Open And Fair Data On Wellcome Open Research:
Sharing Sensitive Data

How you share your data first and foremost depends on any applicable legal and ethical factors – this is especially true in the social sciences where data collected is often personal. You may feel that there is tension between protecting research participants and openly sharing your data, but datasets that contain personal data can often be shared following informed consent, appropriate anonymisation and/or controlled access.

Consent

In order to make sure that research data can be made available for future reuse, it is important that consent for future reuse of the data by other researchers is sought from participants. Participants should be informed how research data will be stored, preserved and used in the long-term, and how confidentiality can be protected when needed.

Consent procedures must be tailored for the specific research context, methods and sample, the nature of the data (personal, sensitive, level of detail), the format of the data (surveys, written, recordings) and the planned data uses and handling. This will influence the type of consent and consent process used. More detailed requirements and examples of these are offered in the sections on gaining written or oral consent, and consent forms of the UK Data Service **here**.

Please note

It is important to note that researchers are not obliged to obtain consent. They are obliged to seek consent and to impartially advise participants about risks and benefits of research participation and data sharing. Participants then decide what they will consent to. Researchers must honour the wishes of the participants. So, if the participants don't give their consent, this means that you can't make your data available for reuse.

Anonymisation

Anonymisation alters direct identifiers (name, postal code, phone number, etc.) and indirect identifiers (occupation, gender, location etc) such that individuals cannot be identified in a dataset. Both quantitative and qualitative data can benefit from anonymisation using the following techniques:

Remove
Remove direct identifiers from your dataset. Better still, plan ahead and avoid collecting identifiable data that is not needed. Where direct identifiers such as name cannot be easily removed while maintaining usefulness of the dataset, use pseudonymisation instead.

Generalise
Where possible, replace disclosive information with more generalised information – whilst still maintaining meaning. For instance, reference to a Catholic Church could be generalised to a place of worship.

Aggregate and Reduce
Variables such as age and location can be aggregated or reduced to decrease the precision of the variable. For instance, recording birth year rather than birthdate is a form of reduction.

Log
Keep a record of each step of anonymisation and be sure to keep this file separate from the anonymised data file.

Reassess
Always double check your dataset following anonymisation to ensure that the risk of disclosure has been removed.

Controlled Access

There may be cases where data cannot be fully anonymised and so, openly sharing data is not feasible. Depending on what the ethical board approving your study said about data sharing, and the level of permission granted from participants, it may still be possible to make your data accessible, in line with the FAIR Principles, to authenticated users via a controlled-access repository. Bear in mind that mixed levels of access control can be put into place; you can combine controlled access to potentially disclosive data while openly sharing non-disclosive data. **Click here** for a list of protected access repositories.

Can't Share the Data? Share the Metadata

In cases where data cannot be shared for legal and/or ethical reasons, you can openly publish a description of your data (known as a 'metadata record'). This helps others to discover your data and provides essential information about how the data can be accessed and cited. For example, you could post a "data codebook" or "data dictionary" (e.g. **https://help.osf.io/hc/en-us/articles/360019739054-How-to-Make-a-Data-Dictionary**) in a repository that describes the variables used in your dataset. In this document, you can cite the article in which it appears in order to connect the data descriptor to the paper.

Please note

The metadata record for sensitive data should never contain identifying information like names.

Third Party Data

Secondary users of data must obtain copyright clearance from the rights holder before data can be reproduced. In cases where data has been obtained from a third party, restrictions may apply to the availability of the data.

Please note

Be aware of any licensing restrictions where your dataset contains data derived from a third party.

Toolbox

We have gathered a number of useful resources to help you share your data.

- UK Data Service:
  https://www.ukdataservice.ac.uk/manage-data/legal-ethical/consent-data-sharing.aspx

- The Anonymisation Decision-making Framework
  https://fpf.org/wp-content/uploads/2016/11/Mackey-Elliot-and-OHara-Anonymisation-Decision-making-Framework-v1-Oct-2016.pdf

- Amnesia
  https://amnesia.openaire.eu/

- QAmydata
  https://www.ukdataservice.ac.uk/about-us/our-rd/qamydata.aspx

- sdcMicro
  https://cran.r-project.org/web/packages/sdcMicro/index.html

- ANDS Publishing and sharing sensitive data
  https://www.ands.org.au/__data/assets/pdf_file/0010/489187/Sensitive-Data-Guide-2018.pdf

- EDCTP Knowledge Hub
  https://edctpknowledgehub.tghn.org/