




Skeletons in the archive: Ethical and methodological challenges of sharing data

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Expanding the scope of research ethics



	Data collection & analysis	Publication and dissemination	Archiving and sharing
Participants			
Scholarly community			
Public, greater good			

Research Ethics Framework (ESRC)

“Researchers who collect the data initially should be aware that ESRC expects that others will also use it, so consent should be obtained on this basis and the original researcher must take into account of the long-term use and preservation of data” (19).

www.esrcsocietytoday.ac.uk/ESRCInfoCentre/opportunities/research_ethics_framework/



Data Sharing Review – 2008 (a)

- * Specific to **personal** data, but broader than research data
- * Specifically to address legal and ethical ambiguities of data sharing

“We support the instinctive view that wherever possible, people should give consent to the use or sharing of their personal information... However, achieving this in practice is not so simple. It is unrealistic to expect individuals ever to be able to exercise full control over the access to, or the use of, information about them. This is because of a number of factors, not least practical difficulties ... Moreover, **there are many circumstances in which it is not useful, meaningful or appropriate to rely on consent, or indeed to obtain fresh consent at a later stage for the reuse of personal information for a different purpose**” (5.8).

“European and domestic laws provide several alternatives to consent as the means of legitimising the processing of personal data (5.13).”

www.justice.gov.uk/reviews/datasharing-intro.htm






Data Sharing Review – 2008 (b)

“As a general rule, it seems right that personal information obtained consensually for a specified purpose should not then be used for an incompatible purpose that goes outside the terms of the original consent... For this reason, the second Data Protection Principle, which prohibits reuse of information in any manner that is incompatible with the original purpose, stands as a significant safeguard. **It is important to note, however, that ‘incompatible with’ is not the same as ‘different from’**” (5.17).

“Consent clauses should be written in a way that provides for reasonable additional uses of information, while giving patients and others sufficiently specific explanations and safeguards to prevent inappropriate uses or sharing of information about them” (5.20).


www.justice.gov.uk/reviews/datasharing-intro.htm

Over-promising to participants?

“In agreeing to take part in a study on women’s experience as mothers conducted by a young woman interviewer, they had established an expectation that their good faith in telling MB about their private lives would be reciprocated by her good faith in representing their lives in a way which would not undermine the interests of the women as mothers in general.” 2205

Miller and Boulton, 2007.





Is any position epistemologically privileged?

"Just as I have argued that a single researcher cannot unequivocally claim epistemological privilege simply because they belong to a specifically defined social group or occupy a specific social location, so too we cannot assume that a single research subject (or even a group of research subjects) unequivocally possesses such privilege."

Mason, 2002; *Qualitative Researching*.



Resources

- UKDA Manage and Share Data [<http://www.data-archive.ac.uk/sharing/>]
- British Sociological Association [<https://www.bsa.ac.uk/ethics/ethics-statement-ethical-practice.htm>]
- British Sociological Association - Visual Sociology Group – Ethical guidelines [<https://www.bsa.ac.uk/ethics/ethical-guidelines-visual-sociology-group>]
- Clark, A. 2006. Anonymising research data. NCRM Working Paper Series 7/06. ESRC National Centre for Research Methods. [www.ncrm.ac.uk/researchoutputs/publications/workingpapers/0706_anonymising_research_data.pdf]
- Data protection Act 1998 [http://www.legislation.hmso.gov.uk/acts/acts1998/ukpga_19980029_en_1]
- ESRC Research Ethics Framework [www.esrcsocietytoday.ac.uk/ESRCInfoCentre/images/ESRC_Research_Ethics_Framework_tcm6-1191.pdf]
- Freedom of Information Act 2000 [www.opsi.gov.uk/acts/acts2000/ukpga_20000101_en_1]
- Human Rights Act 1998 [www.opsi.gov.uk/acts/acts1998/ukpga_19980042_en_1]
- Methodological Issues in Qualitative Data Sharing and Archiving [www.ncrm.ac.uk/qualitative-data-sharing-archiving]
- National Centre for Research Methods - informed consent project [www.southampton.ac.uk/socsci/sociology/research/projects/informed-consent.htm]
- Oral History Society guidelines [www.ohs.org.uk/ethics/]
- Research ethics in art, design, media [www.biad.upe.ac.uk/research/ethics/]
- Social Research Association [www.the-sra.org.uk/ethical.htm]



Further info-not for presentation



Arguments for archiving and sharing data

- Securely store and protect data
 - Not burdening over-researched, vulnerable groups
 - Extend voices of participants
 - Provide greater research transparency
 - Enable fullest ethical use of rich data
- In each, ethical duty to participants, peers and public may be present*



Definitions

- **Personal data**
 - identify a living individual alone or with other data
 - includes any expression of opinion about the individual
 - anonymised data is NOT personal (DPA1998)
- **Sensitive data**
 - data regarding an individual's race or ethnic origin, political opinion, religious beliefs, trade union membership, health, sex life, criminal proceedings or convictions... (DPA1998)
- **Confidential data**
 - data that can be connected to the person providing them
 - directly or indirectly identifying information: names, addresses, occupation, sensitive data that incriminate participant or third party, photograph, health, opinion, etc.
 - data or info given in confidence and agreed to be kept confidential between two parties; not in the public domain



Data Protection Act - I

Principles for handling personal data:

- 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...
- kept secure
- not transferred abroad without adequate protection

Key points for DPA:

- every individual has the right to access info and data held
- if data is anonymised (personal identifiers removed) then DPA will not apply as this no longer constitutes 'personal data'



Data Protection Act – II

Exceptions for personal data used in research:

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



Copyright

- **purpose:** to protect creators' skills by controlling production of copies
- moral right to have name associated with creation and to prevent misuse (e.g., quotation out of context)
- archives need authorisation to make copies
- researchers can grant that authority if they own copyright in deposited materials
- **UKDA does not require or ask for copyright, only licence**



Freedom of Information Act

Purpose: increase transparency in public sector

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

- 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, but copyright stays with original researcher
- does not apply to personal data



Confidential research data can be used and shared

- By combining one or more of these strategies:
 - obtain informed consent
 - protect identity (one option is anonymisation)
 - restrict access (e.g. by group, use, time)

NB: don't collect personal or sensitive data if it is not necessary for your research project



Background on informed consent

- Philosophical
 - consequentialist (e.g. utilitarianism)
 - deontological (e.g. rights or duties)
 - virtue ethics (e.g. contextual, situational)
- Historical – Nuremberg, Geneva Convention, Declaration of Human Rights
 - responses to medical abuses and atrocities
- Informed consent-key to preventing medical abuse
- Expanding to any social research on people-why?
 - society-wide growth in regulation
 - assumption of modern, rational individual
 - limitations on researcher autonomy
 - institutional CYA (no easy alternatives for RECs)
 - DPA grants exceptions if consent obtained
 - authentic collaboration with participants



A good consent form

- Meets requirements of REF and DPA
 - purpose of the research
 - what is involved in participation
 - benefits and risks
 - mechanism of withdrawal
 - usage of data – for primary research and sharing
 - strategies to ensure confidentiality of data (anonymisation, access....)
 - funding source, contact details, complaint procedure
- Simple, not overly simplistic
- Avoids excessive warnings and jargon
- **Complete for all purposes: use, publishing, sharing**



Consent for different types of material

- Ranging from less sensitive (survey) to highly sensitive (NHS protocols for medical)
- Most qualitative research in-between...
- Text and transcripts
- Audio recordings
- Still and moving images
 - different legal position-favours producers (researcher/institution)
 - data more likely to reveal identities
 - data more likely to be made less useful for research by anonymising (blurring or distorting)
 - gaining consent and controlling access are better alternatives