



# **UK Council of Caldicott Guardians**

*5 Year Strategy 2011-2016*

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# UK Council of Caldicott Guardians

## *5 Year Strategy 2011-2016*

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Approved by the Council October 2011

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# A Vision for the UK Council of Caldicott Guardians:

**Developing the wisdom of Caldicott Guardians to ensure information is shared safely in the best interests of the service users and the public**

***A Caldicott Guardian is a senior person responsible for protecting the confidentiality of patient and service user information and enabling appropriate information-sharing.***

The legislative structure of the UK, including the English NHS Constitution, provides that service users have a right to privacy and confidentiality and to expect their care providers to keep their confidential information safe and secure. Although the legal structures may be different in Scotland, Northern Ireland and Wales, the ethics and principles are the same. The Council will apply a joint, harmonised and professional approach to all issues wherever they originate within the UK.

Caldicott Guardians are key to ensuring that these confidentiality and privacy requirements are met, with an equally important role in ensuring that confidential information is shared appropriately and in the best interests of the service user.

## Introduction and Context

The 1997 report of the Review of Patient-Identifiable Information, chaired by Dame Fiona Caldicott (the Caldicott Report), made a number of recommendations for regulating the use and transfer of person identifiable information between NHS organisations in England and to non-NHS bodies. One recommendation was that every flow of patient-identifiable information should be regularly justified and routinely tested against six principles (the 'Caldicott Principles').

Principle 1 - Justify the purpose(s) for using confidential information

Principle 2 - Only use it when absolutely necessary

Principle 3 - Use the minimum that is required

Principle 4 - Access should be on a strict need-to-know basis

Principle 5 - Everyone must understand his or her responsibilities

Principle 6 - Understand and comply with the law

A further recommendation was the appointment in each NHS organisation of a "Guardian" of person-based clinical information to oversee the arrangements for the use and sharing of clinical information. Subsequent work extended the requirement to appoint Caldicott Guardians into Councils with Social Care Responsibilities.

The role of Caldicott Guardians was relatively straightforward at that time however the last 5 years have presented many challenges and issues of varying natures, which would not have been foreseen at the time and will continue to develop during the next 5 years.

The environment we all work in has changed dramatically, technologically, socially and economically.

Technology has seen rapid development of information sources (SMS text messaging and mobile phones and mobile computers with graphical, photographic and video media) along with opportunities for sharing such information across organisational and geographic boundaries at the press of a button. This has led to higher expectations regarding the speed of decisions regarding information sharing and increased reliance on greater more complex content. There has been a number of high profile, detailed information losses which has required increased data security. This is, at times, at odds with other policy and service user needs, a good example of which is the recent Baby Peter death which now requires more information sharing at earlier stages regarding safeguarding children (representatives from the Council are assisting the DH leads with some new policy and guidance as this strategy is written).

Socially we now live with social media networks, in a world of stark wealth and poverty, with people sharing personal information on these networks which then is freely passed on, whilst there is a requirement on organisations to safeguard the same information. However many of these individuals are the very people who need their information safeguarded by Caldicott Guardians to ensure that the fragmented pieces of information are not joined together to put them at risk.

Caldicott Guardians work in rapidly and continually changing environments and organisations. These organisations are being challenged economically, with ever changing structures and processes, many of which are designed to improve things for service users. However, there

are risks that need managing to safeguard service user information (along with commercial information), but allow enough flexibility to ensure improvements in practice and developments. Services are now patient centred and information sharing is required. Due to the planning and commissioning requirements, particularly to address health and social inequality, there needs to be judgements exercised in protecting the individual against the needs of the community.

As finances become restricted and tightened, training and support to Caldicott Guardians and front line staff is reduced at a time when expertise and confidence is most needed.

Structures and organisations are merging and becoming larger whilst decision making and opportunity is being made to smaller, diverse and often limited governed groups of individuals (Commissioning Boards, Clinical Commissioning Groups and smaller providers within the third sector). This is happening at the same time as regulatory, monitoring and advisory groups are being disbanded, e.g. the National Information Governance Board for Health and Social Care, with no clear proposal of who or how these functions will be picked up and where the expertise will sit.

These challenges and changes are sure to continue into the next 5 years whatever the political agenda and picture will be.

The UK Council of Caldicott Guardians is one of the groups that the Government and Department of Health has supported and agreed for it to continue - such is the importance of the group, the agenda and the work it does.

The Council brings together expertise, leadership, wisdom, judgement and pragmatism to enable service user information to be safeguarded but used in service user interest. The links and team-working with the Information Governance leads in organisations has proved invaluable and the Council will seek to build on this relationship in the coming years.

The Council will rise to the challenges and has developed this 5 year Strategy to take it through to 2016, supported by the Communications Strategy and Annual Business/Work Plans.

The Annual Business Plan outlines the projects and work of the Council for the coming year with work streams clearly linked back to the Strategic Objectives within the Strategy.

One of the criticisms of the Council has been a lack of profile and knowledge of others about the work undertaken. The Communications Strategy seeks to redress this balance.

Much work has already been undertaken with enquiries to the Council increasing in numbers and complexity and links having been made with other professional organisations e.g. General Medical Council, Health Professionals Council etc. In addition, work continues linking into other government departments and assisting with expertise (e.g. assistance with the new Safeguarding Children Guidance from DH). The Communications Strategy is an integral part of the 5 year Strategy and each element of the Annual Business Plan will have a communication requirement within it.

Council work and Chairman's Report Progress can be found within the Annual Report for the previous year. This Strategy seeks to build on the excellent achievements to date.

UK Council of Caldicott Guardians

Acknowledgement goes to Magi, Michael, Gill and Stephanie Aitkin (post graduate volunteer) for the writing of this and supporting documents.

## The UK Council of Caldicott Guardians

Caldicott Guardians were put in place originally to protect patient information from non clinical people and processes. The role has now developed into giving advice and assistance on a day to day basis regarding care and clinical issues and information sharing.

The UK Council of Caldicott Guardians was created in 2005 to support Guardians by providing advice and information on confidentiality issues.

- To be the national body for Caldicott Guardians
- To promote the roles and activities of Caldicott Guardians within the United Kingdom
- To be a forum for the exchange of information, views and experience amongst all Caldicott Guardians
- To seek, consider and to represent the views of Caldicott Guardians on matters of policy relating to the organisation and delivery of Information Governance
- To be a channel of communication upon Caldicott matters with national organisations concerned with the NHS, the independent health sector, local government and health and social care professionals
- To act as a resource centre, provide support and arrange learning opportunities for Caldicott Guardians, both current and of the future.

This new strategy recognises the significant changes in the delivery of health and social care since the 'Report of the Review of Patient-Identifiable Information' (the Caldicott Report), chaired by Dame Fiona Caldicott in 1997. These changes, in service delivery and in care providers, present significant Information Governance challenges and have a consequent impact on Caldicott Guardianship. Alongside the major reconfiguration of the health service in England, including the transfer of public health responsibilities to local authorities, well documented data breaches continue to be reported.

**Part one** of this strategy sets out three primary objectives for reforming the Council - leadership, skills and innovation.

**Part two** sets out nine strategic aims for reforming the Council over the next 5 years and how each aim will be achieved.

## Part one: Three primary objectives

Three primary objectives that will allow the Council to promote the use and appropriate sharing of personal information in the best interests of service users and the public.

### Providing leadership on Caldicott and confidentiality matters

Council members have specialised skills and many have several years experience providing advice and guidance on confidentiality issues. It is important that these skills are recognised, shared and utilised, not only by the Caldicott community but also by others seeking such advice. To this end the Council will ensure that:

- As a body it remains relevant and fit for purpose,
- Links with the professional bodies are developed and maintained,
- Council members have the right skills, and
- As a body it adequately represents the wider health and social care environment.

### Developing the skills and wisdom of all Caldicott Guardians

The advice of a Caldicott Guardian must be sought where there is a proposal to use service user information for purposes other than direct care, to ensure that:

- All sharing of confidential service user information is appropriate and lawful.
- Service user preferences are respected, whether to share or not to share.

To support all Caldicott Guardians in effectively carrying out their role the Council will draw attention to resource gaps and ensure there are a range of opportunities available for training, development and support.

### Innovations and practice development

Since its inception the role of Caldicott Guardian has markedly evolved and will continue to do so. Advice provided by the Council has often been reactive, as a result of changes in technologies or changes in working practices. The Council intends to take a more proactive approach by seeking opportunities to be involved at an early design stage of technology or process change so that the impact on information sharing and confidentiality can be adequately considered.

## Part two: Nine Strategic Aims

The nine strategic aims are extrapolated from the primary objectives of leadership, skills and innovation. The aims provide the Council with the basis for a 5 year work plan.

### 1. Leadership: Developing effective routes of communication

#### **In 5 years time**

There will be high awareness of the Council amongst Caldicott Guardians, those working in health and social care delivery, and those with an interest in information sharing and confidentiality matters.

#### **What will the Council do to achieve this?**

Delivery against this aim will be set out in a companion communication strategy.

### 2. Leadership: Developing the capability of the Council to meet the needs of Caldicott Guardians

#### **In 5 years time**

The Council will be the national voice for Caldicott Guardians, working closely with the Department of Health, the NHS Commissioning Board, local authorities, other government departments and professional bodies to meet the new information governance challenges.

#### **What will the Council do to achieve this?**

As a first step the Council will review and revise its membership and rules of engagement, including the constituencies represented; the Constitution (ToR), and the overall agenda. Collaborative working agreements will be developed with other bodies mentioned above to ensure that guidance is aligned and joint referencing of key contacts and the work done is enabled.

### 3. Leadership: Maintaining the relevance of the Caldicott Guardian role

#### **In 5 years time**

The importance of the Caldicott Guardian role is recognised at CEO/senior management level so that Guardians with sufficient knowledge and/or experience are selected for the role. Service users and the public will be aware of the role of the Caldicott Guardian and will be aware of the nominated Guardian for local services. New and existing organisations delivering health and social care will have an effective information governance management framework in place that includes an appropriately supported Caldicott/confidentiality function. This will include maintaining strong links between the English, Scottish, Welsh and Northern Irish Guardians.

#### **What will the Council do to achieve this?**

The Council will explore methods of providing incentives (eg awards or other means of recognition) so that people taking on the role feel valued, and organisations are proud of their Caldicott arrangements.

#### 4. Skills: Developing learning opportunities for Caldicott Guardians

##### **In 5 years time**

All Caldicott Guardians will apply balanced judgements to information sharing requests, so that even if the decision to share or not is different it is arrived at in a logical way, and false barriers to information sharing are overcome/removed. It will also ensure that outcomes are shared showing exemplars of best practice and team working.

##### **What will the Council do to achieve this?**

All Caldicott Guardians and their support staff will have access to appropriate training to assist them in their role. The NHS IGTT provides e-learning materials - current modules are the role of Caldicott Guardian in health and social care, patient confidentiality, information sharing, and access to health records. The Council will seek feedback on what other training Caldicott Guardians believe would assist them in their role. This work has been carried out by the Council in the past as part of a training analysis of Caldicott Guardians and the information collected will provide some useful pointers for future training and support.

The Council will seek out relevant existing courses, obtain the costs and see if the provider will forward the course content for review. The lever could be that appropriate courses will be "UKCCG accredited" as appropriate for Caldicott Guardians and their support staff.

The wider Caldicott community will be asked to forward details of any courses they have attended which they believe were useful to them and would be appropriate for other Caldicott Guardians etc.

Other avenues are networking - workshops, conferences; highlighting links with other roles, eg the SIRO, Information Governance leads etc.

The Council will seek to source sponsorship and resources to hold an annual event to include training and recognition of best practice.

#### 5. Skills: Supporting new Caldicott Guardians

##### **In 5 years time**

New Caldicott Guardians will have the tools to enable them to have sufficient confidence to identify the issues and apply their own judgement to decision making, and to know when they need to seek further assistance.

##### **What will the Council do to achieve this?**

The Council will provide an induction pack for new Guardians, the core documents of which will be the Caldicott Guardian Manual, the Confidentiality NHS Code of Practice and the NHS and Social Care Record Guarantees. Links to training materials or courses will also be provided. The Council will initiate a mentorship scheme whereby a new Guardian will be assigned to a named Council member who will provide support via email and telephone. The Council will also look into setting up a coaching scheme.

## 6. Skills: Contributing to wider IG training

### **In 5 years time**

Caldicott Guardianship will be appropriately included or represented within other IG training. The Council will lead on ensuring a whole information governance team approach to training.

### **What will the Council do to achieve this?**

The Council will take a proactive approach to training of the information governance team which will include the Caldicott Guardians, IG leads, policy makers, and build on lessons learnt from the Clinical Safety Officers training approach.

The Council will link with the Higher Education Institutes, Deaneries etc to ensure that this agenda is included in trainees and student, university and NVQ training.

Links will be developed with training providers with support and the provision of materials offered (eg a presentation about the Council).

## 7. Innovation: Early identification of new developments and influencing national policy and developments

### **In 5 years time**

Confidentiality and information sharing issues are considered at the design phase of development of new processes or new ways of working.

### **What will the Council do to achieve this?**

'Horizon scanning', to see what new developments and processes have been mooted. This will include input into policy development to ensure that the requirements of Caldicott and training are recognised and resourced.

The Council also proposes to develop links with technology suppliers building Caldicott principles into software and hardware processes at the design stage. The focus will be on empowering and protecting individual information whilst being able to use trends and other information for research and planning of services.

The focus will be on supporting patients and service users to be in control of their information to manage their own care needs where appropriate.

This will also assist in the compliance with associated legislation such as the Crime and Disorder Act in a safe way.

## 8. Innovation: Developing guidance in the light of new developments

### **In 5 years time**

The Council will assist in the development of privacy and confidentiality standards and guidance that defines how information should be managed and when it should be shared. This will be achieved within the knowledge that the law overrides everything else and the Council will seek to be a reference point for those developing the law and afterwards with the application of it.

### **What will the Council do to achieve this?**

The Council will seek to have representation on the emerging Information Governance national groups, along with those policy making groups that have particular links to this agenda such as Safeguarding.

The Council will forge strong links with professional registration bodies such as the General Medical Council, Nursing & Midwifery council, Health Professional Council etc as well as national recognised voluntary and independent sector partners.

There will be a process to provide Council members and partners with the opportunity to comment on any perceived Caldicott issues and timely guidance and advice will be issued for practitioners and other interested parties.

9. Innovation: Assisting Caldicott Guardians to understand the implications of new developments

**In 5 years time**

The Council will develop logical guidance regarding how a particular process might affect confidentiality or hinder lawful information sharing, so that Caldicott Guardians know the rules.

**What will the Council do to achieve this?**

The Council will use information and consultation processes from its work with policy maker and technical developers to produce simple guidance. This will be supported with a resource of best practice, exemplars, incidents and near misses, learning and action plans. These will be used to produce periodic toolkits and documents.

## Monitoring and reporting

The success of this Strategy will be monitored against the achievements against the tasks and projects outlined within the Annual Business and Workplan for the Council.

It will be formally reported to the Council twice a year and within the Annual Report.

These reports will be publically available on the website and circulated accordingly

## Priorities for development in Year 1

- Agree the Annual Business / Workplan
- Review and revise the Constitution
- Finalise and implement the Communications Strategy
- Organisation of an event to launch the Strategy and provide training to the wider team

Review date: August 2012