



# RESEARCH DATA & LAW

A VERY BRIEF OVERVIEW

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# RESEARCH DATA & LAW CONTENTS

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# 1) A LEGAL PERSPECTIVE TO RESEARCH DATA – SOME STARTING POINTS

- **What data** you are planning to utilise?
  - Are you collecting/producing the data or utilising pre-existing data?
  - Is the data personal data?
- **Who is the "owner"** of the data? / **Who controls** the data?
- Are you **authorised to use** the data?
  - Agreements, "ownership" issues, protection of personal data & data permits
- Do the **funding terms & conditions** regulate the matter?
- Especially at the Meilahti Kampus: **in which organisation you are carrying out your research?** E.g., at the university or HUS?
  - HUS's patient data cannot be utilised at the university unless agreements are in place (or you have a data permit) and vice versa



## 2) RESEARCH DATA IN AGREEMENTS

- Why agreements are needed?
  - **Compliance with laws and commitments:** the GDPR, procurement and state aid laws & obligations set by funders and contracting parties
  - **Securing the rights of the university & risk management:** ownership results, due payments to the university, ability to publish the results, quality of services procured by the university etc.
- Examples of agreements relating to research data:
  - Collaborative research agreement – parties utilise each other’s background data and agree upon the ownership of data (results) generated in the research project
  - Data/material transfer agreement – the recipient is granted a right to use the pre-existing materials and/or data of the provider (data permit might also suffice)
  - Agreements on processing of personal data, such as: data processing agreement (DPA), joint controller agreement and data transfer agreement (DTA)



### 3) OWNERSHIP OF RESEARCH DATA GENERATED IN A PROJECT

- **Ownership** of and **user rights** to research data generated as a **result** of a project
  - No simple guidelines: discuss with the PI
  - Affected by various factors, such as: source of funding, cooperation with other parties, agreements & employment relationship
    - Contract research v. open research
  - Database right? Copyright protection?
- **Each researcher** participating in a **contract research project** (= project that receives external funding or includes cooperation with third parties) **must give an undertaking on transfer of rights**
  - <https://flamma.helsinki.fi/fi/group/tutkimuksen-tuki/sopimukset-sopimusohje-ja-neuvottelut>



## 4.1) WHAT IS PERSONAL DATA?

- **A wide definition: any information** relating to an **identified or identifiable** living natural person
  - Identifiable: **directly or indirectly**, for example by combining data from multiple sources
  - Example: **A123**, a 45-year-old man, lives in **Smalltown** (a village with 50 residents), favourite color: **green**
  - Data may be personal data even if you do not know a person's name, social security number, contact details or other direct identifiers
- **It is very likely that your project involves processing of personal data**
  - Once a person is identified or identifiable, any information relating to them is personal data



## 4.2) WHEN DO DATA PROTECTION LAWS APPLY AND WHAT IS MY ROLE?

- The GDPR applies **whenever the University of Helsinki processes personal data**, regardless of where the processing takes place
- **Processing**: practically anything you can do to personal data, including for example collection, use, storage and deletion
- Who is the **data controller** – i.e. who has the ultimate responsibility?
  - Determines the purposes and means of processing
  - In the majority of research projects, the data controller is the university
    - However, an individual researcher may also be a controller: e.g., a doctoral candidate not employed by UH and not completing the doctoral thesis in a research project of the university



## 4.3) DATA PROTECTION IN A RESEARCH PROJECT 1/2

**BEFORE** the processing (e.g. collection) of personal data in a research:

- 1) Recognise the **roles** (especially, who is the controller) and **conclude agreements**, if needed
- 2) Define the **purpose** of research and the processing of personal data (also life cycle of the data)
- 3) Define the **necessary personal data** → process only data that is necessary
- 4) Define the **legal basis** for processing → typically: task carried out in public interest, scientific research purposes
- 5) Assess **risks** and plan **safeguards** → preliminary evaluation & data protection impact assessment
- 6) Take into account the **rights of data subjects** and how to implement these
- 7) **Inform** the data subjects → privacy notice





## 4.3) DATA PROTECTION IN A RESEARCH PROJECT 1/2

**DURING & AFTER** the research:

- 8) (Also) during the research, take care of **data security, delete** unnecessary data and **continue/update the risk assessment**
- 9) Execute the necessary **agreements** with partners (data processors, individual controllers/recipients of data)
- 10) After the project, **delete, archive or store** the data in accordance with the research plan, DMP and privacy notice
  - Initially, remember to ensure that these documents do not conflict with each other



## 5) COMMON MISTAKES RELATED TO RESEARCH DATA

- **Missing agreements or permits** regarding data and/or samples
  - Utilising data and/or samples without a permit, an agreement and/or ensuring whether it possible to utilise them in a new research project after their initial purpose of use
  - Not concluding agreements when providing (personal) data to recipients outside the University of Helsinki
    - E.g., partners in cooperation (joint controllers?) and external service providers (cloud services, online survey services, sequencing service providers etc.)
- **Not understanding the wide definition of "personal data"**
  - Not realising that the project involves processing of personal data
  - Promising to delete all personal data while actually meaning that the direct identifiers will be deleted
  - Anonymisation vs. pseudonymisation
    - The threshold of anonymisation is very high – in most cases, the data is actually pseudonymised, not anonymised
- **Lack of information to participants & lack of planning**
  - Need to plan in advance & be able to inform the data subjects about the processing of their personal data when informing is reasonably possible – remember to include data protection information in the documents you provide to participants
    - Simple solution: use the privacy notice template on Flamma/Yammer
  - Make sure that, e.g., all known processing activities, recipients of data, partners in collaboration and plans for keeping and archiving the data are informed to the data subjects prior you start processing their data



## 6) WHOM TO CONTACT AND FURTHER INFORMATION

- **Legal Services for research:** [tutkimuksenjuristit@helsinki.fi](mailto:tutkimuksenjuristit@helsinki.fi) or [researchlawyers@helsinki.fi](mailto:researchlawyers@helsinki.fi)
  - Legal Counsels at the University of Helsinki's Research Services assist researchers with research-related agreements and legal issues related to university's research projects
  - Please contact the Legal Services when planning on cooperating with parties outside the university or procuring services
- **Flamma: Instructions on concluding an agreement & Agreements relating to research:**
  - <https://flamma.helsinki.fi/en/group/tutkimuksen-tuki/sopimukset-sopimusohje-ja-neuvottelut>
- **Flamma: Data protection guide for researchers** (incl. templates for: privacy notice, preliminary evaluation of data protection, data protection impact assessment):
  - <https://flamma.helsinki.fi/fi/group/tutkimuksen-tuki/tutkimuksen-tietosuoja-asiat>
- **Yammer: Data Protection group** (conversation and files available: templates, presentation on GDPR for researchers):
  - [https://www.yammer.com/helsinki.fi/#/threads/inGroup?type=in\\_group&feedId=13861941&view=all](https://www.yammer.com/helsinki.fi/#/threads/inGroup?type=in_group&feedId=13861941&view=all)