

# **The UK Caldicott Guardian Council**

## **Annual Report 2017–18**

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## The UKCGC Annual Report 2017-18

The UK Caldicott Guardian Council (UKCGC) is the national body for Caldicott Guardians. This report for 2017–18 details how the Council has progressed its aims, supported Caldicott Guardians, and is looking ahead to the future.

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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 4500 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 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 as Vice Chair. Christopher had chaired the Council since 2011, successfully steering it through the uncertainties of significant changes in the NHS.

### 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 covered in further detail in this report.

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## Council meetings

The Council holds meetings every two months in London. In addition to standing items (Chairman's report; requests to Council for advice; reports from Independent Members and Regional Networks), topics presented and/or discussed during 2017–18 included:

**June 2017:** The WannaCry cyber security incident; new IG toolkit; support for the social care sector.

**August 2017:** Case studies; information sharing for child protection (CP-IS); NDG's work on sharing patient data/exploring consensus on reasonable expectations; Caldicott support for primary care.

**October 2017:** GDPR update; training providers' update; Council membership; IGA update, IGA/UKCGC conference; FGM update; Caldicott issues in devolved administrations.

**December 2018:** GDPR & Data Protection Bill updates; report on the IGA/UKCGC conference; National Data Guardian Bill update; National Data Opt-Out; Integrated Care and National Records Locator projects.

**February 2018:** Updates on GDPR and proposed revision of the NHS Code of Confidentiality; report from the Office of the National Data Guardian; the Brain Tumour Data Bank; the Data Security and Protection Toolkit (replaces the IG Toolkit from April 2018.)

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## Supporting Caldicott Guardians

### A Manual for Caldicott Guardians

A revised Caldicott Guardian manual was published in January 2017 and has been universally well-received. It provides guidance on the Caldicott Guardian's role, key relationships, learning and development needs, and appraisal, together with advice on the legal and ethical aspects of the role, information sharing colour and research. In addition, it includes brief profiles of 12 Caldicott Guardians from a variety of backgrounds.

Guidance documents such as this quickly become out of date soon after they have been published. The text of the manual has now been converted to web pages and is published on the Council website. This makes it easier to maintain and update, and several sections have now been updated. A particular challenge is to ensure that links to other useful material remain valid.

## Digital forums

Digital health networks, an online publishing company, runs several digital forums and has kindly created a private forum for council members, and an open forum for Caldicott Guardians and others involved in the Caldicott function. The Council forum enables Council members to discuss matters privately in between council meetings; the open forum now has over 200 members and is regularly used. Members also have access to the CCIO and Open forums.

## Caldicott Guardian regional networks

The UKCGC now has active regional networks in the north-east, north-west, south-west, and London run by council members.

**The London regional network** is led by Tim Kendall and Marie Martinalli. Meetings were held in May, June and September 2017 and March 2018. Topics covered include Council updates, data security, GDPR and matters raised by members. Future meetings are planned three times a year, the next in July which will include a guest speaker on cyber security and case studies of interest.

**The North West regional network** is led by Ben Heal. Meetings are held quarterly. Recent topics covered include Council updates, case studies, GDPR, the new Data Security and Protection toolkit, and managing difficult complainants.

**The North East regional network** is led by Helen Dyer. Meetings are held quarterly and hosted by members organisations on a voluntary rotational basis. Discussions at meetings relate to local challenges and initiatives, for example the Great North Care Record and organisation based Caldicott case studies.

**The South West regional network** is led by Adrian Marchbank. Formal meetings are held annually, and the venue rotates around the region. Topics discussed include preparation for GDPR, cybersecurity and the role of the UK CGC. Each meeting has a forum for discussion of current topics of interest.

## UKCGC website

A new, independent, Council website was developed and published during the autumn of 2017. <<https://www.ukcgc.uk/>> It contains background information, Council members' biographies, the Caldicott Guardian Manual, a news page, details of meetings, events & regional networks, and a page of links to relevant guidance for the General Data Protection Regulation.

Future planned developments include regular news bulletins, email notifications for new material and a commenting facility.

## The Caldicott Guardian register

A register of Caldicott Guardians is maintained by NHS Digital in Exeter. In theory all CGs should have an entry but currently only around 4500 do. (It is likely that at least twice that number exist.) The database was poorly maintained until recently and thus

data quality has suffered. The process for registration has been improved over the past two years, but ensuring completeness and accuracy remains a challenge.

The Council is in discussion with NHS Digital regarding the future direction of the register. The IG Toolkit (now the Data Security and Protection Toolkit) requires details of an organisation's Caldicott Guardian and may prove to be a more reliable source of information regarding Caldicott Guardians.

## **UKCGC mailing list**

A contact list of Caldicott Guardians' email addresses is being compiled from various sources. It is hoped that in future it will enable better communication with Caldicott Guardians in the field.

## **Independent members**

In 2016 the Council appointed a number of Council members as 'Independent Members' who are paid for time spent on specific work to further the Council's aims. Independent members for 2017-18 are Christopher Fincken and Ben Heal.

Christopher has worked with the IGA and the Centre of Excellence for Information Sharing on guidance for information sharing with the police which has recently been [published](#). He is presently working on guidance for information sharing in cases of domestic abuse and continues to provide Caldicott Guardian training in association with Healthcare Conferences UK.

Ben has brought together a number of training providers who have agreed to work with the Council (HC-UK, Stay Compliant, DAC Beachcroft), and has organised a June event to be held in Leeds which will explore the general problems of overseeing the sharing of patient/service-user personal information in a small organisation (under 50 staff). The workshop will specifically focus on sharing service-user personal data with relatives or significant others including what should happen after their death.

## **Advice to Caldicott Guardians**

An important aspect of the support the Council provides to Caldicott Guardians is responding to requests for advice. During 2017–18 the Council received and responded to over 45 requests for advice. Topics included:

- are Caldicott Guardians required for small (and very small) organisations undertaking work for the NHS?;
- whether or not if a Caldicott Guardian can be shared with a subsidiary organisation;
- the appropriate level of seniority for a Caldicott Guardian in local authorities;
- the future role of the Caldicott Guardian in light of the GDPR;
- the requirement for Caldicott Guardians to approve their organisation's involvement in national registries, databases and audits;

- how can Caldicott Guardians best seek advice;
- various alleged breaches of confidentiality;
- the status of records maintained by bereavement counsellors;
- visiting specialist nurses' access to patient information;
- access to health records of the deceased;
- retention of emails when someone leaves an organisation;
- disclosure of information in relation to criminal proceedings;
- the need for consent when including patients in a registry;
- the use of anonymised data for research;
- the use of GP data for population analytics and risk stratification;
- access to clinical data for audit and research.

The Council plans to use these and previous requests as a basis for a series of case reports during the coming year.

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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. An important and relevant topic which the Panel has been exploring is the relationship between implied consent and 'reasonable expectations of privacy' to understand better the legal basis for using data collected in confidence from patients as part of their direct care.

### **Information Governance Alliance**

The UKCGC and the Information Governance Alliance (IGA) work closely together. Dawn Monaghan (IGA Director) attends Council meetings regularly to update on the IGA's work and the GDPR, and Dr Chris Bunch and Sandra Lomax attend the IGA's GDPR Working Group for Health and Social Care. Chris is also a member of the newly-constituted IGA/NHSE Information Governance Steering Group, which will be providing guidance on information sharing for the Local Integrated Care Record Exemplar scheme, and a working party that is revising the NHS Code of Confidentiality.

In November 2017, the IGA and UKCGC hosted a very successful conference at the Kia Oval. Delegate places were sold out early, but the event was streamed live via YouTube, providing access to many others. Topics included the new Data Protection legislation, IG leads, CGs and SIROs working together, Public Trust, Cyber Security and Data/Sharing/Processing to support the 5-year Forward View.

## **Small organisations**

The vast majority of Caldicott Guardians work in relatively small organisations, such as GP surgeries, care homes, hospices etc. The Council has held sessions on primary care and care homes with representatives from the sectors.

A workshop on information sharing in small organisations has been arranged for June 8<sup>th</sup> 2018 in Leeds.

## **Police**

Christopher Fincken's work on information sharing with the police is described above.

The Council has also been working closely with the National Crime Agency's UK Missing Persons Unit on behalf of UK policing resulting in a greater understanding and more efficient process between police and health organisations in answering queries whilst maintaining appropriate confidentiality.

## **NHS Digital**

The Council has benefitted from regular updates from NHS Digital on the new Data Security and Protection Toolkit, the implementation of the National Data Opt-out scheme, Cyber Security, and the Integrated Care and National Records Locator projects.

Earlier this year Dr Chris Bunch had a very productive visit to NHS Digital in Leeds, meeting with a number of colleagues to discuss their programmes. These included the Data Services Platform, Data Collections, GP Data Implementation, National Data Opt-out, Data access Request Service teams, and the Data Security Centre. The work being undertaken is impressive both in its content and its sensitivity to public trust.

## **Local Government**

The Council is strengthening its engagement with local government. Sandra Lomax has mentored a new Caldicott Guardian in a local authority, and UKCGC meetings has been attended by more local authority members during the year than in previous years.

## **Caldicott Guardians in Scotland and Northern Ireland**

Dr Chris Bunch and Sandra Lomax have both attended meetings of the Scottish Caldicott Guardian Forum, and Sandra has attended a meeting of Northern Ireland Caldicott Guardians, to act as a conduit and update them on them on UKCGC matters and NDG issues. Council member Dr Alison McCallum is based in Scotland and supports Scottish Caldicott Guardians with locally-tailored advice.



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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.

Dr Chris Bunch  
Chairman  
UK Caldicott Guardian Council

April 2018