UK Data-sharing

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Workshop: Data Analysis with Privacy Protection for Epidemiological Research

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Legal gateways

▶ Principal Legal Gateways
  ▷ Data Protection Act (DPA), 1988
  ▷ National Health Service (NHS) Act, 2006

▶ Other country-specific legislation eg Health and Social Care Act, 2012
  ▷ Problems sharing identifiable data across the UK

Governance

▶ Information Commissioners' Office
- ▷ Independent authority
- ▷ Upholds information rights in the public interest
- ▷ Promotes openness by public bodies and data privacy for individuals

DPA, 1988

▶ **Personal data** relate to a living individual and

▷ Could identify them, or

▷ Could identify them in conjunction with other information

DPA, 1988 contd

► Eight principles
  ▷ used fairly and lawfully
  ▷ used for limited, specifically stated purposes
  ▷ used in a way that is adequate, relevant and not excessive
  ▷ accurate
  ▷ kept for no longer than is absolutely necessary
  ▷ handled according to people's data protection rights
  ▷ kept safe and secure
  ▷ not transferred outside the European Economic Area without adequate protection

DPA, 1988 contd

► Stronger legal protection for sensitive information:
  ▷ Ethnic background; political opinions; religious beliefs; **health**; sexual health; criminal records

► Section 33 Research exemption

► Public data can be personal data

► No distinction between types of data eg administrative, survey

NHS Act, 2006

▶ Provision and promotion of National Health Service

▶ Section 251

▷ Identifiable patient information required for medical purposes, including research

▷ Patient consent not obtained, so no **secure basis** in law

▷ Common law duty of confidentiality overridden to enable disclosure of patient information, where:

▼ it was not possible to use anonymised information and,

▼ seeking consent was not practical with regard to the available cost and technology

► Complex legal picture

  ▷ Interpretation of the DPA, 1988, inconsistent especially when it comes to consent for data-sharing

  ▷ Risk-averse: if in doubt, don't

► It is legal, but is it ethical?

  ▷ Ethical review usually essential

  ▷ Transparency: public engagement with patient groups

Attitudes to data-sharing

▶ Research for the Royal Statistical Society carried out by Ipsos MORI in June-July 2014, published July 2014

  ▷ Media, internet companies, telecommunications companies and insurance companies all come at the bottom of a "trust in data" league table
  ▷ Only between four and seven per cent say they have a high level of trust in these organisations to use data appropriately, compared with 36% trusting the NHS, and 41% trusting their GP
  ▷ Nearly all institutions suffer a "data-trust-deficit", whereby trust in them to use data appropriately is lower than trust generally

Attitudes to data-sharing contd

▶ Wellcome Trust collects information on public views on medical research, science and health

  ▷ In 2015, almost four in five of the public (77 per cent) said they would be willing to allow their medical records to be used in a research study if they were anonymised

  ▷ Little understanding of what this means in practice

Attitudes to data-sharing contd

▶ care.data: press briefing January 2014
  ▷ Database of medical notes of everyone with NHS record
  ▷ Academic, charity and leading-doctor support
    ▼ Help understand the causes of disease, quickly spot the side-effects of new drugs and detect outbreaks of infectious diseases
  ▷ Accessible by doctors, researchers and pharmaceutical companies
  ▷ Strong case studies; data protection in place; benefits of central database would far outweigh the risks; requests for records to be assessed by independent advisory committee

Attitudes to data-sharing contd

▶ Public had not been informed
  ▷ Letters informing NHS patients that their details were to be compiled into a central database were not due to go out until February

▶ Marketing failure
  ▷ Television advertisement didn't air
  ▷ Scientists' and doctors' passionate supporting statements were not included in materials

▶ The importance of the scheme was not sufficiently clear

Attitudes to data-sharing contd

▶ Doctors began advising entire surgeries to opt out
▶ Questions raised about data quality
▶ April 2014
  ▷ Public backlash so severe that launch was cancelled
▶ June 2014
  ▷ Nearly one million people who had opted out of the database were still having their confidential medical data shared with third parties because requests weren't processed
▶ July 2016
  ▷ Review found that care.data had caused NHS to lose the trust of patients and recommended rethink
  ▷ care.data was closed down
  ▷ Decision announced same day as Chilcot Report into the Iraq War
  ▷ £7.5 million spent constructing a database, printing leaflets, setting up patient information helpline and researching public attitudes into data sharing
▶ It is hard to quantify impact

Attitudes to data-sharing contd

▶ care.data led to lock-down on most (all?) access to identifiable health information for about two years

▶ NHS Digital has turned the tap back on – but it's a drip feed

▶ Data access:

  ▷ Process is slow, unstable, and opaque

  ▷ Data can be expensive

  ▷ Information Governance bar is set very high

  ▷ Researchers and their institutions are assumed guilty unless proven innocent

  ▷ Even if (some) consent is in place!

▶ Linking currently only done by NHS Digital

Administrative Data Research Network (ADRN)

► Four centres, one in each country of the UK

► Coordinating body that manages applications

► Funded October 2013 to September 2018

► Infrastructure, principles, policies and procedures to facilitate secure research access to government de-identified administrative data for public benefit

ADRN contd

▶ Data access has been slow
  ▷ England
  ▷ UK

▶ Some excellent exemplar projects
  ▷ Scotland
  ▷ Wales
  ▷ Northern Ireland

ADRN contd

▶ Privacy protected analysis at ADRN
  ▷ Trusted third party (TTP) approach
  ▷ Identifier and research data are separate

ADRN contd

▶ De-identification process

1. Data owners
   a) Give each record a unique reference
   b) Separate personal data (identifiers) from research data
   c) Send research data with unique references to ADRC
   d) Send identifier data with unique references to TTP
2. TTP
   a) Uses identifiers to match datasets
   b) Creates index key showing which reference numbers relate to the same person in the different datasets
   c) Destroys identifiers
   d) Sends index key to ADRC
3. ADRC
   a) Uses index key to link the research datasets
   b) Deletes index key and reference numbers

ADRN contd

▶ TTPs see identifiers and reference numbers

▶ ADRCs see research data and reference numbers

▶ Researchers see research dataset only
  ▷ In secure environment

Changing landscape

- Safe Use of Research data Environments (SURE) training
- UK data-sharing legislation
  - Introduced to parliament July 2016 as part of Digital Economy Bill
  - Three strands
- Brexit
  - EU General Data Protection Regulation
- NHS Digital Anonymisation standard