Your situation

You have *not* informed participants that the research materials, including their personal data, would be shared.

You do *not* hold participants' contact details (e.g. addresses, phone numbers, etc.).

You have *not* promised full confidentiality to participants.

You have *not* promised that all research materials would be destroyed at the end of the research project.

You have *not* promised full anonymization of the data at the end of the collection / project.

You have *not* announced to participants a data collection purpose limited to a specific project.

Your legal obligations

Sharing research materials including personal data via a third-party repository without informing participants may be possible if all of the following conditions hold:

- participants did not explicitly refuse the sharing of their personal data
- you have the rights to possess the data; this implies that you have not promised data destruction or announced a very time-limited collection purpose
- it is impossible (or at least very difficult) to re-contact the participants (e.g. no contact details such as full names, addresses, telephone numbers, etc. are hold)
- the data is deposited in a repository that:
    - is based in Switzerland or in a country considered safe by the Federal Data Protection and Information Commissioner
    - offers storage security guarantees (e.g. servers in Switzerland/EU)
    - offers appropriate data deposit and re-use contracts
    - allows regulation of data access (e.g. research only, with prior agreement of the data producer, after an embargo period, clearly defined re-use conditions)
- the data are shared for research purposes only (see "access control" section), and all promises made in the information sheet and the consent form are respected

Best practices / recommandations

Whenever possible, full anonymization is always the preferred option. This involves permanently deleting all direct and indirect identifiers. However, it is rare (because it is very difficult) to achieve full anonymization.

When full anonymization is not possible, it is recommended to keep only the personal data that is necessary and to permanently delete the rest. Indeed, it is good practice to permanently delete all direct identifiers (including contact details) and as many indirect identifiers as possible, unless they are deemed essential (for practical or scientific reasons). Deleting highly identifying variables is a strong layer of protection, since it makes re-identification more difficult.

It is recommended to always carry out a risk assessment. If disclosing personal data might harm your participants, we recommend that you put in place additional safeguards, such as:

- replacement of identifying information with pseudonyms
- encryption of the data
- controlling and conditioning access to data (see "access control" section)
- implementation of a data use contract that sets out the re –use conditions

If the risk for participants is too high, it is recommended to contact the relevant departments within your institution and consider not sharing the data themselves. In this case, sharing the metadata might be an option.

Access control

Where no explicit consent to share personal research data has been obtained, only sharing for research purposes is possible.

In addition, secondary users must be required to publish their results in a non-identifying form and to delete the data as soon as they have carried out their analyses (for example by means of an appropriate user contract).

For all these reasons it is strongly recommended to use a repository that allows access to be regulated, for example through access and re-use contracts (such as SWISSUbase).

Resources

FORS Guides: consult our guides on key data management topics, including data management planning, data protection, informed consent, data anonymisation, data sharing: https://forscenter.ch/publications/fors-guides

Data management webinar series: discover our webinars on the above topics, as well as on data documentation and security:
https://forscenter.ch/data-management-webinar-series/

FORS archiving resources: check out our wider archiving resources:
https://forscenter.ch/data-services/help-resources/

SWISSUbase resources: get access to SWISSUbase and its resources:
https://resources.swissubase.ch/

Open Science at UNIL: https://www.unil.ch/openscience/en/home.html

Contact us: for any questions, get in touch with us: datago@unil.ch