIGC last year include that in some cases, poor information sharing between different parts of the care and health system is detrimental to patients in terms of delays, continuity and quality of care.

4. Information Governance Alliance

The Information Governance Alliance (IGA) is a group of national health and care organisations that are working together to provide a joined up and consistent approach to information governance.

We are currently providing support to Integration Pioneers through:
• Individual visits to selected Pioneer sites.
• Preparation of national advice and guidance on IG, potentially including that from the Care Quality Commission, stored in one place but shared widely.

We are supporting the development of regional networks of information governance professionals. The networks allow information to flow and issues to be escalated while the IGA draws on local expertise to resolve issues and to provide feedback on new guidance. These networks could be accessible in the same way to CQC.

We are firmly establishing IGA as the authoritative source of advice and guidance on IG matters:
• We plan to launch a national news service aimed at health and care staff with an interest in and/or responsibility for IG. We will welcome news from other sources including the CQC,
• We are preparing guidance to support new legislation on the duty to share information for care. Working with us, CQC can influence the messages in this national guidance,
• National organisations all have the chance to work more closely with us to ensure that our web portal provides access to their guidance, and
• We welcome the chance to work with national bodies so as to better align the national advice and guidance on information governance. This can include advice to CQC on the IG content of the Key Lines of Enquiry that organisations are assessed against.
### Appendix D. Glossary of terms

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<th>Term</th>
<th>Description</th>
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<tr>
<td>CQC Provider Handbooks</td>
<td>Guidance that CQC has written for providers</td>
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<tr>
<td>Information Governance</td>
<td>How organisations manage the way information and data are handled within the health and social care system in England. It covers the collection, use, access and decommissioning as well as requirements and standards organisations and their suppliers need to achieve to fulfil the obligations that information is handled legally, securely, efficiently, effectively and in a manner which maintains public trust.</td>
</tr>
<tr>
<td>Information Governance Toolkit</td>
<td>An online system which allows NHS organisations and partners to assess themselves against Department of Health Information Governance policies and standards.</td>
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<tr>
<td>Open data</td>
<td>Open data is data that anyone can access, use and share</td>
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26 [http://theodi.org/what-is-open-data](http://theodi.org/what-is-open-data)
Appendix E: Caldicott principles

1. Justify the purpose(s)
   Every proposed use or transfer of personal confidential data within or from an organisation should be clearly defined, scrutinised and documented, with continuing uses regularly reviewed, by an appropriate guardian.

2. Don’t use personal confidential data unless it is absolutely necessary
   Personal confidential data items should not be included unless it is essential for the specified purpose(s) of that flow. The need for patients to be identified should be considered at each stage of satisfying the purpose(s).

3. Use the minimum necessary personal confidential data
   Where use of personal confidential data is considered to be essential, the inclusion of each individual item of data should be considered and justified so that the minimum amount of personal confidential data is transferred or accessible as is necessary for a given function to be carried out.

4. Access to personal confidential data should be on a strict need-to-know basis
   Only those individuals who need access to personal confidential data should have access to it, and they should only have access to the data items that they need to see. This may mean introducing access controls or splitting data flows where one data flow is used for several purposes.

5. Everyone with access to personal confidential data should be aware of their responsibilities
   Action should be taken to ensure that those handling personal confidential data — both clinical and non-clinical staff — are made fully aware of their responsibilities and obligations to respect patient confidentiality.

6. Comply with the law
   Every use of personal confidential data must be lawful. Someone in each organisation handling personal confidential data should be responsible for ensuring that the organisation complies with legal requirements.

7. The duty to share information can be as important as the duty to protect patient confidentiality
   Health and social care professionals should have the confidence to share information in the best interests of their patients within the framework set out by these principles. They should be supported by the policies of their employers, regulators and professional bodies.

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