

# *Information governance in the Department of Health and the NHS*

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## Introduction

I was asked by the Programme Board of the National Programme for IT in the NHS to conduct a review of information governance in the light of the creation of the NHS Care Records Service (NHS CRS).

I define 'information governance' as:

*"the structures, policies and practice of the DH, the NHS and its suppliers to ensure the confidentiality and security of all records, and especially patient records, and to enable the ethical use of them for the benefit of individual patients and the public good".*

Effective information governance is necessary to be sure that the new opportunities that the National Programme for IT promises will be effectively and safely realised and so that public confidence in the electronic NHS is secured. Whilst my review focuses on the areas specified in my remit, I undertook it with recognition of the wider context of information governance which includes both the Office of the Information Commissioner and other government departments and organisations.

A wide range of stakeholders provided input into the review and I am grateful for their help and support. Although I am clear that the present arrangements will need to be improved to support an electronic NHS, I found no committee, group or individual not doing their best in the circumstances within which they were working. None of my comments or recommendations should be taken as criticism of individuals.

This document contains a summary of my findings, a full description of my recommendations and information on how these are being taken forward. I hope you find it helpful and informative.



**Harry Cayton**  
**Chair, Care Record Development Board**

## **1. Findings**

- 1.1. All forms of governance require clear lines of accountability for policy, practice and implementation. Clearly accountable bodies with clearly defined purposes do not always exist in the present arrangements around information governance. The coherence, clarity and consistency in the way information is governed within and between the various bodies involved in the development, delivery and monitoring of NHS care and services will need to be improved to support an electronic NHS.
- 1.2. I identified eight different bodies or groups developing, contributing to or interpreting information governance, in addition to the Care Record Development Board itself.
- 1.3. National performance around information governance is not effectively monitored and consistently reported. Where there are disagreements about the interpretation of best practice in information governance or in the pursuit of advice there is no single authoritative source of advice or arbitration.
- 1.4. The Caldicott Guardians generally felt that they could be given more adequate selection, guidance and training to fulfil their role.
- 1.5. Overall the fragmentation of information governance policy and practice and the confusion of roles results in duplicated activity, gaps in activity and in a real lack of impact on practice.
- 1.6. Although we must ensure that appropriate information governance is in place to cover all systems, both paper and electronic, it is inevitable that we focus on new developments.
- 1.7. The NHS Care Records Service and the other services being created by the National Programme for IT have the potential to bring huge benefits to patients and service users, to the NHS and social care, and to secondary users. There is considerable pressure to obtain access to data on the NHS Care Records Service from other government departments, public services such as the police and immigration services, and researchers. Clear ethical values and standard procedures consistently applied are essential if the right uses of the NHS Care Records Service are to be secured and maintained. As the National Programme for IT Programme Board has already acknowledged, ethical, consistent and effective information governance is a necessity if these benefits are to be realised and public confidence maintained.

NHS care and services are now delivered through a diversity of providers. Information governance must include appropriate oversight and control of information within an NHS with a diversity of providers and multiple information users, for example:

- NHS commissioning organisations
- GPs and primary care
- NHS and foundation trusts
- independent sector providers; not-for-profit, commercial and charitable
- social care organisations
- regulators and inspectors including the Healthcare Commission and the NPSA
- audit and fraud investigators
- the Health & Social Care Information Centre
- research bodies and researchers.

1.8. It is the electronic NHS which will both facilitate patient choice and mobility and enable diversity of providers. But in order to meet the necessary standards of confidentiality, security, safety and consistency we will need national standards, locally implemented and monitored and nationally enforced. We have made a start in publishing the Care Record Guarantee.

1.9. As NHS provision becomes more diverse the need for national oversight of consistent local implementation becomes ever greater. If the benefits of the NHS Care Records Service are to be achieved engagement of social care and of independent providers and regulatory bodies in the creation of consistent good practice is essential.

## **2. Objectives for a new system of information governance**

2.1. The recommendations focus on ensuring that future arrangements for information governance:

- demonstrate clarity, accountability, transparency, coherence and consistency
- provide sound policy, standard setting, independent oversight, monitoring, arbitration and enforcement
- be realistic, practicable and deliverable and measurable
- define the roles of the Department of Health, NHS Connecting for Health, NHS bodies, provider organisations, data managers and regulators.

2.2. At local organisational level future arrangements for information governance must deliver the following:

- training and support for Caldicott Guardians
- local monitoring of and accountability for national standards
- full engagement of the registration authority in information governance
- clear and enforceable practice in relation to all providers to the NHS, including independent providers
- contractual requirements for all staff (including staff not employed by the NHS) and appropriate penalties for misuse of information.

### 3. Recommendations

3.1. The recommendations below are intended to address the problems the present system and the objectives for the future set out above. As such they are high-level descriptions, the detail of which will be determined during the implementation phase.

#### 3.2. Recommendation 1

That the Digital and Health Information Policy branch within NHS Connecting for Health, should continue to focus on the policy interfaces with DH and with wider government to ensure that changes to policy can be supported by system development and that policy makers are aware of changes to information system capability which can support the implementation of policy.

#### 3.3. Recommendation 2

That the functions of Caldicott Guardian for the Department of Health should pass to the Chief Medical Officer thus providing independence from policy and creating a line of accountability from him through to the Caldicott Guardians in the NHS for the governance of patient information and thus complying with existing guidance<sup>1</sup>.

#### 3.4. Recommendation 3

That a national Information Governance Board is created for health and social care to advise the DH and ministers, to provide oversight, to develop and interpret best practice, to promote consistency, to arbitrate on the interpretation of policy and give advice and to build public confidence in the NHS Care Records Service. The Board should be independently appointed and its membership drawn from stakeholders including patients and the public, health and social care professionals, NHS and independent providers, regulators and researchers.

The Patient Information Advisory Group provides a vehicle for this development.

#### 3.5. Recommendation 4

That all bodies or organisations supplying services to the NHS and having permitted access to NHS data come within the oversight of the national Information Governance Board and that this is enforced through contract or service agreement.

1. Caldicott Guardians "should be, where practicable, a senior health professional with access to the most senior tier of management within an organisation" (In a hospital trust they must be a health professional). The Guardian "should be seen as separated from other management and sectoral influences, thereby engendering confidence in their independence and integrity" In appointing a Guardian there is a "need to avoid conflicts of interest".

It seems that appropriate statutory frameworks do not exist to support this recommendation. Consideration should be given to the need for appropriate secondary legislation to ensure that those who access NHS systems and data are bound, as a consequence of accessing systems or data, by the relevant NHS statute.

### **3.6. Recommendation 5**

That all organisations providing health and social care are required in addition to having a Caldicott Guardian to have clear process within their overall governance structure to ensure compliance, oversight, and monitoring of information governance within that organisation. There are several ways that this could be achieved, for instance through an organisational information governance board, and it seems appropriate to leave the determination of structure to local decision. I am, however, clear that this role must be fulfilled, and that there must be an annual report on information governance to the directors of the organisation and to the national Information Governance Board and acceptance of its advice and direction where necessary.

### **3.7. Recommendation 6**

That a job description and competencies are created for Caldicott Guardians and that training, support and guidance is provided for Caldicott Guardians and Information Governance Committees. Also that consideration is given to changing the name of Caldicott Guardians so that their role in protecting patient information is apparent to patients and staff.

### **3.8. Recommendation 7**

That all organisations having access to the NHS Care Records Service bring their Registration Authority and procedures under the oversight of their Information Governance Committee and that proper management of user registration is seen as an information governance issue. Also, that the National Registration Board should come under the oversight of the national Information Governance Board.

## **4. Implementation**

- 4.1. Implementation will require time in some areas and also clarification of the detail of relationships. Some suggestions about how implementation might be achieved are set out below.
- 4.2. If real change and benefits are to be achieved from the implementation of the recommendations it is essential that a clear link is established between the policy changes and conformance of both central and local organisations with these changes. A clear standard of information governance will be developed which organisations must achieve, and this will be directly supported by both implementation guidance and conformance criteria, which will enable organisations to know that they have implemented and are using the standard correctly. The Information Governance toolkit in current use and currently being revised will provide a firm basis for developing and monitoring standards.
- 4.3. The new national Information Governance Board should be established as soon as is practicable. The role of those groups currently concerned with information governance should be reviewed with regard to their future relationship to the Board.
- 4.4. Bringing social care within the remit of the national Information Governance Board will require discussion with the Local Authority Association, the Association of Directors of Social Services and Commission for Social Care Inspection. These discussions will take place as part of the implementation process.
- 4.5. Discussions will need to take place with the Healthcare Commission to ensure that its role in inspecting information governance within NHS Trusts and independent providers is consistent with and complementary to the Information Governance Board. The Healthcare Commission will continue to manage patient complaints.
- 4.6. The mechanisms for the creation of consistent, accountable information governance in NHS organisations, including the Registration Authority and training for Caldicott Guardians need to be identified.
- 4.7. The Department of Health will need to ensure that contractual arrangements are fully in place to ensure compliance with NHS information governance requirements by independent providers to the NHS who have access to the NHS information.
- 4.8. When the NHS Care Records Service goes live and the Care Record Guarantee is implemented the Care Record Development Board should cease to have responsibility for this area which should pass to the National Information Governance Board.

You can get more information on the Care Record Development Board from our website:  
[www.connectingforhealth.nhs.uk/crdb](http://www.connectingforhealth.nhs.uk/crdb)

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