

DATA SHARING vs DATA PROTECTION

Information for Research Ethics Committees

Sharing research data

UK research councils and other funders increasingly encourage research data, created through grants they fund, to be shared and made available for long-term use by the wider research community.

For example, the ESRC Data Policy states that "... publicly funded research data should be openly available to the scientific community to the maximum extent possible."

The UK Data Archive administers the ESRC Data Policy through the Economic and Social Data Service (ESDS). The Archive is the designated national centre for preservation and dissemination of all research data arising from ESRC-funded research, with ESRC award holders required to offer all research data to the Archive for deposit. The Archive makes data available, at no cost, to the research, learning and teaching communities.

The UK Data Archive ensures that: all research data are used only in appropriate and ethical ways; research participants are protected; and personal data safeguarded.

Archived data are typically anonymised, unless specific consent has been given for personal information to be included. Archived data are not in the public domain and their use is restricted for specific purposes after user registration.

Users sign an End User Licence, in which they agree to certain conditions on the use of the data, i.e. not using data for commercial purposes, not identifying any potentially identifiable individuals and not sharing data with unregistered users.

For confidential or other sensitive data stricter access regulations may be imposed, such as:

- requiring authorisation from the data owner prior to release of data to a user
- placing selected data under embargo for an agreed period of time

Research Ethics Committees, data protection and ethical review

The role of Research Ethics Committees (RECs) is to protect the safety, dignity, rights and well-being of research participants and to promote ethically sound research.

This involves ensuring that: the research complies with the Data Protection Act 1998 (DPA); personal information collected by researchers is not misused in any way and is treated according to the principles of the DPA.

More and more RECs are currently addressing data sharing in their guidelines or in ethical review procedures. For example:

- Kings College London in its Research Ethics Guidelines: highlights a researcher's responsibility to archive anonymised data and make them available for re-use; and provides a template for a consent form covering the use, retention and re-use of various types of data
- the University of Essex, in its Guidelines for Ethical Approval of Research Involving Human Participants, points out to researchers that informed consent should be obtained for the sharing of research data and for the publication of findings

ESDS working with researchers

ESDS helps co-ordinate data management and data submission for researchers, Research Centres and Programmes.



www.esds.ac.uk/aandp/create

Economic and Social Data Service





Reconciling data sharing and data protection

Tensions or confusion seem to exist between data protection and data sharing, especially when research data obtained from participants contain personal data sensitive or confidential information.

It may appear that the easiest solution is to keep all information confidential and hidden and not share data. This, however, does not help the researcher or the wider research community in the longer term.

Most research data obtained from participants can be successfully archived and shared, without breaching confidentiality.

Firstly, it is important to distinguish clearly between personal data collected in research, and research data in general.

The DPA applies only to personal data. Once such data have been anonymised or removed, the DPA no longer applies.

The DPA defines personal data as "... data which relate to a living individual who can be identified from those data or from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller (e.g. researcher)." Therefore, DPA principles should only be applied to those data which constitute personal data, and certainly not to all data obtained from research participants.

Secondly, research data obtained from participants may contain sensitive or confidential information.

Again this does not automatically mean that all research data are confidential. Researchers may be bound by a duty of confidentiality towards participants. However, even sensitive and confidential data can be shared ethically if researchers apply one or more of the following strategies to managing their data:

- obtain informed consent for data sharing, as well as obtaining consent for participation and for other uses such as publication
- protect people's identities when necessary, by anonymising research data
- decide if access restrictions are required for all or part of the data (e.g. restrict access to personal data)

These procedures should always be considered jointly, not in isolation, and researchers should discuss them openly with participants.

In addition, planning for data sharing should be done at the earliest stages of designing a project and well in advance of beginning fieldwork. For example, if researchers explain how confidential information will be kept, stored and used safely and how personal information may be removed to anonymise data, then informed consent can be obtained for sharing or archiving such anonymised data.

This will allow participants, in consultation with researchers, to make an informed decision whether or not data can be shared.

How RECs can help researchers share data

RECs can help by providing information to researchers on how data sharing can be reconciled with ethical research.

RECs should encourage researchers to address data sharing early in research planning and as part of the consent process, so that measures can be put in place to safeguard participants and the information they provide. This includes obtaining appropriate consent for a variety of uses, not just confined to the immediate needs of the researcher.

Guidance on consent, confidentiality and ethics

The UK Data Archive provides guidance for researchers on consent, confidentiality and ethics in data sharing and information for research participants on the purpose and benefits of data archiving.

www.data-archive.ac.uk/sharing/confidential.asp