



# 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

## More Information

[www.gov.uk/government/organisations/national-data-guardian](http://www.gov.uk/government/organisations/national-data-guardian)