



# UK Council of Caldicott Guardians

Meeting held on Wednesday 8 July 2009, 11:00am – 3:00pm  
Leeds Town Hall

## Minutes

### 1. Present

*Members:* Mr Rob Bellingham; Mr Christopher Fincken; Mr Mike Foster; Mr Stephen Hinde; Dr Emyr Wyn Jones; Dr Alison McCallum; Ms Mary Monnington; Dr Janet Murray; Mr David Riley; Mr Martin Strange; Dr Guy Turner

*Secretariat:* Ms Magi Nwolie

*In attendance:* Ms Penny Hill, NIGB; Ms Clare Sanderson, NHS IC

### 2. Apologies

*Apologies were received from:* Dr Stella Clark; Dr Tom Denning; Mr Ben Heal, Dr Alex Horne; Ms Sandra Howard; Prof Dame Joan Higgins; Mr Phil Walker; Ms Claire Warner; Ms Marie Greenfield

### 3. Minutes of the last meeting

The minutes were accepted as a true account of the last meeting held 8 April 2009.

### 4. Matters Arising

4.1 BH will approach Prof Martin Severs and data standards division at NHS CFH in relation to identifying the 'vulnerable' in a community via the READ codes - item 4.6  
BH had given apologies for this meeting.

4.2 The Secretariat to update the Caldicott website with information about the appointment of vice chairs of the Council - item 5.1

This had been done.

4.3 The Secretariat to invite a representative to speak to the Council about the work of the Information Centre and its impact on Caldicott Guardianship - item 5.2

Clare Sanderson from the NHS Information Centre for Health and Social Care was in attendance at this meeting - see item 9.

4.4 The Secretariat to enquire about feasibility of holding annual workshop events and provide the Council with a breakdown of delegate types that attended the conference - item 5.3

Information about attendees to the national conference had been circulated. A budget had been centrally allocated for a Caldicott event; the Council discussed the format and content. It was felt that an event should have a greater balance of workshops with just one or two keynote speakers. The Council agreed to identify people from within the Caldicott community and NHS / social care who could usefully contribute to such an event. The workshops needed to present practical solutions to problems faced by Caldicott Guardians, IG leads and SIROs. Some topics that could be included were:

- Implementing IG in an acute trust;

- SIRO/Caldicott Guardian balance;
- Research - SUS; NHS IC;
- Role based access controls and registration authorities;
- Amendments of records;
- Overriding patient interests.

There should be a workshop pre-registration questionnaire to enable comparison with the IG resourcing survey previously carried out - see item 6.5 of these minutes.

4.5 The Secretariat to circulate firm dates for future meetings once availability sheet complete - item 5.4

This had been done, future meetings are 7 October 2009 and 12 January 2010.

4.6 Comments on the statement of collaborative working to be reported back to the NIGB - item 7.1

This had been done, paragraph 5d “*Ensure that the Council is appropriately engaged in NIGB activities*” would be amended to read, “*Ensure that the Council is appropriately engaged in NIGB activities. This will be by UKCCG's formal membership of the NIGB and also by direct contact between the NIGB Office staff and the UKCCG Secretariat*”

Clarity had been provided on paragraph 6c to the effect that the NIGB wants to start to publish examples of best practice on its web site and believes that several organisations, not least UKCCG, are in a good position to provide it with these. The source of the good practice will be fully acknowledged and referenced.

Once the amendment has been made by the NIGB the statement will be published on the Caldicott Guardian website and reviewed by the Council in 12 months.

4.7 The Secretariat to edit the IG resourcing document and bring back to next Council meeting item 8

This had been done and would be discussed as item 6.5 of these minutes.

4.8 The Secretariat to forward the Council's response to the Common Assessment Framework consultation to the consultation Secretariat and publish the response on the Caldicott website - item 9

The response had been forwarded although not yet published on the website.

**5. Social Care Record Guarantee - Penny Hill, the National Information Governance Board for Health and Social Care**

PH set out the context for the Guarantee; the NIGB covers both health and social care in England and are owners of the NHS Care Record Guarantee (NHS CRG). It was recognised that a complementary Guarantee for social care was required to ensure there were similar commitments for confidentiality and security of service user information as for NHS patients, particularly in view of the increase in multi-agency working. This would bring uniformity of processes. The Social Care Guarantee is not a literal translation of the NHS CRG as there are differences in the way both work and also in the way compliance can be mandated by central government. That is, although the Department of Health can mandate the NHS CRG for the NHS, there is no single Minister to do the same for social care - there are a number of central government departments that have responsibility. The Guarantee recommends that local authorities adopt and publish it, rather than being limited to social services departments. The NIGB has recognised that other social care providers also need to be made aware of and encouraged to adopt the Guarantee.

The sharing of Ministerial responsibility means that monitoring of implementation and compliance will be challenging. Additionally, although there is wide in principle support for the Guarantee amongst local authorities, their ability to achieve some of the commitments might be limited due to less mature information technology.

It was identified that there was a need to build a framework setting out why and how the Guarantee should be complied with. This should include training to engage all staff. For its part the NIGB is taking several steps to publicise the Guarantee, there will be a formal launch at a national conference and concurrently, the NIGB are seeking the endorsement of a number of bodies including the Council to encourage local authorities to implement the Guarantee as best practice guidance. The NIGB would like the Council to raise awareness of the Guarantee amongst social care Caldicott Guardians.

**Action:** The Council agreed to endorse and promote the Guarantee as best practice

## **6. UKCCG review/comment issues**

### **6.1 The Caldicott Guardian Manual**

It was noted that Scotland is about to begin revision of their Manual which might include more practical guidance, e.g. how to respond to queries etc.

The Council felt that the Manual for England needs more links to guidance and additional revisions regarding the following:

- The relationship with Senior Information Risk Owners;
- The NHS Information Governance Assurance Framework;
- Addition of the independent sector to the table of suggested Caldicott Guardians;
- The links to PIAG need to refer to the Ethics and Confidentiality Committee;
- Addition of the statement of collaborative working with the NIGB;
- The Mental Capacity Act;
- Addition of information for staff about when to seek advice from the Caldicott Guardian;
- Links to e-learning materials.

It was suggested that the Manual should remain as a concise volume, but an online appendix should be made available which could explore some of the points in the list above, for example:

- *Relationship with the SIRO:* defining the difference between the roles; scenarios on what is for the Caldicott Guardian to deal with; what is for the SIRO; when both should be involved;
- *Information for staff:* examples of what can be done with patient information; what definitely cannot be done; and the occasions when advice should be sought from the Caldicott Guardian.

**Action:** The Secretariat to update the Caldicott Guardian Manual and send to the Council for review.

### **6.2 Choose and Book: Information Security guidance**

The Chair asked for comments from the Council as to whether the guidance was in keeping with their understanding of how information should be used and protected. It was felt that the guidance did not make strong links with the Caldicott Guardian role particularly in relation to role based access controls (RBAC). There was a concern that nationally Caldicott Guardians do not fully understand RBAC, which is quite

difficult to tackle and perhaps thought should be given to nationally defined job roles. This would avoid locally determined roles which required a balancing act between giving too wide an access and being too restrictive.

A further comment was that the guidance does not cover general practice and there was agreement that the Council should have been involved at the consultation stage of the guidance.

At this point the Council discussed a query brought to the meeting by the Secretariat which was due to be discussed under AOB, but was more appropriate to discuss here.: *“... concern ...about the ease with which patient’s address, date of birth and telephone number can be obtained nationally by using “chose and book” smartcard and knowing only a persons name and approximate date of birth. There are so many with smartcards that must be a significant risk.”*

This is an issue that should have been covered in more depth in the guidance; however, if legitimate relationships, information security measures, IG training, and confidentiality clauses within contracts are all in place, it substantially reduces the risks. There are also obligations on registration authority staff and on people authorised to use smartcards. There was a case for the guidance placing greater emphasis on organisations routinely using audit trails to monitor behaviour. This should be linked to the commitments in the NHS CRG.

**Actions:**

The Secretariat to write to the authors to give feedback on the document and put forward Council opinion that they should have been consulted before publication, and also to request that CFH ensures the Council is consulted when similar guidance is being developed

The Secretariat to find out how RBAC profiles are developed, and if appropriate invite a member from the relevant team to attend a Council meeting

The Secretariat to write back to the enquirer regarding processes in place for use of smartcards

**6.3 News report: Patient told no electronic record, no care**

The Council discussed the implications of a press report and whether it is ethical to refuse care to someone who declines an electronic patient record. There were two separate concerns, the first related to the Trust local record and the second to the national record.

Under the Data Protection Act people are not entitled to specify how their information is held, i.e. paper or electronic.

It is unlikely that a Trust would actually refuse care on this basis, particularly to the client group in the report, but equally the patient cannot ban a Trust from keeping local electronic records. However, it would have been more helpful if the Trust had emphasised that they cannot treat patients without records, and that locally the way these records are held is electronic. They should have stated that the local records are not part of a national patient record and that when the summary care record is introduced in that locality, patients will be able to opt out.

There needs to be more discussion with patients raising these concerns so that their specific worries can be discussed, additionally the Caldicott Guardian needs to participate in the decision made.

#### **6.4 NIGB: Guidance on the amendment of medical and social care records following a request from a person receiving care**

A working group of the NIGB had developed the guidance, members of the Council and other Caldicott Guardians had been involved in the drafting. The guidance is now ready for public consultation.

**Action:** The Secretariat to forward the Council's response to the NIGB secretariat and publish on the Caldicott website.

#### **6.5 IG resourcing document**

This was a useful document which required wider dissemination and could be used by an individual organisation for internal debate and used as a baseline.

On the distribution list should be the following: the NIGB; NHS CE's; the Care Quality Commission; Caldicott Guardians; IG leads; SIROs; independent healthcare providers; Scotland; Northern Ireland and Wales. The report should go out with a covering letter from the Council.

The introduction should include information that the document represents a snapshot in a point of time which predates all the data loss issues and new information assurance requirements. The point should also be made about the disappointingly low levels of time allowed to carry out the Caldicott Guardian role.

It was also felt that it might be useful to re-do the survey and compare whether any progress had been made.

#### **Actions:**

The Council to forward any further comments on the document  
The Secretariat to make the amends and begin distribution

#### **6.6 E-learning module – the role of the Caldicott Guardian in the NHS and social care**

The Council felt this was a useful and informative addition to the learning materials.

#### **Actions:**

The Council to forward any further comments to the Secretariat by Friday 17 July 2009  
The Secretariat to forward the revised document to the e-learning suppliers

### **7. Updates**

#### **7.1 National IG Board**

SH reported the NIGB were considering the following:

- What IG controls should be in place for the GP extraction service - a reference group had been set up;
- What guidance the NHS requires from the NIGB;
- What type of consent was required for diagnostic tests;
- Summary Care Record opt-out and deletions of a SCR;
- Parental controls on information sharing for children.

Other work included:

- Preparation for launch of the Social Care Record Guarantee;
- Approval of an update to the NHS Care Record Guarantee - primarily legislative changes, and this had now gone to the Plain English Society for review;
- Review of IGT results for the last 2 years and members would be working with the Digital Information Policy team to develop version 8.

Regarding the Ethics and Confidentiality Committee:

- Two additional NIGB members were now attending the ECC and consideration should be given to the Council having a permanent seat on the ECC as well;
- An appeals/complaints process was considered for s251 applications, but it had been concluded that these should be dealt with on a case by case basis;
- There had been an increase in s251 applications.

Minutes of the NIGB are on their website at: [www.nigb.nhs.uk](http://www.nigb.nhs.uk)

**Action:** SH to propose that the Council has a permanent seat on the ECC to the Chair of that Committee

## **7.2 NHS IG Assurance Framework**

The Secretariat informed the Council that version 7 of the IG Toolkit had been released on time and that it included the following changes:

- A new 3 stage reporting process;
- Updated information security guidance to reflect the need for information governance staff to work closely with risk managers;
- IGSoC requirements aligned with IG assurance requirements - this list represented the “key requirements” referred to in the NHS Operating Framework.

## **8. Discussion: Joint working with the GMC to develop revised guidance**

### **8.1 Access to deceased patient records**

The Secretariat set out the context regarding lack of access by persons not falling into the categories of “personal representative” or having a “claim arising from the death”. That this was being applied differently in different trusts, and that there was a sense that such requests should be treated more sympathetically. The Council agreed work was required, and believed that the starting point for any new guidance was to better define the terms above. Four members of the Council volunteered to assist with this work: Christopher Fincken; Stephen Hinde; Alison McCallum and Mary Monnington.

### **8.2 Development of case studies to illustrate circumstances under which a decision could be made to override patient preferences in the patient's own interests or to protect others**

The Chair presented one scenario to illustrate what was required, the Council agreed to forward other relevant examples

#### **Actions:**

The Secretariat to inform the DH Policy lead of the three volunteers to assist with access to health records guidance.

The Council to forward example scenarios of when a patient's decision could be overridden

## **9. The NHS Information Centre for Health and Social Care - Clare Sanderson**

CS was seeking the Council's assistance in drawing up a procedure for managing access requests to a database held jointly by the IC and NHS CFH. The aim was to get a consistent approach in place. There would be one workshop and then the rest of the work would be done by email.

Four members of the Council volunteered to assist with the work: Rob Bellingham; Janet Murray; David Riley and Guy Turner.

**Action:** The Secretariat to forward the contact details for the volunteers to CS

#### **10. Consultation: NHS Constitution readiness**

The DH was seeking information about how best the Constitution could be deployed in the NHS, including what measures were required locally and what centrally would assist.

**Action:** The Secretariat to forward the Council's response to the Constitution secretariat and publish on the Caldicott website.

#### **11. Any other business**

**11.1** SH raised a report published by the Care Quality Commission

**11.2** There was an issue raised about doctors in training recording patient ID numbers on MP3 players and PDAs.

**Action:** The Chair to write to the Royal Colleges to clarify the information they require for their training logs.

**11.3** The current flu pandemic has resulted in a great many more flows of patient data, e.g. to finance. There was discussion over whether this should be raised centrally.

The Chair reported that his Chief Executive sits on the national group dealing with the pandemic.

**Action:** The Chair to ensure the issue of data flows is raised with the national group

**11.4** CF raised the issue of multi-agency risk assessment conferences (MARAC) and whether there was any central guidance available around information sharing. If not, it was proposed that the Council develop guidance.

**Action:** The Secretariat to add this as an agenda item for the next meeting

#### **11. Next meeting**

Wednesday 7 October 2009 at BMA House, London