Priority areas for the National Data Guardian relating to consent and control of patient records in health and social care

Workshop on Patients' Control over Patient Records
ICO and University of Manchester

Dame Fiona Caldicott
10 March 2016

National

Data

Guardian

Earning public trust for the use of data

- Why trust matters and the role of the National Data Guardian for health and social care

- Review of data security, consent and opt-outs

- Next steps to data sharing to serve the needs of patients, clinicians, commissioners, researchers and others

National

Data

Guardian

Trust matters

- People expect that what they tell their health or care professional will remain confidential

- There should be no surprises for patients or service users

- Lessons of the recent past tell us that much more needs to be done to earn trust

- National Information Board

National

Data

Guardian

National Data Guardian

- November 2014: SoS announced new role and first holder September 2015: consultation launched. Key theme: trust

- Role must provide a strong, independent voice

- Holds users of data to account across health and social care - ALBs, DH, NHS England and Ministers. Supports, guides, encourages, scrutinises, challenges, reports

- Advised by panel of independent experts

- To have a statutory footing

- Meanwhile office is hosted by HSCIC, independent status recognised

National

Data

Guardian

Previous reviews

1997: Caldicott Report reviewed the use of patient identifiable data.

- Recommended six principles to protect confidentiality, which became known as the 'Caldicott principles'

- Led to creation of Caldicott Guardians in organisations to ensure patient confidentiality safeguarded

2013: Information Governance Review

- New Caldicott principle: duty to share information can be as important as the duty to protect confidentiality

- Called for culture change – everyone in system should see information governance as part of their responsibility

National
Data
Guardian

Review of data security and consent

- September 2015: Secretary of State commissioned review

- Care Quality Commission (CQC) to review current approaches to data security across the NHS

- The National Data Guardian asked to propose

- a set of data security standards applicable across the NHS and social care system and method to assess compliance with CQC

- new model of consents /opt outs

National

Data

Guardian

Review engagement

Proposals developed iteratively with input from wide range of stakeholders, including:

- Patient and service user groups - focus groups with members and online survey of 400 patients
- Information Commissioner's Office (ICO)
- Service providers
- Commissioners
- Research community
- Civil society
- Providers of IT systems
- Data security experts

National

Data

Guardian

Review: data security

- Examples of good practice and most organisations are concerned about data security…but still issues with people, processes and technology.

- Need for simple, consistent standards

- Feedback on standards will be important

National
Data
Guardian

Review: consent/opt-out

- Low levels of understanding among public about how data is collected and used for purposes beyond direct care

- Most trust NHS to do the right thing and want to see the benefits of data sharing

- Transparency and controls are important

- Complex to define an opt-out to apply across the health and care system

- More to be done to engage and inform the public about data sharing, its benefits and their choices

National

Data

Guardian

Next steps

- Publication of the Review is the first step in engagement process with public, commissioners, researchers and other users of data

- Engagement is essential to trust. It is not a one-off event. It is a two-way and ongoing process.

- Today's event and the citizens' jury project makes a very constructive contribution to the discussion

- More thought: how best to listen to and engage public

National

Data

Guardian