Anonymisation   source UK Data Archive[2]

Before data obtained from research with people can be shared with other researchers or archived, you may need to anonymise them. Anonymisation may be needed for ethical reasons to protect people's identities in research, for legal reasons to not disclose personal data, or for commercial reasons. Procedures to anonymise data should always be considered alongside obtaining informed consent for data sharing or imposing access restrictions[3].

What is pseudonymous, de-identified or anonymous data? See A Visual Guide to Practical Data De-Identification (from the Future of Privacy Forum): https://fpf.org/2016/04/25/a-visual-guide-to-practical-data-de-identification/

Data may be anonymised by:

- ✓ removing identifiers, e.g. name or address
- ✓ Replacing identifiers
  - ✓ e.g. replacing date of birth by age groups
  - ✓ e.g. replacing a doctor's detailed area of medical expertise with an area of medical speciality
- ✓ using pseudonyms
- ✓ restricting the upper or lower ranges of a variable to hide outliers, e.g. top-coding salaries

How to anonymise quantitative and qualitative data? See the Overview from the UK Data Archive: https://ukdataservice.ac.uk/learning-hub/research-data-management/#anonymisation

Manage anonymisation:

- ✓ plan anonymisation early in the research at the time of data collection (to reduce the costs)
- ✓ retain original unedited versions of data (safe place)
- ✓ create an anonymisation log of all replacements, aggregations or removals made
- ✓ store the log separately from the anonymised data files
- ✓ identify replacements in text in a meaningful way, e.g. in transcribed interviews indicate replaced text with [brackets] or use XML markup tags <anon>…..</anon>

Audio-visual data

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[1] The Center for Digital Scholarship is based in the University Library, Witte Singel, and provides support for many different aspects of digital scholarship such as data management, open access, text & data mining etc.

[2] Information based on : Managing and sharing research data : a guide to good practice / Louise Corti, Veerle Van den Eynden, et al., Los Angeles : Sage, 2014

[3] https://www.ukdataservice.ac.uk/manage-data/legal-ethical/anonymisation

Digital manipulation of audio and image files (voice alteration, image blurring) can be labour-intensive and expensive and might damage research potential of the data. It is better to obtain participant's consent to use and share the data unaltered, with additional access controls if necessary.

Informed consent (source UKDA)

Do your participant consent forms include information about intentions for sharing, retention of data and steps taken to protect participants privacy and confidentiality?
Where possible, consent should also take into account any future uses of data, such as the sharing, preservation and long-term use of research data. At a minimum, consent forms should not preclude data sharing, such as by promising to destroy data unnecessarily.
- ✓ inform participants how research data will be stored, preserved and used in the long-term
- ✓ inform participants how confidentiality will be maintained, e.g. by anonymising data
- ✓ obtain informed consent, either written or verbal, for data sharing

UKDA : "for data to be ethically reused, consent for future reuse must be thought through at the time of the original research proposal planning and writing"

Levels for data access to mention in an informed consent : http://talkbank.org/share/irb/options.html

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Useful links

"When and how to publish sensitive data as openly and ethically as possible", see the Publishing and Sharing Sensitive Data flowchart (by the Australian Research Data Commons (ARDC)): https://ardc.edu.au/wp-content/uploads/2020/05/Publishing-and-sharing-sensitive-data-flowchart.pdf . See also the ANDS Guide to publishing and sharing sensitive data[4].

The Dutch National Coordination Point (LCRDM created an Anonymization Reference Card: https://doi.org/10.5281/zenodo.3584842 (Dutch)

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[4] https://ardc.edu.au/resources/working-with-data/sensitive-data/