

Caldicott Guardians

National Annual Conference

Tuesday 6th October 2015

Caldicott 2

An update on implementation
and more

Fiona Caldicott

Background

Information Governance Review

2012-13

Key finding; 'should ensure the right balance between sharing and protecting information'.

What does this mean for;

- **IG in the increasingly linked health care and social care sectors**
- **Data security and protection**
- **The much greater awareness of the citizen about these issues**

Key Message – ‘*The culture must be changed*’

- **New duty to share**
- **Reduce the harm caused by not sharing**
- **Clinicians to use their clinical judgement on decisions about sharing data**
- **Greater trust between Health and Social Care**

The Caldicott Principles

The new 7th Principle...

‘The duty to share information can be as important as the duty to protect patient confidentiality.’

Health and Social care professionals should have the confidence to share information in the best interest of their patients/service users within the framework set out by these principles. They should be supported by the policies of their employers, regulators and professional bodies.

Another Key Message - Trust

- **Build and sustain public trust**
- **A strong and independent voice**
- **Challenge to the system**
- **The public voice**
- **Who and or which organisations are trustworthy**
- **IG should be part of clinical governance**

No surprises – Review recommendations

- **All health and social care organisations must publish, in a prominent and accessible form, information about disclosure of personal confidential data**
- **People must have access to all the electronic care records about them, across the whole health and social care system, without charge.**
- **An audit trail of everyone who has accessed PID should be made available to patients, and carers with the patient’s consent, including both in the trail. This will take time to implement.**

The Independent IG Oversight Panel

Established in September 2013 to have:-

- **Oversight of IG in the Health and Social Care system**
- **To be independent - crucial**
- **To provide advice and challenge**

To report directly to the Secretary of State for Health, including on system's progress on implementing the Caldicott Recommendations

IIGOP's Key Areas of Focus through 2013-14

- **Developing an IG knowledge and information service (established as the Information Governance Alliance)**
- **Commissioning**
- **Legislation development (EU Data Protection Regulations and Law Commission Review)**
- **Consent Management, now often called preferences (IT system consent flags to record sharing decisions and opt outs)**
- **Accredited Safe Havens**
- **Care.data**

There is no silver bullet

- **There must be a legitimate [legal] relationship with the patient**
- **‘To care appropriately, you must share appropriately’**
- **A culture of anxiety amongst staff must be changed to one of confidence**
- **IG has become a barrier to sharing, and**
- **n.b. Nice Guideline 138 [2012] on Patient Experiences in adult NHS services**

National Information Board established 2014

- **Personalised Health and Social Care 2020**
- **Using data and technology to transform outcomes for patients and citizens**
- **Published November 2014**
- **10 work streams**
- **Digital access to health and care information and transactions**
- **Access to recommended NHS and social care apps**

Work stream 4

- **Build and sustain public trust**
- **Roadmap to consent based information sharing and assurance of safeguards ie security of data**
- **Health and social care data as rich resource for UK citizens**
- **Access to newest and most effective treatments including earlier diagnosis, e.g. 100,000 genome**

Stop Press ...

Caldicott becomes first government health data tsar and National Data Guardian

'Appointed to oversee safeguards for schemes like care.data as NIB publishes new framework for integrated NHS patient records strategy'

**Kable - Government Computing
Published 13 November 2014**

Europe's Data Guardian or Data Protection Supervisor

- **Greater effort to protect health data**
- **collected by mobile devices**
- **Though great potential to improve healthcare and lives**
- **Both app designers and legislators should do more to enhance security in 'complicated' market**
- **May 2015**

Medical Devices

- **Rapidly expanding range**
- **Record data about patient in absence clinician**
- **Data available to patient, professional, or both**
- **? How certain is the identity of the patient**
- **? Effective use device so that data is reliable**
- **? Awareness that monitoring is creating a personal record, so all duties must conform to legislation. Is patient informed about this?**

Consent

- Approval or agreement for something to happen after consideration
- *Explicit* – informed, has capacity, gives consent voluntarily
- Is required for sharing with staff who are not part of team
- Needed if it is to be used for a purpose other than that for which information originally collected
- *Implied* – only acceptable in context direct care.
No action needed on part of patient. But lawyers...

Consent post Lanarkshire judgement

- Or Nadine Montgomery v Lanarkshire H Board
- from paternalistic practice or 'doctor knows best'
- to transparency and choice
- comparison to patient having more rights over the information they give a clinician

2013-2015 care.data

- **Publicity campaign failed**
- **BMA and RCGP withdrew support in February 2014**
- **care.data paused**
- **NDG and IIGOP to inform Secretary of State when appropriate for data to be extracted from GP practices, November 2014 -**

Care.data 1

- 2014 - Advise care.data PB on Pathfinder Phase
 - Address key questions & concerns
 - Outstanding issues
 - Identify wider matters to be addressed
- The rights of the individual / preferences
- Unresolved issues
 - For CDPB & national organisations > Section 4 NDG Questions
 - For Pathfinders > Section 5 Tests of local readiness

Care.data 2

- Key messages
 - Clarity of policy & clarity of communications?
 - Is my data safe?
 - How are citizens informed & what choices do they have?
 - Gaining the confidence of the GP community?
 - Transparency around purposes & processes?
 - Responsibilities of data controllers & system safeguards?
 - Responses to all questions & tests

What will make the difference?

- **The IG Review recommended**
 - **Improved training and on-going education for all staff not just IG staff**
 - **Better information for all patients and service users**
 - **Stronger oversight for IG at board level**
- **Much of this has been said before, if not all of it – what will make a real difference now?**

Where We Are...

- **The Review of IG was published in March 2013.**
- **Government accepted the report and made recommendations that summer**
- **HSCIC Guidance on Confidentiality and Code of Practice have now been published**

Where We Are continued...

- **IIGOP report to care.data Programme Board published 18 December 2014**
- **IIGOP's first Annual Report to Secretary of State for Health published January 2015.**
- **Cross party support for National Data Guardian emerged before general election.**

National Data Guardian

- **Consultation on powers 17 September 2015**
- **Statutory footing – what will legal vehicle be?**
- **[No new health and social care legislation]**
- **Meanwhile hosted by HSCIC – independent status recognised.**
- **Essential that is independent.**

...The independent oversight provided by Dame Fiona will also be strengthened. Her role will be put on a statutory footing – similar to the role of the Chief Inspector of Hospitals – and the government will consult over the autumn on the best way to do that.'

**The Rt. Hon Jeremy Hunt MP
Secretary of State for Health
2 September 2015**



Department
of Health

Consultation on the roles and functions of the National Data Guardian for Health and Care

Prepared by the Department of Health

National Data Guardian

- **Consultation on powers has started**
- **Statutory footing**
- **Meanwhile hosted by HSCIC**
- **Essential that it is independent**
 - Supports
 - Guides
 - Encourages
 - Reports

Review of Data Security

- Develop a set of new, easily understandable standards for security of personal data
- Whether held on paper or electronically
- For whole health and care system
- How can standards be assured through CQC inspections and NHS England commissioning processes

CQC

- To review effectiveness of current approaches to data security
- In NHS organisations in relation to their handling of patient confidential data
- NDG and CQC to devise a method of testing compliance with the new standards
- Critical that health and care organisations are held to account for their data security capability

Propose a New Consent/ opt outs model for data sharing

- A single question consent model
- Giving absolute clarity to patients / users of care
- When information about them will be used ie for the purposes of direct care and to allow health and care organisations to discharge their statutory functions
- In what circumstances they can opt out eg research

Caldicott Guardians

- Are crucial to work on security of health and care data
- What do you/they need for that enhanced role?
- Process of work, to be completed by end January 2016

References

Information: to share or not to share? The Information Governance Review

Published 26 April 2013

<https://www.gov.uk/government/publications/the-information-governance-review>

Caldicott information governance review: Department of Health response

Published 12 September 2013

<https://www.gov.uk/government/publications/caldicott-information-governance-review-department-of-health-response>

References

IIGOP Terms of Reference

[https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/269528/IIGOP Terms-of-reference-V1_0.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/269528/IIGOP_Terms-of-reference-V1_0.pdf)

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**IIGOP Annual Report to Secretary of State for Health
Published 2 January 2015**

<https://www.gov.uk/government/publications/iigop-annual-report-2014>

References

National Information Board

<https://www.gov.uk/government/organisations/national-information-board>

Health Secretary outlines vision for use of technology across NHS

Speech by Secretary of State for Health at NHS Expo Manchester

Published 2 September 2015

<https://www.gov.uk/government/news/health-secretary-outlines-vision-for-use-of-technology-across-nhs>

Thank You

Your questions are welcome

**For any other queries
please contact**

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