National Data Guardian for Health and Care

Review of Data Security, Consent and Opt-Outs

Dame Fiona Caldicott

The King’s Fund, 6 July 2016
Previous Reviews

1997: Caldicott Report reviewed use of patient identifiable data
• Recommended six principles to protect confidentiality - the ‘Caldicott principles’.
• Led to establishment of Caldicott Guardians.

2013: Information Governance Review ‘Caldicott 2’
• 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’s Data Security Standards

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

Leadership Obligation 1: People: Ensure staff are equipped to handle information respectfully and safely, according to the Caldicott Principles.

Leadership Obligation 2: Process: Proactively prevent data security breaches and respond appropriately to incidents or near misses.

Leadership Obligation 3: Technology: Ensure technology is secure and up-to-date.
National Data Guardian’s Consent/Opt-Out

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.
Thanks

Katie Farrington and her independent review team
The National Data Guardian Panel
The National Data Guardian Office team

And many more including...
Academy of Medical Royal Colleges
Academy of Medical Sciences
Association of Directors of Adult Social Services
Association of Medical Research Charities
Asthma UK
British Medical Association
British Heart Foundation
Cabinet Office
Cancer Research UK
Care Quality Commission
Centre of Excellence in Information Sharing
Chief Medical Officer
Department of Health
Dilys Jones Associates
Health and Social Care Information Centre
Health Research Authority
Healthwatch
Information Commissioner’s Office

Information Governance Alliance
Local Government Association
Local Government UK
Macmillan Cancer Support
Medical Research Council
National Voices
NHS England
NHS Improvement
Nuffield Council on Bioethics
Public Health England
Richmond Group
Royal College of General Practitioners
Royal College of Nursing
Royal College of Physicians of London
Royal College of Psychiatrists
Royal Statistical Society
Skills For Care
Society of Local Authority Chief Executives and Senior Managers
The Genetic Alliance
The King’s Fund
The Patients Association
UK Council of Caldicott Guardians
Wellcome Trust