Data sharing and human subjects

There seems to be a consensus that all (or nearly all) anonymous data within research should be made available to the wider research community to make best use of research findings. Typically, a research paper may have online supplementary material that constitutes the breadth of data accrued. Data may be derived endpoints (e.g. via an algorithm) rather than raw (sample-level) data that could be described as high-resolution data from digital technologies. Data may be deposited with repositories or publishers.

Why data sharing

- Maximizes the research opportunities that the data provide
- Encourages informed use beyond the originating research teams
- Enables new research questions to be answered with existing data
- Promotes collaboration between different research teams and diverse disciplines
- Allows sharing of knowledge about best methods for data collection, linkage and analysis
- Allows independent verification of research findings
- Potentially reduces data fabrication and falsification

Consent and data sharing

- Research participants should consent to anonymized data sharing at the start of a study
- Data sharing should be detailed in the participant information sheet and consent form
- Participants should understand the purpose of data sharing, for instance with regard to future research and learning

Challenges to data sharing

- Changes in archiving policy
- Destruction of original records (the research may have been undertaken decades previously)
- Corruption of electronic records
- Compliance with current data protection legislation
- Lack of consent to data sharing by human subjects

Submissions for publication need to contain data sharing statements indicating what can be accessed, for what purpose, by whom and how.

Data sharing is problematic for case reports as it risks identifiable data being made publicly available, breaching patient privacy.

Further information

American Psychological Association. Data sharing https://www.apa.org/pubs/journals/resources/data-sharing

Elsevier Database linking https://www.elsevier.com/en-gb/researcher/author/tools-and-resources/research-data/data-base-linking

Institute of Electrical and Electronic Engineers (IEEE). IEEE DataPort https://ieee-dataport.org/why-ieee-dataport

Sharing clinical trial data: A requirement of the International Committee of Medical Journal Editors (ICMJE) https://icmje.org/news-and-editorials/data_sharing_june_2017.pdf