People, technology and health: 
Information governance in the UK

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The future is about new therapeutic relationships not new therapeutic technologies.
Dr John Moore, New Medicine Media Lab MIT
Ultra- large scale systems

• Are multi-dimensional networks
• Depend on interoperability (rules) not structures
• Change over time
• Are built by users
• Are not amenable to conventional management
• Create surprises
Health information and communication technologies enable us to do new things in new ways not merely old things in new ways
Alert: Important information about swine flu

The number of new swine flu cases in England has again risen, with an estimated 9,000 in the week to September 24, up from 5,200 the week before. Read the latest official advice to help protect yourself, your family and others.

› Find out now what you should do
HealthMap widget – Swine Flu near you!
In 2003 the NHS Care Record service aimed to provide individual electronic NHS Care Records for 50+ million patients.

In 2010 the new Co-alition Government announced it was abandoning a national plan.
Clear information governance

- Provides interoperability rules
- Builds trust
- Helps people use networks reliably
- Supports data quality
- Enables data sharing
Information governance

The NIGB definition

‘Information governance describes the frameworks, policies and practices which are used to ensure the confidentiality and security of records of patients and service users.

Correctly developed and implemented it enables the appropriate and ethical use of information for the benefit of individuals and the public good’.
The Care Record Guarantee

The Social Care Record Guarantee
The guarantee for social care records in England
Trust

• In consent
• in confidentiality
• In security
• in physicians/nurses/researchers
• In quality of data
• In institution
• In oversight and supervision
• In government
...all mediated by utility.
The National Information Governance Board

Has 22 members

• 12 public members appointed through external advertisement including an independent chair

• Representatives of 10 organisations appointed by Secretary of State for Health

Supported by

• Advisors

• Observers

• Statements of Collaborative Working with key stakeholders
Commitments to patients

• Will give you access to your records
• Will share your record only within the care team
• Will keep it confidential
• Will not share identifiable data
• Will seek your consent and respect your wishes
• Will deal fairly with questions and complaints
• Will ensure your records are accurate
• Will ensure staff understand their duties
• Will keep records secure
• Will keep an audit trail
• Will take action against those who break these commitments
NIGB guidance/advice

- How to amend errors in care records
- Sharing of smart cards for record access
- An ethical framework for ‘honest brokers’ - anonymising data for research
- Governance, access and sanctions in relation to UK Biobank
- Information governance standards for contractors
Research and quality
Legal use of identifiable data

• In the UK it is illegal to use identifiable patient data for research without consent
• Power to give consent is delegated to the NIGB by the Health Secretary
• Two tests
  o Is obtaining consent impossible or unduly onerous?
  o Is the research so important as to justify breach of confidence?
Examples of sharing without consent

• Ethnic risks and outcomes in cardiometabolic syndrome – APPROVED

• National Child Data Set for Wales- REJECTED

• National neonatal research database –APPROVED WITH CONDITIONS

• Managing anti-coagulated patients with head injury- APPROVED

• National Dementia and antipsychotic prescribing audit- APPROVED

• Linking primary care records with cancer registry- REJECTED
The Learning Health System

Data doesn’t improve quality. Research doesn’t improve quality.

Only the *use* of data and the *application* of research may improve quality.

...this is why the learning health system is so important