

Understanding Patient Data

*A new initiative to support better conversations about
the use of health information*

Nicola Perrin

Care.data: How did it go so wrong?

Insurance bosses buy medical records of all NHS hospital patients

By Laura Donnelly, Health Correspondent

THE medical records of every NHS hospital patient in the country have been sold to insurers. *The Daily Telegraph.com*

by the Staple Inn Actuarial Society – a major organisation for UK insurers – details how it was able to use NHS data covering all hospital in-patient stays between 1997 and 2010 to track the medi-

were able to better calculate the likelihood of conditions, with “amazingly” clear forecasts possible for certain diseases, in particular lung cancer. Phil Beath, from privacy campaign

NHS England scraps controversial Care.data programme

Care.data: trust is on the line

Why Google DeepMind wants your medical records

19 July 2016 | Technology

29 April 2016

The lesson from the NHS Care.data row: You can't keep privacy issues private any more

Revealed: Google AI has access to huge haul of NHS patient data

A data-sharing agreement obtained by *New Scientist* shows that Google DeepMind's collaboration with the NHS goes far beyond what it has publicly announced

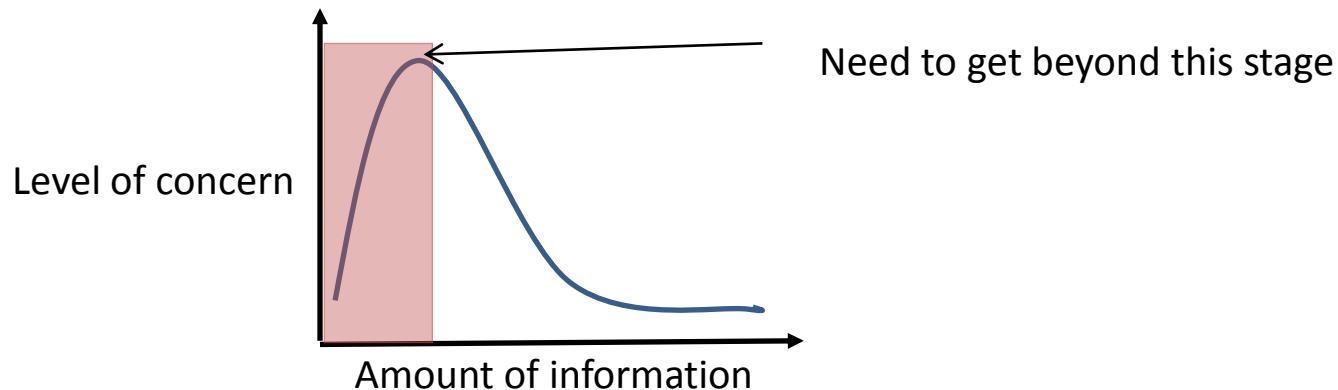
“We owe it to citizens to enable them to understand data usage as fully as they wish, and ensure that information about how data is accessed, by whom, and for what purposes, is available.”

Dame Fiona Caldicott

*National Data Guardian for Health and Care
Review of Data Security, Consent and Opt-Outs (July 2016)*

Context

- Set up in response to a call from the National Data Guardian for a full conversation with the public
- Currently low awareness of how data is used in the NHS:
 - 33% feel they have good awareness
 - 18% aware of academic uses; 16% for commercial use
- Studies suggest that more information leads to greater acceptance of wider uses of data
 - But a little information can lead to greater wariness



Our aims

- To facilitate better conversations about uses of health data:
 - developing resources for objective discussions about benefits, risks and safeguards
 - helping people make informed decisions
 - providing evidence for improved sharing of data, for care and research
 - examining emerging issues from new data-driven technologies
- Ways of working:
 - practical, ongoing outputs
 - developing advocates who can champion responsible use of data
 - working with the media to present a more balanced portrayal
 - bringing together a range of existing initiatives
 - broad ownership and engagement

Work programme



Social attitudes/ public engagement

Policy and governance to build public confidence

Resources & tools for conversations

- Case studies
- Vocabulary
- Mapping data flows
- Risks
- Safeguards
- Myth busters

Stakeholder engagement

- Patients
- Public
- Clinicians/HCPs
- Media
- Researchers
- Policy makers
- Parliamentarians
- Industry

Horizon scanning + analysis

- New digital technologies
- Data linkage across sectors
- Balancing privacy and public benefit

Supporters

Funding from:



Supported by:



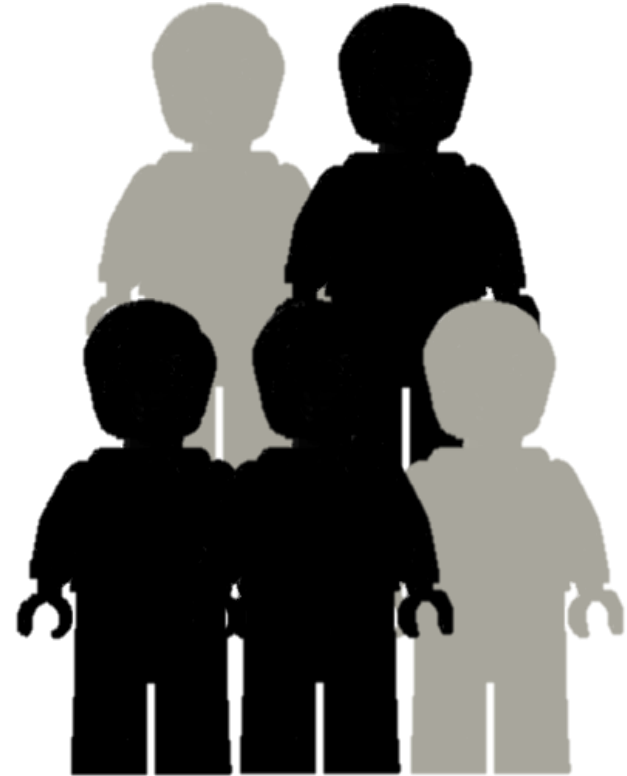
INVOLVE, National Voices, Genetic Alliance, Rare Diseases UK, Arthritis Research UK, Asthma UK, Macmillan, BHF, MQ, Richmond Group, Information Governance Alliance, PRSB, NHS Digital, NHS England Genomics England, CPRD, NIHR, Science Media Centre, Nuffield Foundation, Kings Fund, Involve, National Data Guardian, UK Council of Caldicott Guardians

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website coming soon

Imagery



- Very well received
- Instantly comprehensible, most felt it would help people 'get it'