

Managing and sharing data in research with people

Managing and sharing social science research data
UK Data Archive, 18 June 2010

Workshop topics

- Legal and ethical aspects of managing and sharing confidential research data
- Dealing with confidential research information and personal data
- Developing agreements for obtaining informed consent from participants (incl. consent for data sharing)
- Anonymisation techniques and access regulations to enable re-use and sharing of research data
- Data copyright
- Contextualising and describing research data

Focus

- Research with people as participants/studied subjects
- Confidential / sensitive research data
 - Legal aspects
 - Ethical aspects
- Managing and sharing data:
 - Primary research data use
 - Data use in teams of researchers/institutions
 - Data re-use
 - Data publishing
 - Data archiving

Confidential data

Data or info given in confidence and data agreed to be kept confidential (secret) between 2 parties that is not in the public domain

Sensitive 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,... (DPA1998)

Stakeholders in research

- Researchers
- Participants
- Funding agencies
- Research ethics committees
- Institutions
- Government bodies
- Archives / libraries
- Wider research community
- Public

All play a role in how we deal with confidential research data

Researchers' obligations

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

(based on guidelines from various professional bodies)

Policies on data sharing

- ESRC data policy – research data to be offered to UKDA:
http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Images/DataPolicy2000_tcm6-12051.pdf
- Research Council data policies – mandate or encourage data sharing: <http://www.sherpa.ac.uk/juliet/>
- OECD, UNESCO, European Strategy Forum on Research Infrastructures (ESFRI) and the Committee on Data for Science and Technology (CODATA) have policies that promote or recommend data sharing (Ruusalepp 2008; http://www.jisc.ac.uk/media/documents/programmes/preservation/data_sharing_report_main_findings_final.pdf)

Legal aspects

- Data Protection Act (1998)
- Freedom of Information Act (2000)
- Statistics and Registration Services Act (2007)
- Human Rights Act (1998)
 - enshrines the right to respect for private and family life (Art. 8)

Data Protection Act

Applies only to personal data, not to all research data, not to all confidential data; but what are personal data?

- relate to a living individual
- the individual can be identified from those data or from those data and other information
- include any expression of opinion about the individual

Data Protection

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

- only disclosed if consent has been given to do so (exception e.g. legal reasons)
- every individual has the right to access info and data held

If data are anonymised (personal identifiers removed) then DP laws will not apply as these no longer constitute '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 protection is not intended to, and does not, inhibit ethical research

Data Sharing Review of the DPA

- Carried out in 2008 , requested by Prime Minister
- Concludes 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>)

Freedom of Information Act

Little relevance for researchers, for data sharing and for dealing with confidential research data

Primary purpose: increase transparency in public sector

- People have right to request access to recorded information held, or be informed whether info is held
- Applies to public sector only (incl. universities)
- Research data can be requested; copyright stays with original researcher
- Might be superseded by terms of Depositor Agreement (UKDA)
- Does not apply to personal data

Exceptions (applicable to research):

- Info accessible by other means (e.g website, publications for sale,..)
- Info intended for future publication – balance between when publication intended to be due and what is in public interest (if in public interest to release info earlier, then may be granted)
- Commercial interest (applicable to certain research)
- Collating and providing info too costly

Statistics and Registration Services Act

No immediate relevance for research data created by academics

- Applies only 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’

Which ethical/legal aspects apply?

- Ethical guidelines – crucial
- Data Protection Acts – only for personal data
- UK: FoIA, SRSA, HRA– marginal (fears far greater than real effects)

Implications for research with confidential data

- Not all research data are personal data !
- Is there a need to collect personal data or confidential data in research?
- Levels of confidentiality needed are research related
e.g. oral history vs. community study
- Take reasonable steps to protect identities
- Avoid over-estimating confidentiality (no paranoia)

Data sharing and ethical concerns

- Most UK research with human participants requires ethical review by a Research Ethics Committee (REC)
- Potential tension between data sharing and data protection/research ethics
- RECs ensure ethical conduct in research and protection of safety, rights and well-being of research participants
 - guidelines/regulations on ethical aspects of data collection, dealing with participants, primary data uses
 - few guidelines on data sharing or re-use
- Data archives (UKDA/ESDS) ensure ethical re-use of research data, protection of participants and safeguarding of personal data
 - data anonymisation
 - regulate data access
- Data sharing is NOT violation of DPA or research ethics

How enable confidential research data to be shared

- Obtain informed consent (early planning)
also for data sharing and future storage
- Protecting identities
e.g. anonymisation
- Restricting/regulating access
e.g. by group, use, time
- Securely storing personal or sensitive data

Always in dialogue with participants

The future ...

- Increased drive by Research Councils, funders and publishers towards data sharing (national & international)
- More formal data sharing policies
- Data Management Planning requirements
- Better guidelines, technologies and support for researchers to enable data sharing, especially where confidential data are involved

Resources

- British Sociological Association [<http://www.britsoc.co.uk/equality/Statement+Ethical+Practice.htm>]
- British Sociological Association - Visual Sociology Group – Ethical guidelines [http://www.visualsociology.org.uk/about/ethical_statement.php]
- Clark, A. 2006. Anonymising research data. NCRM Working Paper Series 7/06. ESRC National Centre for Research Methods. [http://www.ncrm.ac.uk/research/outputs/publications/WorkingPapers/2006/0706_anonymising_research_data.pdf]
- Data protection Act 1998 [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]
- Freedom of Information Act 2000 [http://www.opsi.gov.uk/acts/acts2000/ukpga_20000036_en_1]
- Human Rights Act 1998 [http://www.opsi.gov.uk/acts/acts1998/ukpga_19980042_en_1]
- Methodological Issues in Qualitative Data Sharing and Archiving [<http://www.cardiff.ac.uk/socsci/hyper/QUADS/index.html>]
- National Centre for Research Methods - informed consent project [<http://www.southampton.ac.uk/socsci/sociology/research/projects/informedcontent.html>]
- Oral History Society guidelines [<http://www.ohs.org.uk/ethics/>]
- Research ethics in art, design, media [<http://www.biad.uce.ac.uk/research/rti/ethics/>]
- Social Research Association [<http://www.the-sra.org.uk/ethical.htm>]