



# Reconciling the sharing of research data with ethical review

for research with people as participants

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UK Data Archive

Research Data Management Support Services

Presentation for University of Brighton Research Ethics Committee

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# Tensions between data sharing, data protection and ethical review

## Examples:

“Our ethics committee insists that our data is not shared with users beyond the research team.”

“The guidelines provided by our REC state that all research data obtained during interviews should be destroyed at the end of research.”

“Herewith consent pro forma drawn up following ethics committee approval, where we promise to destroy transcripts and recordings after the research has been written up. So while datasets were physically produced, they are not available for deposit.”

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# Different policies drive UKDA and Research Ethics Committees



## Social science perspective

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# UKDA

- ESRC Data Policy

“publicly funded research data should be openly available to the scientific community to the maximum extent possible ”

[[http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Images/DataPolicy2000\\_tcm6-12051.pdf](http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/Images/DataPolicy2000_tcm6-12051.pdf)]

- UKDA administers ESRC Data Policy

(Economic and Social Data Service)

- archives research data from ESRC funded research
- makes archived data available to academic community

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# University Research Ethics Committees



- protect the safety, dignity, rights and well being of research participants
- promote ethically sound research
- ensure research complies with Data Protection Act 1998
- partly driven by medical protocols of research ethics

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# No need for tensions!

- RECs care about data sharing – may address data sharing in guidelines
  - Univ. of Essex [[http://www.essex.ac.uk/reo/research/ethics/ethics\\_guidelines.asp](http://www.essex.ac.uk/reo/research/ethics/ethics_guidelines.asp)]
  - Kings College London – ‘use, retention and reuse of participant contribution form’
- UKDA equally concerned about protecting dignity, rights, well-being of research participants – ensuring that archived data are used ethically
- UKDA staff keep apace with current research ethics policies debate
  - online guidance on research ethics, data confidentiality, consent and data sharing: <http://www.data-archive.ac.uk/sharing>
  - training workshops for researchers
  - project-specific advice for researchers
  - ESRC Working Party on data consent and confidentiality
  - BSA Ethical Guidance working group
  - working with NHS National Research Ethics Service
  - member of NATCEN REC
  - NCRM visual ethics focus group
  - Research Ethics Review publication

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# Key principles for ethical data sharing in research with people

- avoid DPA confusion: not all research data is personal
- not all research data are confidential or sensitive
- sharing and archiving research data should not compromise confidentiality
- enable ethical data sharing - researchers must consider:
  - **consent** for data sharing / archiving
  - **anonymise** - protect people's identities when needed
  - **access** regulation / restriction to data, when needed

to be considered jointly!

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# UKDA enabling ethical data sharing

Regulating access to data to safeguard them:

- archived research data is 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 confidential data (case to case basis):
  - access to approved researchers only
  - requiring data access authorisation from data owner prior to data release
  - confidential data under embargo for a given period of time
  - secure access to data (data analysis of confidential data without actual access or download)



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Guidance and training for researchers on ethical data sharing



# RECs can help

- encourage researchers to address data sharing early in research planning and in consent process
- provide info on how to enable data sharing, whilst protecting participants and conducting ethical research (REC guidelines typically provide DPA info; what about data sharing info?)

- Examples:

## ESRC Framework for Research Ethics (2010):

“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 the long-term use and preservation of data”

## MRC data sharing policy + Personal Information in Medical Research guidelines:

“... researchers should foresee the need for sharing and archiving research data when obtaining consent “... “consent to this should be distinct from consent to the primary use of the information”



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# How can UKDA help RECs?

- UKDA guidelines on ‘Consent, Confidentiality and Ethics in Data Sharing’ [<http://www.data-archive.ac.uk/sharing/confidential.asp>]
- info for research participants on purpose and benefits of data archiving [<http://www.data-archive.ac.uk/sharing/participants.asp>]
- info on data sharing for RECs [<http://www.data-archive.ac.uk/sharing/consentrecs.asp>]
- training workshops, e.g. 2 Dec 2009, London [<http://www.data-archive.ac.uk/news/eventdetail.asp?id=2293>]
- exemplars of problem research

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