

Data - the big conversation

SCIMP & SNUG Conference 2016

Wednesday 21 September 2016
Dr Alan Hassey

The National Data Guardian for Health and Care (NDG)

Dame Fiona Caldicott appointed as the first postholder in 2014.
Government has committed to putting into law a role that:

- is an independent and authoritative champion for the public
- considers the uses made of data health and care data
- has formal advice giving powers
- does not issue or enforce sanctions but works with existing regulators

The NDG review of Data Security, Consent and Opt-outs

- Secretary of State commissioned in September 2016 to assure the security of confidential information
- Care Quality Commission (CQC) 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
 - a method to assess compliance with CQC
 - new model of consent /opt outs

A strong evidence base

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

- Patients and service user groups
- Clinicians, Royal Colleges, British Medical Association
- Information Commissioner's Office
- Service providers
- Commissioners
- NHS Digital
- Research community
- Civil society
- Providers of IT systems
- Data security experts
- UK Caldicott Guardian Council

Altruism and scepticism

- Little knowledge among general public about how data is used
- Benefits may be clear to experts - but not yet to public
- Our evidence shows that most people want to support their data being used to improve care...
- ...but transparency, security, and red lines matter
- ...and people expect a choice
- Spectrum of opinion

Recommendations: NDG Data Security Standards

Ten new standards, grouped under three themes - people, processes, technology

Key data security recommendation:

The leadership of every organisation should demonstrate clear ownership and responsibility for data security, just as it does for clinical and financial management and accountability.

Recommendations: opt-out model

1. You are protected by the law.
2. Information is essential for high quality care.
3. Information is essential for other beneficial purposes.
4. You have the right to opt out of your personal confidential information being used for these other purposes beyond your direct care:
 - A. Personal confidential information being used to provide local services and in running the NHS and social care system.
 - B. Personal confidential information being used to support research and improve treatment and care.
5. This opt-out will be respected by all organisations that use health and social care information.
6. Explicit consent will continue to be possible.
7. The opt-out will not apply to anonymised information.
8. Arrangements will continue to cover exceptional circumstances.

A big conversation

The Review recommended much more is done to engage public and specifically:

- all health, social care, research and public organisations share responsibility for making the case for data sharing
- a full and comprehensive formal public consultation on review recommendations
- full testing of opt-out questions with the public and professionals
- a new tool to help people understand how sharing their data has benefited other people
- ongoing work to look at review outcomes and how to **National** build greater public trust in data sharing for health and **Data** social care

Next steps

- Recommendations accepted in principle by Government - Department of Health
- Consultation ran to September 7
- Government responses expected October/November
- Nothing changes yet
- NDG and panel to continue to advise on how public should be engaged and will watch progress on implementation with interest

More information and contact

www.gov.uk/government/organisations/national-data-guardian

ndgoffice@nhs.net