

**UKCGC**

The United Kingdom Caldicott Guardian Council

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**Annual Report 2018–19**

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# The UKCGC Annual Report 2018-19

The UK Caldicott Guardian Council (UKCGC) is the national body for Caldicott Guardians. This report for 2018–19 details how the Council has progressed its aims to support Caldicott Guardians.

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## Background

A Caldicott Guardian is a senior person responsible for protecting the confidentiality of individuals' data and making sure it is used properly. All NHS organisations and local authorities which provide social services must have (and register) a Caldicott Guardian. Guardians have also been appointed in many non-NHS health and social care institutions. There are presently over 5350 registered Caldicott Guardians, but the actual number is thought to be much larger.

In October 2003, the then NHS Information Authority announced a new national organisation specifically for Caldicott Guardians working in Health and Social Care. Following this announcement, a small group of Caldicott Guardians worked on a constitution for the national group, which launched in 2005 as the United Kingdom Council of Caldicott Guardians, under the chairmanship of Stephen Hinde, at the time the Caldicott Guardian for BUPA.

At its inauguration, the Council was sponsored by the National Programme for IT (NPfIT). Subsequently its sponsors were NHS Connecting for Health, which later became the Health and Social Care Information Centre (HSCIC) which is now NHS Digital. Since 2015 the Council has been under the wing of the [National Data Guardian \(NDG\)](#).

In April 2017 Dr Chris Bunch succeeded Christopher Fincken as Chairman and Sandra Lomax was appointed Vice Chair. During 2018 the council has moved to a new resource model and refreshed council membership. This has provided representation from additional health and care sectors including digital primary care, local authorities, ambulance service NHS trusts, special health authorities and arm's length bodies.

## Aims of the Council

The Council's principal aim is to provide support for Caldicott Guardians and others fulfilling the Caldicott function within their organisation. In addition, it aims to:

- be a point of contact for all Caldicott Guardians and for health and care organisations seeking advice on the Caldicott principles;
- enable Caldicott Guardians to share information, views and experience;

- encourage consistent standards and training for Caldicott Guardians;
- help to develop guidance and policies relating to the Caldicott principles.

To support these aims and those fulfilling the Caldicott function within health and care the UKCGC has been developing and implementing a wide range of processes, resources and supporting mechanisms which are described in in this report.

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## Council meetings

The Council holds meetings every two months in London. In addition to standing items (Chairman and Vice-Chair's reports; requests to Council for advice; reports from Regional Networks), during 2018–19 Council received from and discussed presentations and/or topics, including:

**April 2018:** Understanding Patient Data; the Health Research Authority's integrated online research application process (IRAS); the Faculty of Clinical Informatics; and a General Data Protection Regulation (GDPR) update from NHS England.

**June 2018:** The Centre for Data Ethics and Innovation being established by Department for Digital, Culture, Media and Sport; the launch of the National Data Opt-out; and an update to the NHS Code of Confidentiality.

**August 2018:** The NHS Digital Citizen Identity programme; Fire and Health Services working in partnership to prevent fire and improve well-being; and the Security of Network & Information Systems (NIS) Regulations 2018.

**October 2018:** The Strategic Information Governance Network (SIGN), digital primary care services provided GP at Hand, the emerging information governance framework for Local Health and Care Record Exemplars (LHCREs) and the NHS Code of Confidentiality.

**December 2018:** Dr Simon Eccles (NHS England' CCIO) discussed the ongoing digital transformation programme; a National Data Opt-out update and the GP Data for secondary uses programmes from NHS Digital.

**February 2019:** The National Cancer Registration and Analysis Service (NCRAS) guidance: raising awareness of cancer registration; the Secondary Uses Data Governance Tool, the Care Quality Commission (CQC) 'Well Led' inspections, and guidance on missing persons & domestic violence.

## Supporting Caldicott Guardians

### UKCGC website

The [Council website](https://www.ukcgc.uk/)<sup>1</sup> has been regularly updated during 2018-19. It contains background information, Council members' biographies, the Caldicott Guardian Manual, a news page, details of meetings, events, training courses and regional networks, and a page of links to relevant guidance for the General Data Protection Regulation.

### A Manual for Caldicott Guardians

The text of the [Caldicott Guardian manual](https://www.ukcgc.uk/manual/contents)<sup>2</sup> has been converted to web pages to facilitate updates, such as the General Data Protection Regulation (GDPR) and the Data Protection Act 2018.

### Digital forums

Digital Health Networks (DHN), an online publishing company, kindly provides a private online digital forum for council members, and an open forum for Caldicott Guardians and others involved in supporting the Caldicott function. The Council forum enables Council members to discuss matters privately between council meetings. The open forum now has over 270 members (a 35% increase from 2017-18) and is actively used. Members of certain other DHN forums (e.g. for Chief Information Officers and Chief Clinical Information Officers) are able to read and comment on posts to the Caldicott Guardians forum

### Caldicott Guardian regional networks

The UKCGC now has regional networks active in the North, South-West, and London, run by council members. These enable Caldicott Guardians to network, share experiences and address issues which affect them more locally. Network meetings are held every few months and feature guest presenters from across the health and care system.

The Northern network was formed in 2018 from the previous North-East and North-West networks and meets in Leeds every 6 months for a workshop-style event, supported by our affiliated training providers. In the past year, events have been run for small organisations and for the CG role in Data Protection Impact Assessments as well as discussing case studies and learning lessons from those raised with the UKCGC.

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<sup>1</sup> <https://www.ukcgc.uk/>

<sup>2</sup> <https://www.ukcgc.uk/manual/contents>

## The Caldicott Guardian register

A register of Caldicott Guardians has been maintained by NHS Digital in Exeter since 1998, primarily to facilitate authentication of forms signed by Caldicott Guardians. In theory, all Caldicott Guardians should have an entry: currently around 5350 do (an increase of c.1350 during 2018-19). The process for registration has been improved over the past two years, but ensuring completeness and accuracy remains a challenge. The Council is exploring ways of improving the register and is examining the possibility of re-creating it with data from the Data Security and Protection Toolkit, which has a mandatory field for Caldicott Guardian details.

## Requests for advice

The Council responds to requests for advice from Caldicott Guardians across health and care. Requests are submitted via Council the website or directly to the Council mailbox, and cover a range of subjects and specialties. Requests are handled by the Council Secretariat and referred to the Chairman and Vice-Chair and as appropriate to other Council members and/or subject matter experts or shared on the Council and/or Caldicott Guardians' digital forums for wider discussion. Response times are improving with the majority of advice requests fulfilled within a few days.

Where other organisations are better placed to handle these enquiries the Council also provides the appropriate advice and contact details required to resolve the query. The Council reviews a summary of requests received and responses at its bi-monthly meetings.

## Events

Council members have spoken at several events during 2018-19 including:

- Caldicott Guardians National Conference (May 2018)
- Royal College of General Practitioners' webinar on the National Data Opt-out (August 2018)
- Improving Cyber Security in the NHS (December 2018)
- The Digital Health Networks Rewired Conference (April 2019)
- Police National Missing Person's Conference
- Caldicott Principles and End of Life Care (Healthcare Conferences UK)
- Caldicott Guardians Leadership Summit (Healthcare Conferences UK)
- Ethical Decision Making & the Duty of Candour (Healthcare Conferences UK)

## **UKCGC mailing list**

We are in the process of compiling a contact list of Caldicott Guardians' email addresses (mostly from the register). Once this has been tested for validity it will be possible to contact the majority of registered CGs directly.

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## **Working with others**

### **National Data Guardian**

The UKCGC is a sub-group of the National Data Guardian's Panel, which meets bi-monthly. Dr Chris Bunch attends Panel meetings, with Sandra Lomax attending when he is unable to.

### **Devolved Nations Caldicott Guardian Networks**

Although the NHS is governed separately in England and in the devolved administrations in Wales, Scotland and Northern Ireland, all four nations have chosen to have Caldicott Guardians. During 2018-19 the Council has further developed strategic relationships with Caldicott Guardian networks in Wales, Northern Ireland and Scotland.

An example of this is the standing invitation from the Scottish Caldicott Guardian Forum which was accepted during all meetings in 2018/19. This closer relationship included the Vice Chair speaking at the Scottish CG and SIRO training event and the UKCGC Chair attending and presenting on Council matters. Also, the UKCGC has agreed to support the production of a Scottish Caldicott Guardian manual in 2019.

### **Understanding Patient Data**

Council member Carey Bloomer worked with colleagues at Understanding Patient Data to explore the journey of patient data beyond traditional health boundaries and into specialised care providers (care homes and hospices for example). The work aims to support discussions with the public, patients and healthcare professionals about uses of health and care data.

### **Faculty of Clinical Informatics**

The Council has engaged with the Faculty of Clinical Informatics (FCI) regarding the potential for collaboration with the National Data Guardian (NDG) and the Council. The proposed Core Competency Project will be relevant to specialist clinical informatics roles in the UK Care System (e.g. Caldicott Guardians and CCIOs) and will help to ensure that those working in specialist clinical informatics roles within the health and care system are equipped to handle and share data with confidence.

## National Crime Agency

The UKCGC and the [UK Missing Persons Unit](#)<sup>3</sup>, part of the National Crime Agency, have published formal guidance that outlines the good practice considerations that should be borne in mind when information is being sought from health and care. It makes clear the sort of information that the police should provide upfront, and also describes the legal bases that underpin and allow such information sharing – which some organisations can find it difficult to establish.

This joint approach has helped to highlight what happens behind the scenes in health and care when a request for information is made, and what the police can do better upfront to make it easier for health and care to provide the information needed to progress the missing persons case. Better partnership working and taking the time to understand each other's viewpoints and organisational cultures, is one significant way the UKCGC is supporting national issues.

## NHS Digital

The Council has benefitted from regular updates from NHS Digital. During 2018-19 Council members had the opportunity to provide feedback on the implementation progress of the National Data Opt-Out and the Data Security Protection Toolkit (DSPT). The UKCGC has significantly influenced the DSPT from a CG perspective, ensuring that the 10 data standards from the Opt out report are included and the importance of having a CG is understood for organisations handling patient data. It is anticipated that the quality of data held in the Caldicott Guardian Register will be vastly improved by using the latest information provided to the DSPT as at the end of March 2019.

The Council has also been an important stakeholder on proposed future deliverables for NHS Digital such as the GP Data for secondary uses programme and the well led inspections (NHS Digital in collaboration with CQC).

## NHS England

Dawn Monaghan Head of Data Sharing and Privacy at NHS England is a regular attendee at the bi-monthly Council meetings. The Council is a member of a few stakeholder working groups to support and feedback on the proposed direction and progress of these streams of work including the NHS Code of Confidentiality, the Local Health and Care Record Exemplar Information governance framework, and the General Data Protection Regulation.

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<sup>3</sup> <https://missingpersons.police.uk/en-gb/about-mpu/who-we-are>



## The Healthcare Quality Improvement Partnership (HQIP)

HQIP aims to improve health outcomes by enable those who commission, deliver and receive healthcare measure and improve services. The UKCGC is a member of the HQIP Information Governance Advisory Group.

### Training Providers

The UKCGC is pleased to promote/support training providers who provide training in line with the Caldicott Manual. Details of these providers and their courses can be found [on our website](#).<sup>4</sup> Several hundred Caldicott Guardians from a wide range of sectors including GPs, hospitals, hospices, CCGs, commissioned services, social services, emergency services, Ministry of Defence, charities, and private organisations handling patient data have been trained in the past year.

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## Looking forward

During the coming year the Council and its Officers will build on progress made this year. Our principal aim is to enhance further our communication channels for Caldicott Guardians, to respond quickly to requests for advice and support, and to promote training opportunities. We will also continue to play a role nationally and to contribute to initiatives of importance to patients and all who provide their care.

May 2019

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<sup>4</sup> <https://www.ukcgc.uk/events>