When you are embarking on your masters thesis

https://www.sdu.dk/da/om_sdu/institutter_centre/ist_sundhedstjenesteforsk/ist-specialestuderende

Different kinds of theses

1. Thesis with data from other institutions in EU (e.g. OUH)
2. Thesis with data from SDU
3. Thesis with data that you collect
4. Thesis without data, e.g. litterature review

Are those data personal data?

If you are certain that your thesis does not contain personal data, then you don't need to worry about GDPR

What are personal data?



- → Register data
- → Survey data
- → Interviews (sound recordings and transcriptions)
- → Case studies, e.g. patient records
- → Photos of or with individuals
- → Videos or sound bits with individuals
- → Blood samples and other biological material
- → Written observations of individuals, dairy observations
- → Artefacts relating to individuals

- → All of this are personal data if you can recognize individuals from data

Examples of personal data

Please note that data is NOT anonymised, even though CPR-number and name are encrypted or removed

- → Register data: A 68-year old woman, who has surgery for breast cancer on October 1st at 10h15 at Slagelse hospital.
- → Survey data: Citizen in Assens municipality, who identify as 'other gender' and reports that they are in a wheelchair.
- → Interview: The respondent is a parent of a young person with brain injury. They talk about a very long and complicated hospitalization and a court case against Nyborg local council in April 2018.
- → Case studies usually pertain to rare diseases and always mention age and gender
- → Blood samples, photos, dairy notes, observations, videos and sound bits can contain information that can lead to identification of an individual

My data are personal data – now what???



→ **You can't do anything with data without approval/registration:**
- → Approval for data collection
- → Approval for data storage
- → Approval for data analysis
- → And approval for publication of data – if individuals can be recognised in any way
- → For SDU-prjects this means RIO-registration

→ OR: you have to make sure that data are anonymised.

→ This means that nobody can recognise anybody in your data.

→ You can't decide if data are anonymised, yourself. That decision requires thorough checks and you'll need help for that.

→ Pseudonymised data are also personal data

What does approval/registra-tion mean?

What does all of this imply for YOUR thesis?

What YOU should do, depends on the type of thesis

→ There needs to be **a data controller** for all personal data that are collected, stored or analysed. A data controller is responsible for complying with the law (GDPR) and makes sure that there are no data security violations.

→ In all projects where personal data are processed there needs to be a **legal basis** (”hjemmel” in Danish)

- → If you use register data there will normally be ***research***-hjemmel.
- → In interviews there is normally ***consent***-hjemmel

1. Thesis with personal data, where another institution is the data controller

→ E.g. personal data, collected at OUH, or SHARE-data (http://share-project.org) .

→ You still need approval to use data in your thesis

→ You need to be affiliated with the institution as data processor. For SHARE there is a form you need to fill out at their web-page. For the regions it can take a bit longer.

→ An affiliation can also be regular employment

If you are working at the data controller institution, you have to comply with their rules. You still need to apply for approval but you are part of the data controller

1. Thesis with personal data, where another institution is the data controller …contd

→ You have to comply with the rules given by the data controller, also after your defense.

→ If you are data processor you must comply with the instruction from the data controller, also after the defense.

If another institution is the data controller you have to comply with their rules and not SDU's
Most information in the next slides may therefore not apply to you

2. Thesis with personal data where SDU is the data controller

In this model, both you and your data should be part of SDU

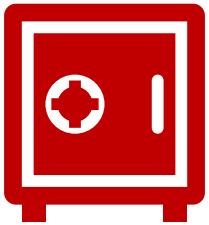
- → E.g. your supervisor or some of their colleagues have some personal data they are working on.
- → Talk to your supervisor if you should apply to the legal office (RIO) for your project or if it falls under the larger registration. In either case, you need to know the RIO-number
- → You should be affiliated to IST by means of an affiliation agreement.
- → At IST, we require that everyone knows and comply with our research instruction (Link) . Further, we require that you complete the SDU GDPR-course before working with data.
- → You must comply with the instruction, also after the defense.

3. Thesis with personal data you collect yourself for your own project

→ You are the data controller yourself but we will help you comply
→ The law (GDPR) applies always, even if you send out a survey-monkey to your facebook friends.
→ You don't need to register your project but you need to make sure that GDPR is adhered to.
→ At IST we prefer students to fill out an affiliation agreement, talk to your supervisor about this option.
→ At IST, we require that everyone knows and comply with our research instruction (Link) . Further, we require that you complete the SDU GDPR-course before working with data.
→ You must comply with the instruction, also after the defense.

Option 2 and 3.:We expect you to store data according to the **rules**.

How do I store data in a secure manner?





- → OneDrive/Sharepoint/
- → NextCloud
- → Secure server (S5)
- → External data processor, e.g. Statistics Denmark

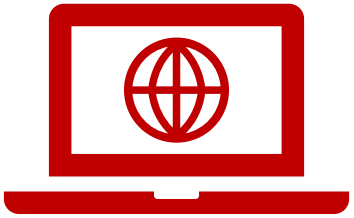


- → **Under and after analysis**:
  - → Secure server (S5)
  - → External data processor, e.g. Statistics Denmark



- → **What about:**
  - → Your own cell phone
  - → Your own computer
  - → Dropbox
  - → Mail
  - → Facebook
  - → …?
  - → Chat-GPT!?!?

Before you start - legal

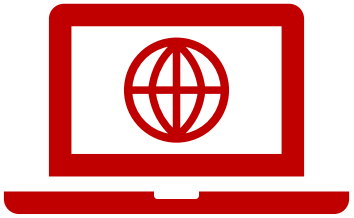


Option 2 and 3

- → Make a documentation package with:
  - → **OPTION 2 only** The approval from the legal office (SDU RIO)
  - → Consent and information letter if you are collecting data. Remember to only use anonymized consent, also in the final thesis…
  - → Mini-data management plan, e.g. from here: https://dmponline.deic.dk/plans or the enclosed template
  - → Sceen shot of completion of the SDU GDPR-course*
  - → Affiliation agreement with IST

- → * how to find it:
  - → Open it's learning, home page. Click 'all courses' top right. Search for 'databeskyttelse' and select the course called SUND – Databeskyttelseskursus for studerende på SDU

Before you start - IT



Option 2 and 3

→ Either you need access to Statistics Denmark or similar, where data is already located (contact Marie mkru@health.sdu.dk)

→ Or you need access to the secure server S5 (contact Sonja swehberg@health.sdu.dk)

→ In both cases you need to send the documentation cf last slide (affiliation agreement and DMP)

→ Time frame: If you write in the spring:

- → It is best to do this, when you sign your thesis contract. December-January
- → The documentation should be completed and handed in before you start working with data. Start February the latest
- → IT/GDPR workshops

January and start February

The following slides are meant as an appetizer for the GDPR-course

What you need to know about:



- → **Legal basis/”Hjemmel”**:
  - → If you send out a questionnaire, it is voluntary to respond. So respondents give consent by replying, right?
  - → Right, but it is NOT a legal consent, and does not count as consent-hjemmel. Such a questionnaire requires research-hjemmel.
  - → Consent-hjemmel needs to fulfil a number of requirements, including the right to be forgotten. Which means that under consent-hjemmel, the respondent always can withdraw their consent. If your thesis is based on two interviews, and one respondent withdraws, you need to delete their and all the results. That is if you’ve used consent-hjemmel.
  - → We advise you to use research-hjemmel if possible.
  - → There are some other limitations to research-hjemmel, including stricter transfer-rules.

What you need to know about :



→ **Duty to inform**

→ In interviews and surveys you are required to inform your respondents about:

- → The aim of the data collection. This doesn't need to be the same as your research question.
- → How data are used. Will data be transferred, linked with register data, etc.
- → If data are anonymized or deleted after the project is completed.
- → Who the respondents can contact: you, and if SDU is the data controller, the SDU DPO.
- → That data are treated confidentially and the characteristics of the group of people with access to data, not the names but, e.g. you and a group of reseachers based on IST, SDU.

→ Remember also need to know (data minimisation)

What you need to know about:



→ **What happens afterwards?**
→ When you have defended your thesis, you still have to comply with your DMP
→ If you wrote in your DMP that you will delete data, you have to delete them such that they can't be recreated
→ If you wrote in your DMP that data will be anonymised, someone else should check if nobody can be recognised
→ If you are working on your supervisor's data, it is only your own access that should be closed
→ You may not, at any time, tell others about individual information that you had access to during the work with your thesis.

More info

→ Link to datatilsynet Danish data protection agency, in Danish
→ Link to RIO (SDU legal office)
→ Link to IST research instruction
→ Link to SDU health GDPR page for students, in Danish

