

# Sharing and managing sensitive data in research with people

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Dealing with Sensitive Data: managing ethics, security and trust

# Focus

- What can researchers do to enable sensitive research data to be shared?
- How can data archives help researchers?
- research with people as participants / studied subjects

## Managing and sharing data:

- primary research data use
- data use in teams of researchers / institutions
- data re-use
- data publishing
- data archiving

# Plan and act

- Consider data sensitivity and data sharing / managing at planning stages of research
- Take action:
  - adapt methodology
    - e.g. need to collect personal data or sensitive data in research?
  - consider data sharing during ethical review
  - informed consent procedures
  - how should data be managed during and after research

# What are sensitive data?

- DPA 1998: ‘sensitive personal data’  
*data regarding an individual's race or ethnic origin, political opinion, religious beliefs, trade union membership, physical or mental health, sex life, criminal proceedings or convictions,...*
- DPA 1998: ‘personal data’
  - *relate to a living individual*
  - *the individual can be identified from those data or from those data and other information*
  - *includes any expression of opinion about the individual*
- data that may incriminate a person
- data a person prefers not to share with wider society  
*e.g. business, income, health, medical details, opinion*
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# Ethical / legal framework

How should sensitive data be managed?

Can sensitive data be shared?

- research ethical guidelines - crucial
- legislation:
  - Data Protection Act (1998)
  - Statistics and Registration Services Act (2007)
  - Human Rights Act (1998)  
enshrines the right to respect for private and family life (Art. 8)

# Research ethics

Researcher has:

- duty of confidentiality towards informants and participants
- duty to protect participants from harm  
e.g. not disclosing sensitive information
- duty to treat participants as intelligent beings, able to make their own judgements and decisions on how the information they provide can be used, shared and made public (through informed consent)
- duty to inform participants prior to obtaining consent how information and data will be used, processed, databased, shared, disposed of
- duty to wider society to make available resources produced by researchers with public funds  
e.g. data sharing required by research councils

# Data Protection Act

- applies only to personal data, not to all research data, not to all sensitive data

Personal data should be:

- processed fairly and lawfully
  - obtained and processed for a specified purpose
  - adequate, relevant and not excessive for the purpose
  - accurate
  - not kept longer than necessary
  - processed in accordance with the rights of data subjects, e.g. right to be informed about how data will be used, stored, processed, transferred, destroyed; right to access info and data held
  - kept secure
  - not transferred abroad without adequate protection
- personal data should only be disclosed if consent has been given to do so (exception e.g. legal reasons)
  - anonymised data (personal identifiers removed) - the Act will not apply as this no longer constitutes 'personal data'

# Data Protection Act – cont.

Exceptions for personal data collected as part of research:

- can be retained indefinitely (if needed)
- can be used for other purposes in some circumstances, but people should still be informed
- sensitive personal data can only be processed for research purposes if:
  - explicit consent (ideally in writing) has been obtained; or
  - medical research by a health professional or equivalent with duty of confidentiality; or
  - analysis of racial/ethnic origins for purpose of equal opportunities monitoring; or
  - in substantial public interest and not causing substantial damage and distress



# Data Sharing Review DPA, 2008

Concludes *inter alia* that greater use could be made of the ability to share personal data safely, particularly in the field of research and statistical analysis, e.g.:

- allow important statistical and research analysis to proceed, while minimising the risk of identifying individuals from within datasets
- ‘safe havens’ to be developed as an environment for population-based research and statistical analysis in which the risk of identifying individuals is minimised

(<http://www.justice.gov.uk/reviews/datasharing-intro.htm>)

# Statistics and Registration Services Act

- applies to ONS data (Office of National Statistics)
- Section 39 of Act – disclosure of ‘personal information’ is a criminal offence
- exceptions, e.g. notion of an ‘approved researcher’
- no immediate relevance for research data created by academics

# Key principles for ethical data sharing / managing

- avoid DPA confusion - not all research data obtained from people is personal data
- not all research data are confidential or sensitive
- sharing sensitive / confidential data is possible - needs careful consideration

# Key principles for ethical data sharing / managing

Researchers to consider:

- obtaining **informed consent** , also for data sharing and future storage
- **protecting identities**  
e.g. anonymisation, aggregation,...
- **restricting / regulating access** where needed (all or part of data)  
e.g. by group, use, time period
- securely storing personal or sensitive data

Consider jointly and in dialogue with participants !

# Informed consent

Needs information to be 'informed'

- info on strategies for anonymisation, access restrictions, security of personal data
- why share data important

# Data security

- physical security
- separate sensitive / personal data from other data
- access control to restricted materials
  - encryption
  - password protection
- secure data transfer, encryption
  - e.g. Safeguard PrivateCrypto; Pretty Good Privacy (PGP), GnuPG

# Role of data archives

- data access safeguards (UK Data Archive)
  - archived research data NOT in public domain
  - use of data for specific purposes only after user registration
  - data users sign legally binding End User Licence
    - e.g. not identify any potentially identifiable individuals*
  - stricter access regulations for sensitive data (case to case basis):
    - access to approved researchers only (special license)
    - data access permission from data owner prior to data release
    - data under embargo for given period of time
    - secure access to data (data analysis without actual access to or download of data)
- open access?

# Role of data archives

- guidance and training for researchers on ethical data sharing / managing  
*informed consent, anonymisation, data security, access regulation*
- guidance on data sharing for Research Ethics Committees
- disclosure checks and data anonymisation during data archiving



# Examples

- Annual Population Survey, Labour Force Survey  
*Special Licence and End User Licence versions of datasets*
- British Household Panel Survey  
*subsets of geographical variables available via conditional access alongside main survey*
- SN 5827 Rape in the 21st Century: Old Patterns, New Behaviours and Emerging Trends, 2000-2002 (quantitative)  
*some removal of variables, rounding of dates, combined with permission-only access*
- SN 5407 Health and Social Consequences of the Foot and Mouth Disease Epidemic in North Cumbria, 2001-2003 (qualitative)  
*data archiving discussed extensively with participants and consent sought; minimal anonymisation (pseudonyms), standard access to interview transcripts and diaries, permission-only access to audio files, 20 year embargo for selected interviews / diaries set*
- SN 4596 -Conflicts and Violence in Prison, 1998-2000  
*methods undisclosed regarding English prisons studied, minimal anonymisation, explicit detail in data, permission-only access*

# Resources

- Data protection Act 1998 [[http://www.uklegislation.hmso.gov.uk/acts/acts1998/ukpga\\_19980029\\_en\\_1](http://www.uklegislation.hmso.gov.uk/acts/acts1998/ukpga_19980029_en_1)]
- ESRC Research Ethics Framework [[http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Images/ESRC Re Ethics Frame tcm6-11291.pdf](http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Images/ESRC_Re_Ethics_Frame_tcm6-11291.pdf)]
- Human Rights Act 1998 [[http://www.opsi.gov.uk/acts/acts1998/ukpga\\_19980042\\_en\\_1](http://www.opsi.gov.uk/acts/acts1998/ukpga_19980042_en_1)]
- Info for research participants on purpose and benefits of data archiving [<http://www.data-archive.ac.uk/sharing/participants.asp>]
- Managing and sharing data – a best practice guide for researchers [<http://www.data-archive.ac.uk/news/publications/managingsharing.pdf> UKDA guidelines on ‘Consent, Confidentiality and Ethics in Data Sharing’ [<http://www.data-archive.ac.uk/sharing/confidential.asp>]
- training workshops [<http://www.data-archive.ac.uk/sharing/dmstraining.asp>]