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PSNC Briefing 109/13: Information: To Share or not to Share - Government Response to the Caldicott Review

This PSNC Briefing summarises [Information: To Share or not to Share - Government Response to the Caldicott Review](#) which was published by the Department of Health (DH) in September 2013.

The NHS Future Forum called for a review of the current rules on information governance, and how they are applied. The Government's Information Strategy, [The Power of Information: Putting all of us in control of the health and care information we need](#), accepted the need to be clearer about when to share data between professionals and DH subsequently initiated a review of information governance to ensure that there is an appropriate balance between the protection of confidential data and the use and sharing of information to improve people's health and social care and for the benefit of wider society.

Dame Fiona Caldicott was asked to undertake the review and in April 2013 she published [her Report](#). The report includes revisions to the original Caldicott principles to emphasise the need to give greater focus to sharing information. In the Government's response it accepts in principle all of the recommendations in Dame Fiona's report and it states that DH will be looking to deliver the spirit of the review, rather than confine itself to the recommendations.

The revised 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 should not be included unless it is essential for the specified purpose(s) of that data 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.

The Department accepts the revised Caldicott principles and will ensure that the principles and the actions in this response, particularly those relating to information sharing, are aligned. The principles will be included in the Confidentiality Code of Practice to be published by the [Health and Social Care Information Centre \(HSCIC\)](#).

What these principles should mean when applied

For patients, care service users and their families and carers:

- People will feel more in control of their personal confidential information. This would include knowing how their information will be used, stored, transferred, etc. and being confident that everything will remain safe within information governance (IG) guidelines. People will also know how to object if they don't want their information to be shared; and
- People will be increasingly able to access their own health and care records.

For everyone working in the health and care system:

- Health and care professionals will make informed decisions about how information is shared and used in the best interests of people and patients using the five rules of confidentiality set out in new HSCIC guidance (see below);
- Health and care staff will adhere to the principles of the Caldicott Report and the NHS Constitution on data sharing in their efforts to improve care and support for patients and people who use services; and
- There will be appropriate training and education for different groups of staff including social care workers.

For organisations within health or social care:

- Boards or their equivalents will make sure that their organisation has due regard for information governance;
- Employing organisations will adhere to the principles of the Caldicott Report and the NHS Constitution on data sharing in their efforts to improve care and support for the benefit of patients and people who use services. They will help professionals to share information appropriately in order to help to integrate care and improve services;
- Organisations will be open and honest – explaining and apologising if a data breach happens, and taking action to prevent it happening again;
- Organisations will have a Caldicott Guardian or a Caldicott lead and will offer suitable training and education for all staff on information governance; and
- Over time, social care providers and commissioners will adopt more of the best practice that is already in place across much of the NHS so that the way personal information is treated is the same whether the care is provided by a GP, hospital or care home.

People's right to access information about themselves

The Report made the following recommendation:

People must have the fullest possible access to all the electronic care records about them, across the whole health and social care system, without charge. An audit trail that details anyone and everyone who has accessed a patient's record should be made available in a suitable form to patients via their personal health

and social care records. The Department of Health and NHS Commissioning Board should drive a clear plan for implementation to ensure this happens as soon as possible.

NHS England is leading work on electronic access to health records to deliver the Information Strategy commitment to providing online access to all GP records by 2015 as a first step towards providing electronic access to all health and care records. The Department will work with partner organisations to consider how this might be extended to care records outside the NHS.

Direct care of individuals

Perhaps the most important recommendations of the Report relate to the emphasis that should be placed upon sharing information to support direct care:

For the purposes of direct care, relevant personal confidential data should be shared among the registered and regulated health and social care professionals who have a legitimate relationship with the individual.

Health and social care providers should audit their services against NICE Clinical Guideline 138, specifically against those quality statements concerned with sharing information for direct care.

Sharing information to support care is essential; it is not acceptable that the care a patient or service user receives might be undermined because the different organisations providing health and care to an individual do not share information effectively.

The common law 'duty to care' includes a requirement to share information, but often professionals and staff are prevented from doing this by their own organisation's procedures. The Department does not expect professionals to act against their employer's information governance arrangements, but does expect these employing organisations to make it easier to share information and to follow the best practice of the organisation. The Department is calling on all organisations to examine their existing arrangements, and to lead by example.

What needs to be done following the review?

All staff and workers within the health and care system are expected to:

- be aware that the duty to safeguard children or vulnerable adults may mean that information should be shared, if it is in the public interest to do so, even without consent; and
- look at information governance best practice and how it affects their work.

All health and care organisations are expected to:

- examine their existing arrangements, and lead by example with their local partners to make it easier to share information;
- expect that relevant personal confidential data is shared among the registered and regulated health and social care professionals who have a legitimate relationship with the individual;
- seek advice from [the Information Commissioner's Office](#) and refer to the HSCIC's Confidentiality Code of Practice (when published) for further advice on managing and reporting data breaches;
- explain and apologise for every personal data breach, with appropriate action agreed to prevent recurrence;
- clearly explain to patients and the public how the personal information they collect could be used in de-identified form for research, audit, public health and other purposes;
- make clear what rights the individual has open to them, including any ability to actively dissent;
- use the best practice contained in the HSCIC's Confidentiality Code of Practice (when published) when reviewing their information governance practices to ensure that they adhere to the required standards;
- appoint a Caldicott Guardian or Caldicott lead with access to appropriate training and support;
- strengthen their leadership on information governance;
- ensure that the information provided to inform citizens about how their information is used does not exclude disadvantaged groups; and

- use the revised Caldicott principles in all relevant information governance material and communications.

Local NHS providers are expected to:

- audit their information sharing practices in adult NHS services against NICE Clinical Guideline 138

A Guide to Confidentiality in Health and Social Care

In September 2013 the HSCIC published a [Guide to Confidentiality in Health and Social Care](#) which explains the various rules about the use and sharing of confidential information. It has been designed to be easily accessible and to aid good decision making. It also explains the responsibility organisations have to keep confidential information secure.

The guide is supported by a [references document](#) which provides more detailed information for organisations and examples of good practice.

If you have queries on this PSNC Briefing or you require more information please contact [Barbara Parsons, PSNC Head of Pharmacy Practice](#).