



UiO : University of Oslo Library

Ethics, privacy, and data protection

Agata Bochynska and Elin Stangeland, Open Research, University of Oslo Library
Lars Soligard, USIT



Materials developed as part of the *Skills development for research data* project:

<https://www.ub.uio.no/english/about/projects/rdm-skills/>

Today's course

60-minute lecture

30-minute Q&A session

Please feel free to write comments and questions in the Chat!

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TYPE IN: 6542 7000

Research ethics

Research ethics

- Research ethics is an important **foundation for good research practice**. Anyone who conducts research at UiO is required to be aware of ethical aspects of research.
- The term research ethics refers to a **wide variety of values, norms, and institutional arrangements** that help constitute and regulate scientific activities.
- Research ethics is a codification of **scientific morality** in practice.
- Guidelines for research ethics specify the basic norms and values of the research community.

Rettskilder

Lov om organisering av forskningsetisk



Innholdsfortegnelse ▾



Lovens forskrifter



§ Lover



Stortingsvedtak



⚠ Sentrale forskrifter



§ Lokale forskrifter

🇳🇴 Norsk Lovtidend

🌐 EØS-avtalen



🌐 Norges traktater



Dommer



🤝 Tariffavtaler

➔ [Gå til opprinnelig kunngjort versjon](#)

Lov om organisering av forskningsetisk arbeid (forskningsetikkloven)

Dato	LOV-2017-04-28-23
Departement	Kunnskapsdepartementet
Ikrafttredelse	01.05.2017
Endrer	LOV-2006-06-30-56
Kunngjort	28.04.2017
Korttittel	Forskningsetikkloven

Jf. tidligere lov 30 juni 2006 nr. 56.

Ethics principles

- **Respect.** People who participate in research, as informants or otherwise, shall be treated with respect.
- **Good consequences.** Researchers shall seek to ensure that their activities produce good consequences and that any adverse consequences are within the limits of acceptability.
- **Fairness.** All research projects shall be designed and implemented fairly.
- **Integrity.** Researchers shall comply with recognized norms and to behave responsibly, openly and honestly towards their colleagues and the public

14 guidelines for research ethics

1. Quest for truth
2. Academic freedom
3. Quality
4. Voluntary informed consent
5. Confidentiality
6. Impartiality
7. Integrity
8. Good reference practice
9. Collegiality
10. Institutional responsibility
11. Availability of results
12. Social responsibility
13. Global responsibility
14. Laws and regulations

Guidelines

Medical and health research

Science and technology

Social Sciences, Humanities, Law and Theology

General guidelines

A Guide to Internet Research Ethics

Published: 8/6/2019

Issued by the The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH) in 2003. Second edition published in Norwegian in 2018 and in English May 2019.

For employees

 All content[Work support](#)[Research support](#)[Contracts](#)[Forskpro](#)[Funding](#)[Innovation](#)

Research ethics

[Norwegian](#)[See also](#)

UiO maintains a strong focus on research ethics, and has prepared a special plan of action for preventing academic dishonesty.

[Quality assurance system for health research](#)

(procedures and templates)

Responsibilities

The university is responsible for ensuring that research proceeds in compliance with the regulatory framework laid down in the Act relating to universities and colleges, the Public Administration Act, and the conditions stipulated by external funding sources. Deans and the heads of institutes shall maintain constant vigilance to ensure that the

Research Ethics Committee at the University of Oslo

The Research Ethics Committee at the University of Oslo (UiO) is the University's advisory body on research ethics.

The Research Ethics Committee may, on its own initiative, express opinions on research ethics. It also handles individual cases where there is a claim of possible violations of recognised research ethics norms at UiO.



The Science Ombud at UiO



The Science Ombud is an independent and impartial authority for all academic staff at the University of Oslo, for issues and disputes concerning good scientific practice, research integrity and research ethics.

Ethical self-assessment

Regardless whether there is a formal requirement, we recommend you to perform an ethical self-assessment. The type of questions which are generally to be answered in an ethical review is shown in the illustration below. These questions are derived from the [Ethical guidelines for research](#) by the Norwegian National Research Ethics Committees (n.d.)



Question 1: The project's aim and method

Could the project's aims and methods come into conflict with commonly recognised values? Could carrying out the project involve risk of injury to people, animals, or nature to an extent that should not be neglected? If so, are the persons involved aware of the risk?

Privacy and data protection

The principles of privacy and data protection

1. Legality
2. Fairness
3. Openness
4. Purpose limitation
5. Data minimisation
6. Accuracy
7. Storage limitation
8. Integrity
9. Confidentiality
10. Responsibility



Data controller & Data protection officer

Data controller - is the person, business, or institution which alone, or with others, decides the goal of the processing and what means are used to achieve the goal.

For any research taking place at the University of Oslo – the University is the data controller.

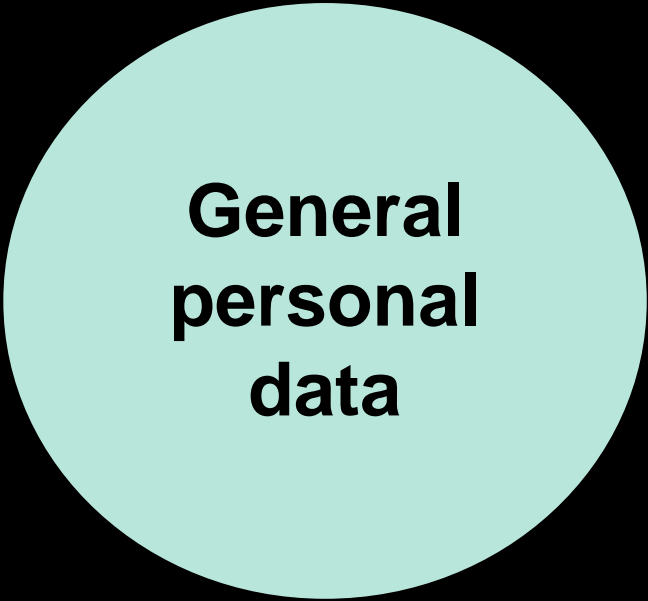
Data protection officer – safeguards the personal privacy interests of UiO employees, students, guest researchers, guests and respondents or informants in research projects.

What is personal data?

Any piece of information about an identified or identifiable physical person.

In other words, any data about living people from which they can be identified.

What is personal data?



**General
personal
data**



**Special
categories of
personal data
(sensitive
data)**

What constitutes as general personal data?

- Name, address, age, phone number, e-mail and Norwegian national identity number
- Content of exam papers or grades
- Content of case documents, investigations or considerations
- Contents of email communication
- Video- and audio recordings where individuals are recognizable
- Identifying images of individuals
- Logging of activity in computer systems where the logs can be associated with individuals, for example when registering who is logged in to a computer system at any given time

Special categories of personal data (sensitive data)



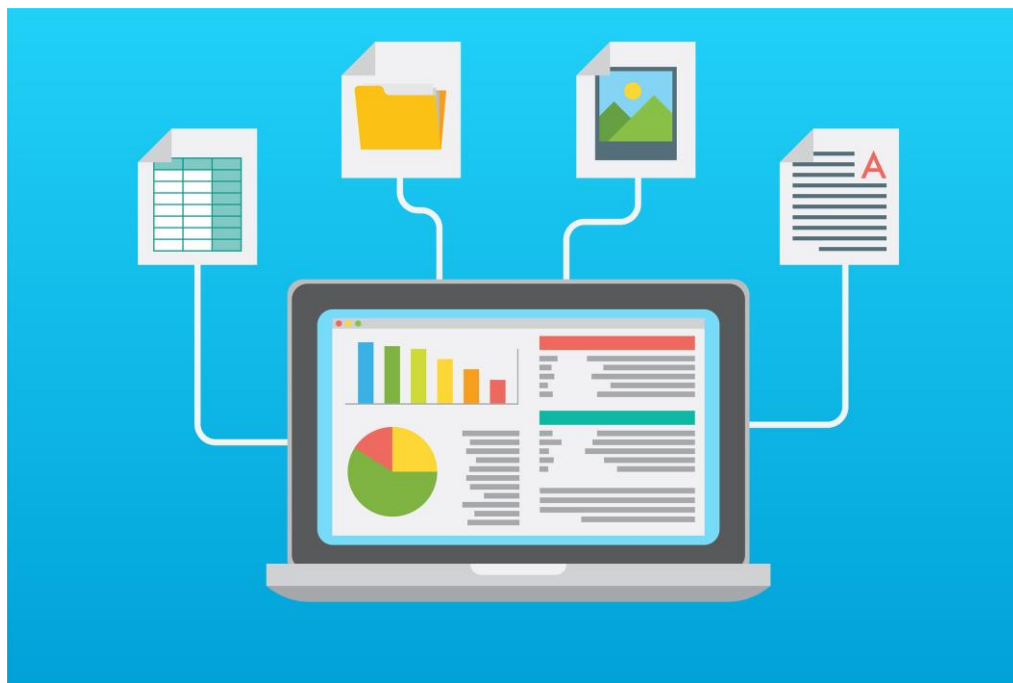
- health information and health related conditions
- genetic or biometric information which can be used to identify a physical person
- ethnic or racial origin
- political, philosophical or religious perceptions and beliefs
- sexual orientation or sexual relationships
- trade-union membership

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What is considered processing of personal data?

- Collection
- Registration
- Storage
- Compilation
- Use
- Transfer
- Publication
- Erasure



De-identified and anonymous data?

De-identified data means that information used for identification have been replaced by a code with an associated key. De-identified data are seen as personal data. If you delete the associated key, de-identified data can be anonymous.



Anonymous data means that NO ONE can identify persons in a dataset. Anonymous data are not seen as personal data. Data can in some cases be anonymised by deleting any information that contributes towards identification.

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Direct and indirect identifiers

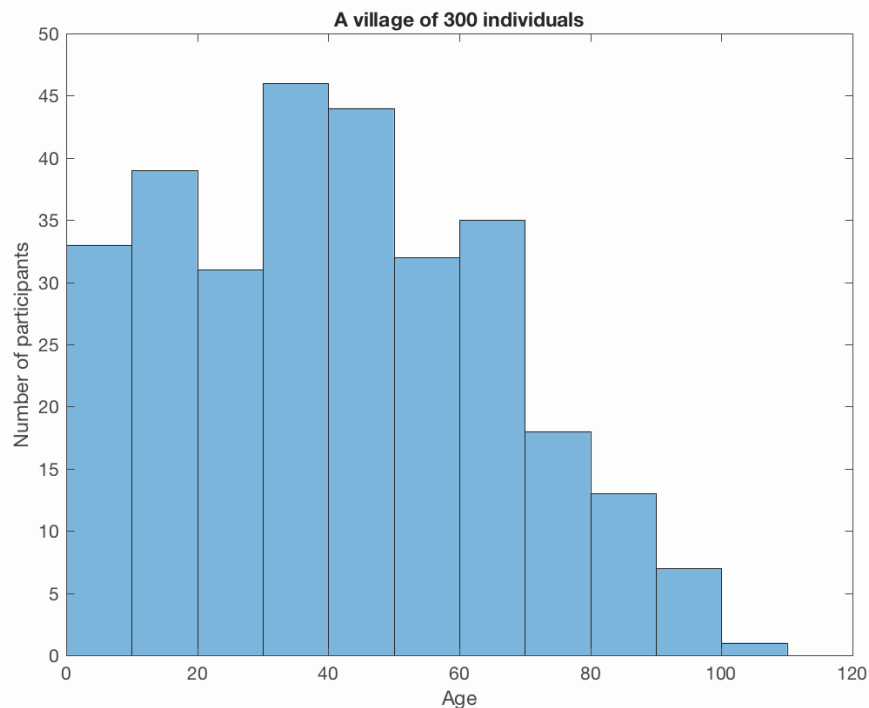
A direct identifier is information that is sufficient on its own to identify an individual.

e.g. a person's name, personal identification number, a facial image, brain scan images, fingerprints

An indirect identifier is information that might fairly easy identify an individual or lead to identification when linked with other available information.

e.g. location data, online identifiers, unusual job title, a position held only by one person at a time, age, education, ethnic background

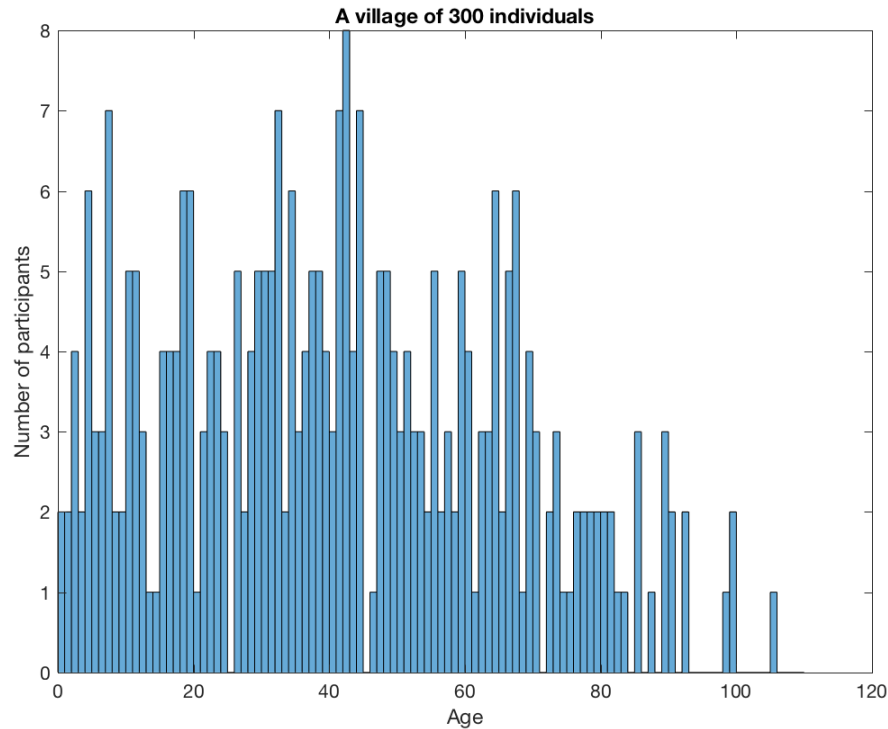
Indirect identification: a small village of 300 people



People counted together based on their “decade” age

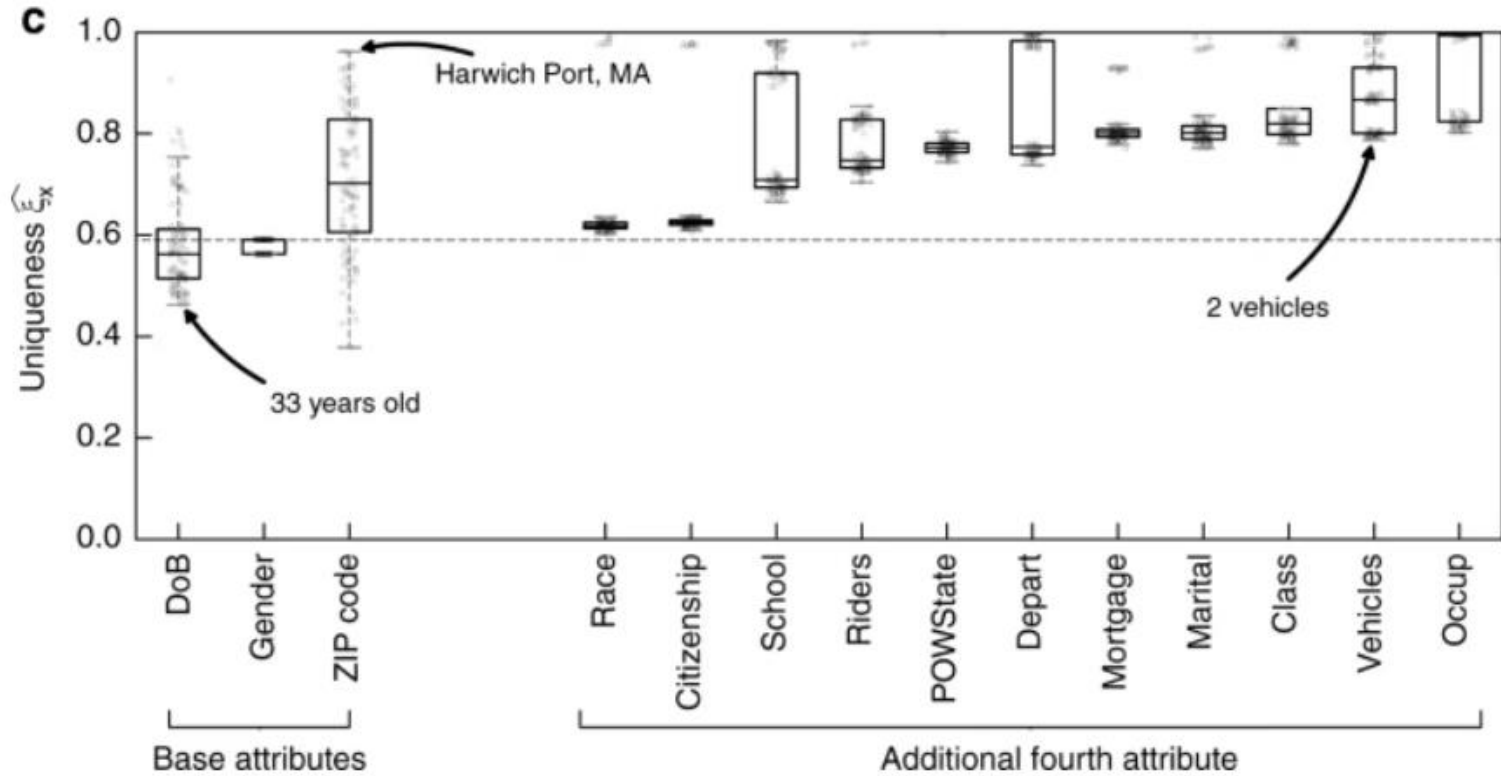
We can single out one very old individual which most likely everybody in the village knows

Indirect identification: a small village of 300 people



People counted together based on their age as integer year

We can single out more than one individual



Intention to issue € 10 million fine to Grindr LLC

The Norwegian Data Protection Authority has notified Grindr LLC (Grindr) that we intend to issue an administrative fine of NOK 100 000 000 for not complying with the GDPR rules on consent.



Intention to issue € 10 million fine to Grindr LLC

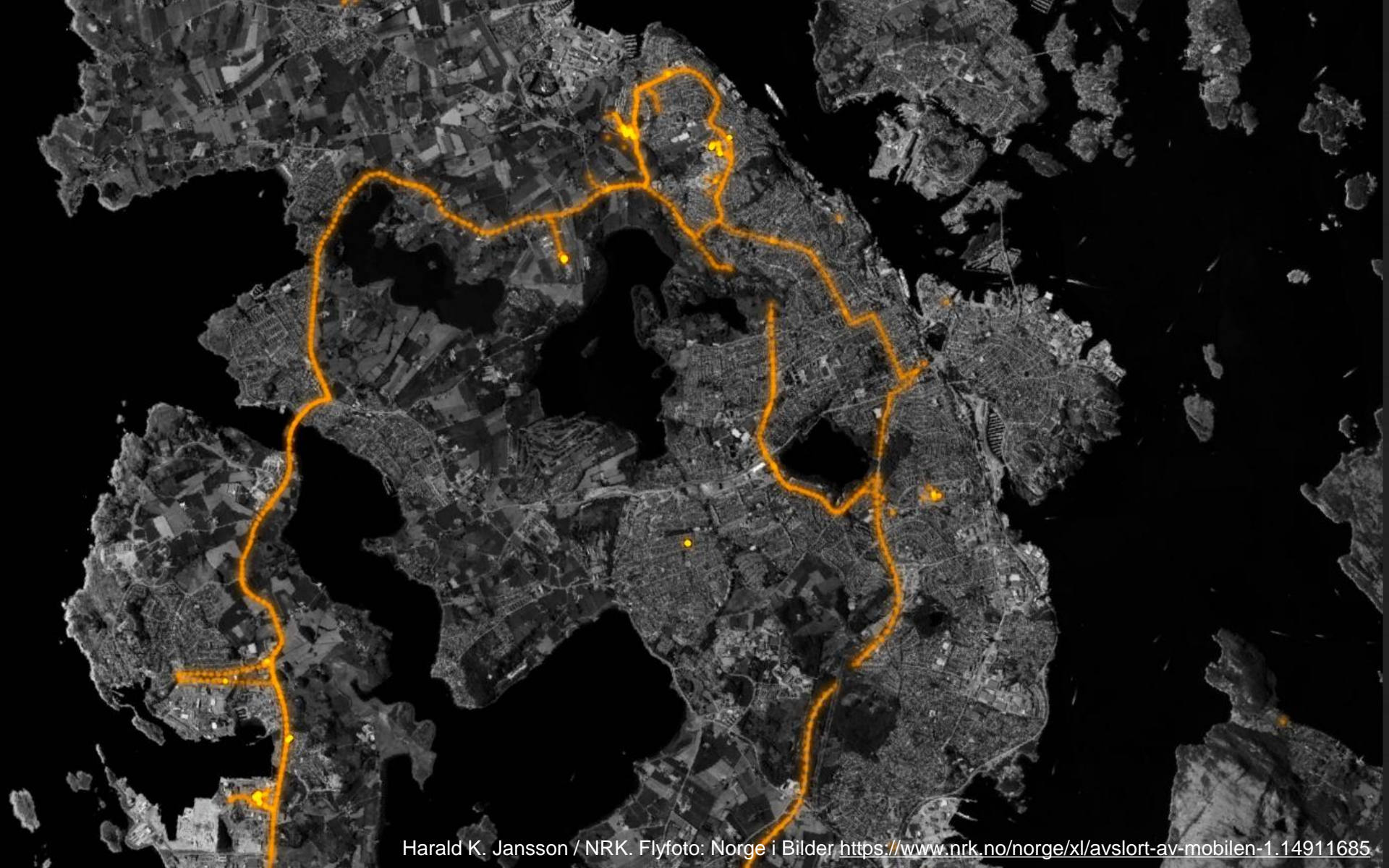
The Norwegian Data Protection Authority has notified Grindr LLC (Grindr) that we intend to issue an administrative fine of NOK 100 000 000 for not complying with the GDPR rules on consent.



Our preliminary conclusion is that Grindr has shared user data to **a number of third parties** without legal basis. (...)

Grindr is a location-based social networking app for gay, bi, trans, and queer people. (...) **The data shared include GPS location, user profile data, and the fact that the user in question is on Grindr.**

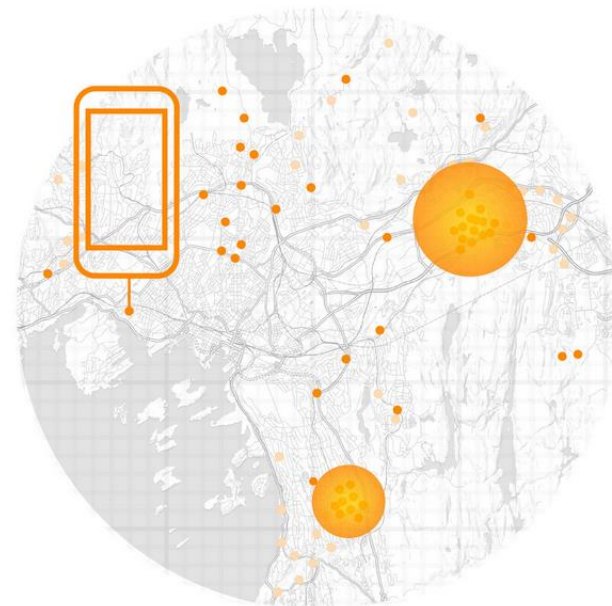
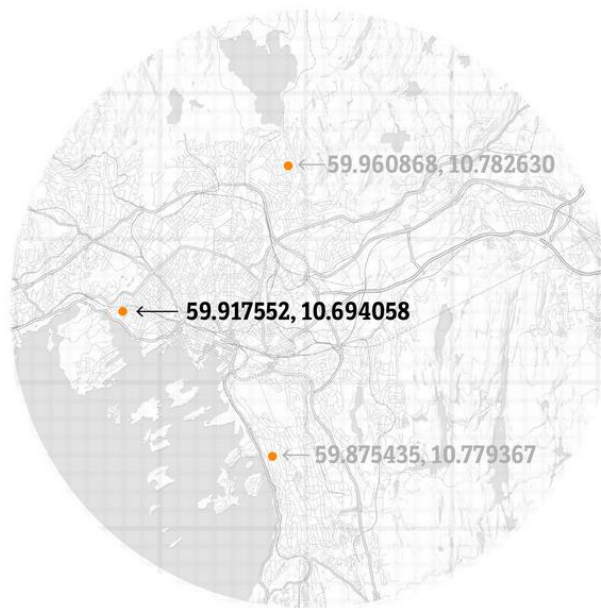
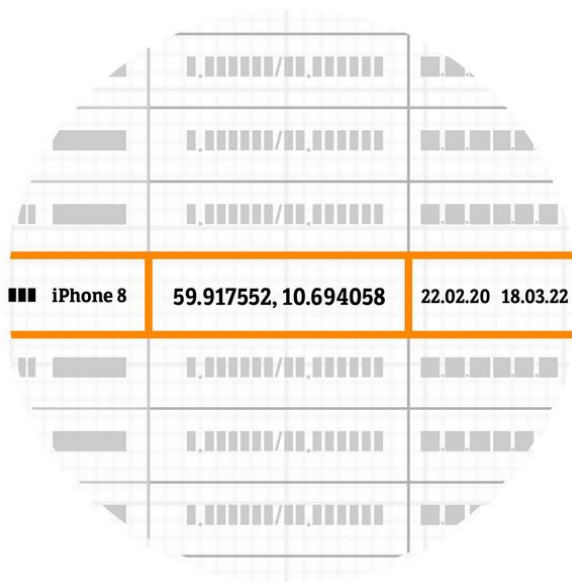
Our preliminary conclusion is that Grindr needs consent to share these personal data and that Grindr's consents were not valid. Additionally, we believe that **the fact that someone is a Grindr user speaks to their sexual orientation, and therefore this constitutes special category data that merit particular protection.**



Avslørt av mobilen

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Anonymisation: how to

- Delete all directly identifiable data (such as names/lists of reference numbers/scrambling key)
- Delete, rewrite, or categorize (group together) indirectly identifiable data (i.e. background variables such as residence/workplace/school, age, and gender)
- Delete (or edit) photos and audio or video records
- If you use an external data processor, the data processor must also delete all personal information connected to the project which they possess.

Identifier type	Direct identifier	Strong indirect identifier	Indirect identifier	Anonymisation method
Personal identification number	x			Remove
Full name	x			Remove/Change
Email address	x	x		Remove
Phone number		x		Remove
Postal code			x	Remove/Categorise
District/part of town			x	Categorise
Municipality of residence			x	Categorise
Region			x	(Categorise)
Major region			x	
Municipality type			x	
Audio file	x			Remove
Video file displaying person(s)	x			Remove
Photograph of person(s)	x			Remove
Year of birth		x		Categorise
Age			x	Categorise
Gender			x	
Marital status			x	

How to anonymise direct and indirect identifiers?

When anonymisation is not possible...



TOOLS AND RESOURCES



A synthetic dataset primer for the biobehavioural sciences to promote reproducibility and hypothesis generation

Daniel S Quintana*

Norwegian Centre for Mental Disorders Research (NORMENT), Division of Mental Health and Addiction, University of Oslo, and Oslo University Hospital, Oslo, Norway

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[NSD](#) / [Data protection services](#) / Notification Form for personal data

Notification Form for personal data

On this page you will find useful information about NSD's notification form. You can read about what personal data is, who should send in a notification form, and what you need to have ready in advance.

NSD's notification form is a digital form that you as a researcher or student fill in when you are going to process personal data in a research project. We at NSD then carry out an assessment of the processing you have planned.


We help you find solutions that fit your project and ensure that the planned processing is in accordance with data protection legislation.

By filling out the notification form your institution will also have an overview of the processing, something it is legally required to have.

Which personal data will be processed?

[What are personal data?](#)

[What is processing?](#)

Name (also with signature/written consent) 

Yes	No
-----	----

National ID number or other personal identification number 


Yes	No
-----	----

Date of birth


Yes	No
-----	----

Address or telephone number

Yes	No
-----	----

Email address, IP address or other online identifier 

Yes	No
-----	----

Photographs or video recordings of people 

Yes	No
-----	----

Sound recordings of people 

Yes	No
-----	----



Chat with us on
weekdays from 12-14

Personal data

Type of data

Project information

Data controller

Samples and details

+ Add sample

Third Persons

Documentation

Approvals

Processing

Information security

Duration of processing

Additional information

Send in

Will you be processing special categories of personal data or personal data relating to criminal convictions and offences?

Racial or ethnic origin ?

Yes No

Political opinions ?

Yes No

Religious beliefs ?

Yes No

Philosophical beliefs ?

Yes No

Trade Union Membership ?

Yes No

Health data ?

Yes No

Sex life or sexual orientation ?

Yes No



Chat with us on weekdays from 12-14

Consent

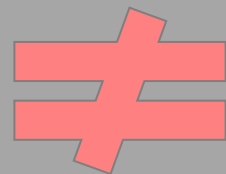


For a consent to be valid and work as a basis for processing, it must be:

- Voluntary
- Specific
- Informed
- Unequivocal
- Given actively
- Documentable
- Possible to withdraw as easily as it was given

If you wish to use the data for a new/different purpose, a new consent must be obtained from the data subject.

**Consent to
participate**



**Consent to
reuse data**

I have received and understood information about the project [*insert project title*] and have been given the opportunity to ask questions. I give consent:

- to participate in (*insert method, e.g. an interview*)
- to participate in (*insert other methods, e.g. an online survey*) – if applicable
- for my/my child's teacher to give information about me/my child to this project (*include the type of information*)– if applicable
- for my personal data to be processed outside the EU – if applicable
- for information about me/myself to be published in a way that I can be recognised (*describe in more detail*)– if applicable
- for my personal data to be stored after the end of the project for (*insert purpose of storage e.g. follow-up studies*) – if applicable

I give consent for my personal data to be processed until the end date of the project, approx. [*insert date*]

(Signed by participant, date)

Consent in TSD

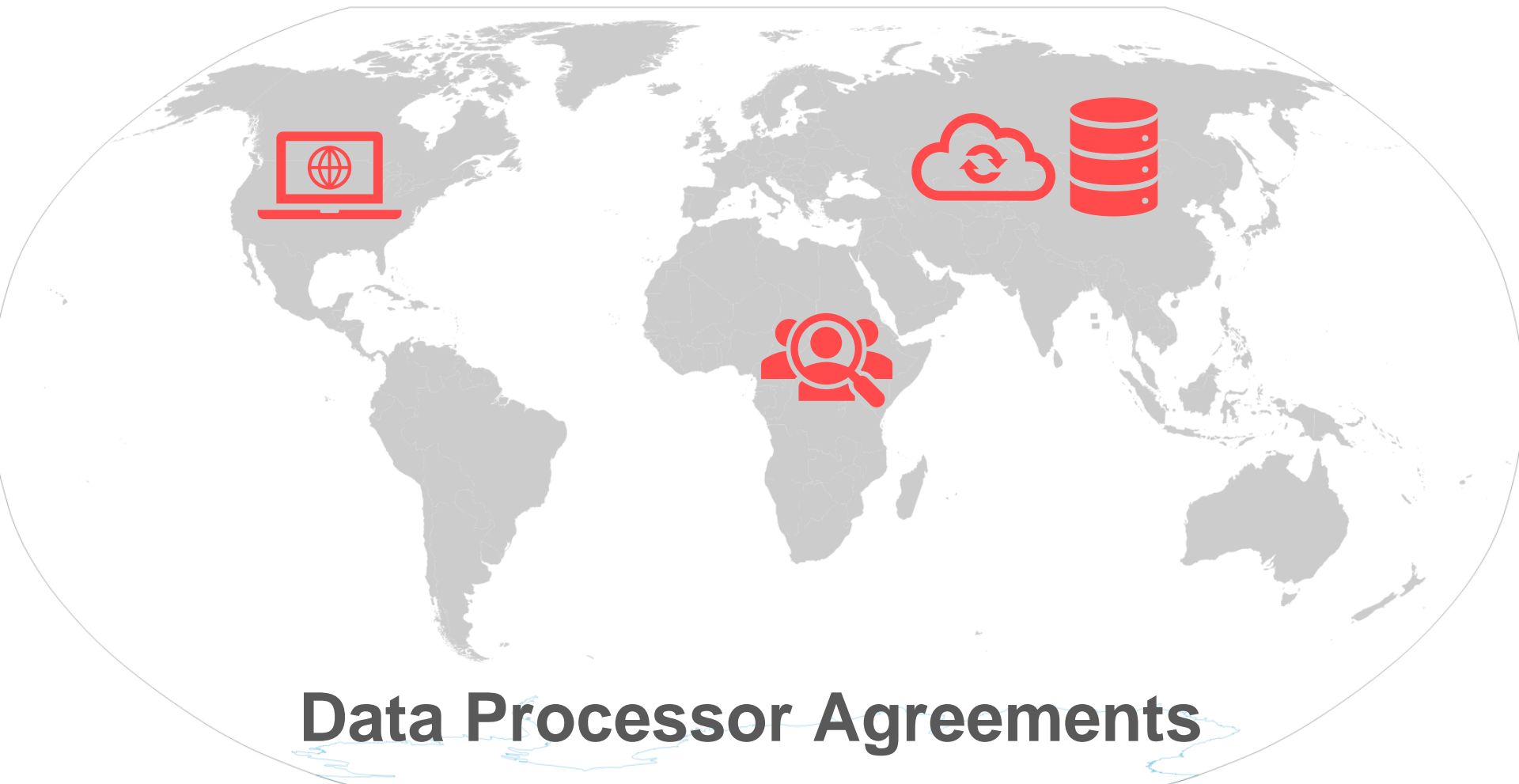
TSD = UiOs service for sensitive data

If you use digital consenting in TSD:

- Makes it easier to manage consents
- And for research contributors to log in and remove consent
- Data is captured via the nettskjema.no tool or it can be imported

Information can be found on the TSD web pages:

<https://www.uio.no/english/services/it/research/sensitive-data/use-tsd/datacollection/nettskjema/consent/consent.md>



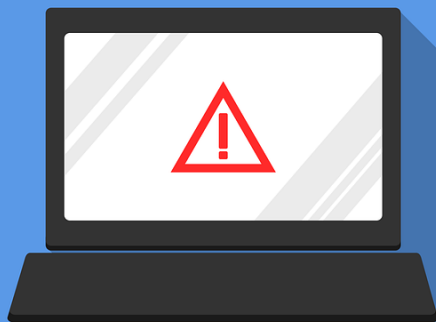
Data Processor Agreements

Data Processor Agreements

- The subject and duration of the processing
- The nature and purpose of the processing
- The type of personal data and categories of the registered
- The rights and duties of the data controller
- What the data processors can do with personal data for which UiO is the data controller
- How personal data is safeguarded against unauthorised access, alteration, erasure, loss or damage



Data Protection Impact Assessment (DPIA)



- A DPIA is needed in situations when the processing involves **high risks for people's rights and liberties**
- The assessment takes place **before** the research can start
- Involves an **extensive review** of the planned data processing, and its potential privacy protection consequences
- For projects that you notify NSD about, the DPIA will be conducted by NSD

Responsibilities



The University

ensuring that research proceeds in compliance with the regulatory framework



Heads of departments

maintain constant vigilance to ensure that the regulations are complied with



Researchers

ensuring that research proceeds in accordance with good research practice and recognized ethical principles

What is the researchers responsibility?

Project managers are responsible for the privacy of the participants when their personal data are to be processed. They must:

- determine and maintain an overview of what types of personal data shall be processed in the research project
- prepare a consent form and information about rights to be presented to respondents or informants
- Notify the project to NSD
- If needed, enter data processor agreements with external information or service providers
- Ensure that appropriate technical solutions for collection, storage, transmission and analysis are utilised.
- Ensure that project staff are trained in securely processing of personal research data



Do you need help, or are uncertain about something? Have you made an error? Fear not! The Data Protection Officer can help!



For employees

Search in For employees

Search

☰ All content

< [Work support](#)

Privacy and data protection

[Norwegian](#)

What role do you have?

- [I am writing my bachelor's/master thesis](#)
- [I am a manager/case handler](#)
- [I am a system owner](#)
- [I am a researcher](#)
- [I am a student supervisor](#)

Contact

Find out who to contact if you need help.

[→ Contact information](#)

Thank you!

Questions?

Email research data experts at:
research-data@uio.no

Read about research data laws and regulations:
[Laws and regulations - For employees - University of Oslo \(uio.no\)](#)



Final course modules this week!

- Sharing and Archiving Research Data
20/05 9:00-10:30
- Data Discovery
21/05 9:00-10:30

Sign up here: <https://www.ub.uio.no/english/courses-events/courses/other/research-data/>

Sources

NSD Data Protection services: <https://nsd.no/personvernombud/en/index.html>

University of Oslo. Privacy and data protection. <https://www.uio.no/english/for-employees/support/privacy-dataprotection/>

Routines for processing personal data in research projects:
<https://www.uio.no/english/for-employees/support/privacy-dataprotection/personal-data-in-research.html>

TSD consent portal. <https://www.uio.no/english/services/it/research/sensitive-data/use-tsd/datacollection/nettskjema/consent/consent.md>

Quality assurance system for health and medical research:
<https://www.uio.no/english/for-employees/support/research/quality-system-for-health-research/>