

## Processing of personal data in research projects

When processing personal data for research or statistical purposes, you need to be aware of a number of requirements under the General Data Protection Regulation.

- You must know which clause you are using as the legal basis for processing.
  - o If you process personal data on the basis of the *clause on research* in §10 of the Data Protection Act and the article of the General Data Protection Regulation's § 6(1)(e), data <u>may ONLY</u> be used for research. This means that you cannot use any of your data for teaching, quality assurance, administration or the like, as long as the data is personally identifiable. Anonymised results can be used for more than just research.
    - If you are to disclose personal data to third countries, it requires the approval of the Danish Data Protection Agency.
    - If you are to disclose biological material, it requires the approval of the Danish Data Protection Agency.
    - If you are to publish personal data in a recognised journal, it requires the approval of the Danish Data Protection Agency.
  - o If you process personal data based on consent, what you have informed the participants prior to collecting date is crucial. Consent is the framework for the processing, and therefore participants must be able to trust that the process described in the declaration of consent is complied with. This means that you may only process data in accordance with the consent. This also gives you the opportunity to design the declaration of consent to fit the specific circumstances and the processing parts you need.
  - If you process data on the basis of an VEK consent (National Committee on Health Research Ethics), you need to be aware of any special legislation.
- Regardless of which legal basis you use, you need to be aware of the duty of disclosure according to the
  General Data Protection Regulation's § 13 or 14. The duty of disclosure consists of a set of information to
  be provided to the data subjects. It is a condition of validity of the processing and can only be waived in
  very few cases.
  - The data subject/participant must be informed of
    - the name of the data controller,
    - o information on the DPO,
    - o the purpose of the project,
    - o the data retention period,
    - the legal basis for the processing and the types of data to be processed,
    - o the fact that participation is voluntary and of the possibility to withdraw consent,
    - the identity of any recipients of the data and the purpose for disclosing the data,
    - their right to file a complaint to the Danish Data Protection Agency, obtaining access, rectification and deletion,
    - as well as any other information necessary for the data subject/participant to safeguard his/her interests.



- If you use the clause on research, personal data may only be disclosed to third parties if there is prior permission from SDU RIO. If you want to reuse personal data in another project, it is possible to do so as long as it is research. Transfer of data to a new project must be requested.
- If you process data on the basis of consent from the participant, you have the opportunity to obtain consent for the transfer either subsequently or at the time of collection. If you do not receive consent from the participant, you cannot transfer data collected on the basis of consent. Reuse of personal data in new projects also requires consent and it is therefore crucial to know exactly what has been agreed in the consent.
- When using data processors, a written data processor agreement must be concluded before the data
  processor is granted access to data. Data processors are external parties (not employed at SDU) tasked
  with processing personal data on behalf of SDU. All data processing agreements must be approved and
  signed by SDU RIO. Contact sdu.persondata@sdu.dk.
- Data must, to the extent possible, be processed in a form where they are not directly personally identifiable in encrypted or pseudonymised form.
- All research projects involving personal data must be notified to SDU RIO so that they appear on SDU's list of processing activities. Afterwards, you will get an approval and a project number.
- Research results must be anonymised and no personal data may be published unless there is consent from the data subject or approval from the Danish Data Protection Agency.
- Personal data must be deleted, anonymised or archived when the project is completed unless there is consent from the data subject for continued processing.

In addition, there are a number of security measures that must be established prior to processing. You must therefore be aware of the following:

- Employees who handle personal data must have received instruction and training in the protection and processing of data.
- Access to personal data must be restricted so that employees only have access to relevant data.
- At least every six months, a check must be carried out to ensure that the employees in question still have a need for access to data.

Find more information and relevant forms at: <a href="https://www.sdu.dk/da/anmeldelse">https://www.sdu.dk/da/anmeldelse</a> or contact Legal Services by email: <a href="mailto:sdu.persondata@sdu.dk">sdu.persondata@sdu.dk</a>