

# Data Sharing and Data Privacy

A Caldicott Guardian's perspective

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# Background

- ▶ Caldicott Guardians were introduced following the 1997 Caldicott Report into patient confidentiality.
- ▶ Increasing concerns about ways in which patient information was being used in the NHS.
- ▶ Dame Fiona Caldicott (Psychiatrist and academic)

- ▶ 18 Recommendations
- ▶ 6 Principles
- ▶ Audit of conformance by organisation (now superseded by IG toolkit)
- ▶ Since the Caldicott Report was published in 1997, the law regarding confidentiality and consent has been strengthened:
  - § 1998 new DPA (paper as well as computerised)
  - § 1998 European Convention of Human Rights
  - § 1998 Audit Commission Act
  - § 1998 Public Interest Disclosure Act
  - § 2000 Terrorism Act
  - § 2000 Regulation of Investigatory Powers Act
  - § 2001 Health & Social Care Act (section 60)
  - § 2005 Freedom of Information Act

# 6 Principles

1. Formal justification of purpose
2. Information transferred only when necessary
3. Only the minimum required
4. Need to know access
5. All to understand their responsibilities
6. Comply with and understand the law

▶ Handy mnemonic – FIONA C !

# Recommendations (some of 16)

- ▶ 1. Every dataflow (current or proposed) should be tested against basic principles of good practice. Continuing flows should be retested regularly.
- ▶ 3. A senior person, preferably a health professional, should be nominated in each health organisation to act as a guardian - responsible for safeguarding the confidentiality of patient information

- ▶ 5. Protocols should be developed to protect the exchange of patient-identifiable information between NHS and non-NHS bodies.
- ▶ 8. The NHS number should replace other identifier wherever possible, taking account of the consequences of errors and particular requirements for other specific identifiers.
- ▶ 9. Strict protocols should define who is authorised to gain access to patient identity where NHS number or other coded identifier is used.

- ▶ 10. Where particularly sensitive information is transferred, privacy-enhancing technologies (eg encrypting identifiers or “patient-identifying information”) must be explored.
- ▶ 11. Those involved in developing health information systems should ensure that best practice principles are incorporated during the design stage.
- ▶ 12. Where practicable, the internal structures and administration of databases holding patient information should reflect the principles developed in this report.

# Sharing and Confidentiality

Legislation and guidance require the NHS to use and share information in fulfilment of its duties, as well as to protect the rights of individuals in respect of their personal detail

The trick is to reconcile the apparent conflict between the need to use (and share) information and the need to protect confidentiality

In the case of patient information, whilst it is vital for the proper care of individuals that the professionals involved have ready access to the information they need, it is also essential that service users and their carers are assured that their personal information will be kept confidential and that their privacy is respected.

This delicate balance lies in the domain of the Caldicott Guardian.

# The Data Protection Act 1998

- ▶ Applies to ALL data, not just medical information. Also paper as well as electronic.
- ▶ 8 Principles:
  - 1 Personal data shall be processed fairly and lawfully and, in particular, shall not be processed unless certain conditions (set out in Schedules of the Act) are met.
  - 2 Personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.
  - 3 Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed.
  - 4 Personal data shall be accurate and, where necessary, kept up to date.
  - 5 Personal data processed for any purpose or purposes shall not be kept for longer than is necessary for that purpose or those purposes.
  - 6 Personal data shall be processed in accordance with the rights of data subjects under this Act.
  - 7 Appropriate technical and organisational measures (ie, security measures) shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.
  - 8 Personal data shall not be transferred to a country or territory outside the European Economic Area, unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.

# Care Record Guarantee

From the start, this new system will:

- ▶ hold records about your care in a national computer system so that, wherever in the country you need care, health care professionals can have access to the most up-to-date information when caring for you;
- ▶ allow only those involved in your care to have access to records about you from which you can be identified;
- ▶ show only those parts of your record needed for your care;
- ▶ allow only authorised people to access your records (who will need a 'smartcard' as well as a password);
- ▶ allow you to control whether information in electronic records made about you by the organisation providing your care can be seen elsewhere in the NHS;
- ▶ allow us to use information about your health care to improve the services we offer, in a way that doesn't reveal your identity;
- ▶ keep a note of everyone who looks at the records about you; and be operated in line with internationally approved information security standards.
- ▶ We must maintain a balance between sharing records about you to provide you with high-quality care and preserving your confidentiality.
- ▶ By 2008, we plan to give you even more control over who may use the records held about you. A summary of future plans is given at the end of this guarantee.

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- ▶ We plan to make information from the care record available to you at all times, free of charge, over a secure internet connection through the service currently called 'HealthSpace' ([www.nhs.uk/healthspace](http://www.nhs.uk/healthspace)).
- ▶ If you are concerned about particular entries in the record about your health care, rather than about the whole record, you will be able to ask us to keep parts of the record about your health care from general view and only share them with your permission, except:
  - § in an emergency if you are not able to give permission;
  - § when allowed by law; or
  - § when health care staff have good reason to believe that failing to share the information would put someone else at risk.

# Consent is King!

- ▶ With the patient's consent, anything is possible.
- ▶ Informed consent is the holy grail of information sharing
- ▶ Tempered by practicalities

Questions?

