



Information Governance Review March 2013 A Summary

The Information Governance Review was published in March 2013. The aim of the review is to ensure the delivery of the best care possible to every citizen, and to address the issue that not all of those involved in providing health and social care see Information Governance as part of their responsibility.

Chapter 1: Introduction

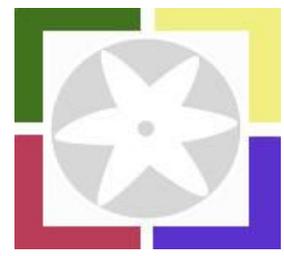
- People using health and social care services are entitled to expect that their personal information will remain confidential.
- Professionals are expected to share information to provide a seamless, integrated service. So good sharing of information, when sharing is appropriate, is as important as maintaining confidentiality.
- The *Review of the Uses of Patient-Identifiable Information*, chaired by Dame Fiona Caldicott, in 1997 devised six general principles of Information Governance that could be used by all NHS organisations with access to patient information. These six principles are still relevant and appropriate for the health and social care system today.

Chapter 2: People's Rights to Access Information About Themselves

- Patients who attempt to become involved in decisions about their care are often thwarted by 'information governance rules' that ignore their express wishes, which causes great frustration. Problems mainly originated from local Information Governance policies, which vary between organisations.
- The chapter includes examples of good practice. It recommends that all communications between different health and social care teams should be copied to the patient or service user. There should be 'no surprises' for the patient about who has had access to information.
- People's access to their care records should be improved, with individuals gaining electronic access to their own care records where they request it. The Review Panel thinks this right of access should cover hospital records, community records and personal confidential data held by all organisations within the health and social care system. It believes that access should become available within the next decade.

Chapter 3: Direct Care of Individuals

- When it comes to sharing information, there is a culture of anxiety and mistrust within the health and social care sector. Organisations are fearful that they might breach data protection laws, so restrictive rules are put in place.
- The Review Panel found a strong consensus of support among professionals and the public that safe and appropriate sharing in the interests of the individual's direct care should be the rule, not the exception.



- It is felt that organisations should pay closer attention to the appropriate transfer of information when people move across institutional boundaries, such as leaving hospital, coming out of the army or prison, or changing their GP.
- The problem that staff have when distinguishing between an individual such as a relative legitimately seeking information about a patient's progress and a 'blagger'; a person making improper inquiries, was also considered. The review panel recommends protocols to assist in good decision-making and procedures for informing and helping people if mistakes are made.

Chapter 4: Personal Data Breaches

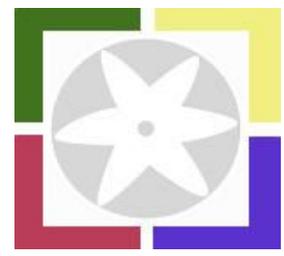
- Serious data breaches are a major concern to the Department of Health. Most involve the loss or theft of data, but almost one-third of breaches reported last year concerned unauthorised disclosures.
- There is a need for a new, consistent reporting channel to ensure that breaches of patients' confidentiality do not escape the attention of senior managers, ministers and regulators of health and social care.
- There should be a standard severity scale for breaches agreed across the whole of the health and social care system. The board or equivalent body of every organisation in the health and social care system should publish all such data breaches, as part of a quality report/annual report/performance report.

Chapter 5: Information Governance and the Law

- The Review Panel believes further effort is needed to increase patients' understanding of how their personal and confidential data is used.
- There are four legal bases for processing personal, confidential data which meet the common law duty of confidentiality.
 - With the consent of the individual concerned.
 - Through statute, such as the powers to collect data in specific acts.
 - Through a court order, where a judge has ordered that specific and relevant information should be disclosed and to whom.
 - When the processing can be shown to meet the 'public interest test.'
- New rights and pledges were set out in the Government's consultation on revisions to the NHS Constitution. The Review Panel proposes that these rights and pledges should be extended to cover the whole health and social care system.

Chapter 6: Research

- There is an enormous untapped potential in the information captured in social care records to support



better research. The Review Panel examined how these opportunities might be realised without weakening confidentiality and trust.

- The Review Panel recommends that information from more than one organisation should be kept in specialist, well-governed, independently scrutinised environments known as ‘accredited safe havens’ and should be supported by a system of external independent audit and other requirements to give the public confidence.

Chapter 7: Commissioning

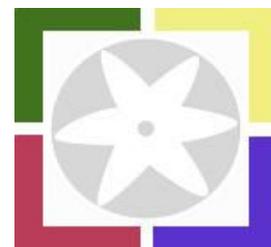
- Commissioners cannot organise the improvement of services unless they know about the people using them. However, knowing about service users need not necessarily require commissioners to know their identities.
- Commissioners in local authorities and Public Health England must adhere to the same standards, guidance and good practice and be subject to the same penalties for poor practice as the NHS when commissioning services. Commissioners should ensure their organisation complies with the legal and statutory framework for Information Governance.

Chapter 8: Public Health

- Healthcare professionals who are responsible for health protection sometimes need to know personal confidential data about specific individuals. (e.g. Identifying those at risk during an outbreak of an infectious disease.) However, accessing personal confidential data does not apply to other aspects of public health work. (e.g. Health improvement programmes are considered equivalent to the direct care of patients.)
- The Review Panel considers that the rules and procedures that have developed to provide the Information Governance for research can usefully be applied to public health intelligence, such as linking environment, personal behaviours and disease.
- There is a lack of regulatory coherence across the public health arena. The Review Panel suggests detailed and consistent remedies.

Chapter 9: Education and Training

- Across the health and social care system, most staff are required to undertake annual training in Information Governance. But it should not be a ‘tick-box exercise’ that staff can go through without thinking.
- Health and social care professionals should be educated and not simply trained in effective policies and processes for sharing of information. They should have formal Information Governance education focused on their roles, and this should be at both undergraduate and postgraduate level.



Chapter 10: Children and Families

- The safeguarding of children is a well-established system, underpinned by legislation, but there have been specific issues raised by professionals when dealing with children.
 - When should automatic parental access to a child's medical record be turned off?
 - When should a child's automatic access be activated upon their reaching sufficient maturity?
 - To what extent should individual members of a family have access to family records?
 - In order to provide effective care for children, information often needs to be shared beyond the normal boundaries of health and social care services, in particular, organisations such as schools.
- The Review Panel concludes that there would be clear benefits if a single, common approach to sharing information for children and young people could be adopted. The Department of Health should work with the Department for Education to investigate jointly ways to improve the safe sharing of information between services relevant to children.

Chapter 11: New and Emerging Technologies

- The Review Panel found a lack of clarity about a patient's right to access the record of new virtual consultations and uncertainty about how long records would be kept. It proposes ground rules for ensuring patients have access to information about themselves.
- The personal confidential data gathered through new processes and technologies must be treated in exactly the same way as any other personal confidential data, and providers of these services must adhere to the existing legislation and best practice.

Chapter 12: Data Management

- The Review Panel welcomes the focus that professional bodies for health and social care are placing on data quality. Organisations in health and social care need good quality data. Patients are at risk if clinicians base their decisions on inadequate data.
- Data quality standards must be improved. If data quality is sound, a pseudonym may be used to link data and thus protect the identity of an individual. The Review Panel calls for consistency in the Information Governance requirements for providers. It seeks to clarify the legal framework for sharing personal confidential data.
- Important summaries have been drawn from the Administrative Data Taskforce report on *Improving access for research and policy* published in 2012.



Chapter 13: System Regulation and Leadership

- There is currently no method of regulating the health and social care system as a whole. There is an opportunity for the Information Commissioner's Office and the Care Quality Commission to work together in ensuring the health and social care system is properly monitored and regulated in this regard.
- The Information Centre is to become responsible for producing and maintaining a code of practice on collecting, analysing, publishing or disclosing confidential information. (The code of practice will follow the updated Caldicott Principles.)
- The Informatics Services Commissioning Group (ISCG) is responsible for providing advice on commissioning informatics services across the health and social care system. A sub-group of the ISCG is to be established to provide specialist expertise, advice and support on Information Governance.

Chapter 14: Conclusions and Recommendations

- There was widespread support for the original Caldicott principles, which are still relevant and appropriate for the health and social care system today. However, evidence received during the Review persuaded the Panel of the need for some updating, and inclusion of an additional principle. The revised list of Caldicott principles therefore reads:
 1. Justify the purpose of the transfer of data.
 2. Don't use personal confidential data unless it is absolutely necessary.
 3. Use the minimum necessary personal confidential data.
 4. Access to personal confidential data should be on a strict need-to-know basis.
 5. Everyone with access to personal confidential data should be aware of their responsibilities.
 6. Comply with the law.
 7. The duty to share information can be as important as the duty to protect patient confidentiality.
- These principles should underpin Information Governance across the health and social care services.
- The Review Panel also concludes that the Secretary of State and the Department of Health should oversee the implementation of the recommendations of this review, and report on the progress made.