GDPR for researchers

Making your data management GDPR proof

Emilie Kraaikamp - Legal Support Officer| DANS

June 14, 2021

Introduction and session outline

- Learning goals

  - How to make your research data management GDPR proof?

  - What needs to be covered in your DMP?

- Session outline

  - Warming up (Mentimeter)

  - GDPR beginners guide for researchers

  - Practical part: Before, during and after research

  - Sharing experiences (Mentimeter)

  - Q&A session afterwards

ODISSEI

cessda

Data Archiving and Networked Services
DANS

Which words come to mind when you think of the GDPR?

- Go to www.menti.com

- Fill in mentimeter code

GDPR beginners guide for researchers

GDPR beginners guide for researchers

- What does the GDPR regulate?

- When do your research data fall under the GDPR?

- What do you need to collect personal data?

- How do you process personal data?

- What are the rights of data subjects?

ODISSEI

cessda

Data Archiving and Networked Services
DANS

What does the GDPR regulate?

- Protection of personal data

- Rights and obligations regarding data subjects, controllers and processers

- The GDPR has implications for research

When do your research data fall under the GDPR?

- When you collect *personal* data your research falls under the GDPR

- Personal data: *Personal data are any information which are related to an* **identified** *or* **identifiable natural person**.

- *Special categories of personal data* (sensitive personal data): stricter rules apply

Special categories of personal data

Religious & philisophical belief

Trade Union membership

Biometric data

Genetic data

Data related to sexual orientation or sex life

Racial or ethnic origin

Health data

Political stand

ODISSEI

cessda

Data Archiving and Networked Services
DANS

What do you need to collect personal data?

- A legal basis is required in order to process personal data under the GDPR (lawfulness)

Consent
Individual has provided genuine, informed, explicit consent to processing of personal data.

Contract
A company can process personal data to fulfil a contractual obligation.

Legal Obligation
If you need to process the personal data to comply with common law or statutory obligation.

Vital Interests
A company can process the personal data to protect someone's life.

Public Task
Processing of personal information by organizations that exercise official authority or serves public interest.

Legitimate Interests
The most flexible lawful ground for processing personal information.

ODISSEI

cessda

Data Archiving and Networked Services
DANS

What are the rights of data subjects?

- Data subjects need to be informed about how their personal data are processed (transparency). This also applies when you reuse data.

- Data subjects have the right to withhold and withdraw consent, during and after research

➢ Practical overview:
https://www.tilburguniversity.edu/about/conduct-and-integrity/privacy-and-security/research-data/respondents

ODISSEI

cessda

Data Archiving and Networked Services
DANS

How do you process personal data?

- Data processing needs to be in line with the *seven principles* of the GDPR

Lawfulness, fairness and transparency

Purpose limitation

Data minimisation

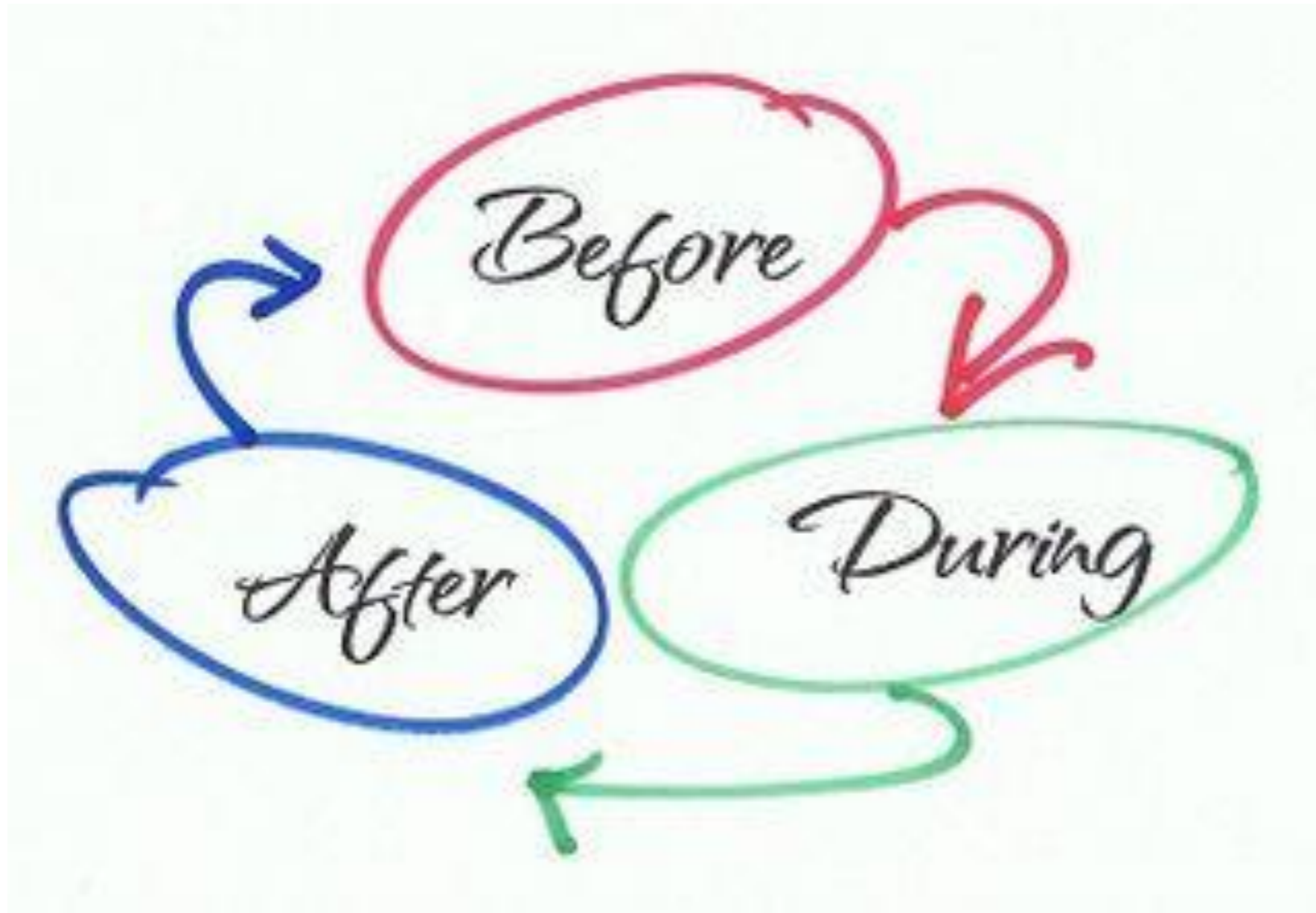
Accuracy

Storage limitation

Integrity and confidentiality (security)

Accountability

ODISSEI

cessda

Data Archiving and Networked Services
DANS

GDPR and research practice

Before research: how to start my research GDPR proof?

First step: Do you use personal data?

A fictional research:

Research question: *What are the trends in banana consumption amongst 20 to 30 year olds?*

Method: Randomly survey, passer-by's in the street

With what proposed research set up? => => =>

ODISSEI

cessda

Data Archiving and Networked Services
DANS

Is this personal data?

Questions research set up 1:

- 1 What is your age?

- 2. How many banana's do you eat per week?

- 3. In what town do you live?

Is this personal data?

Questions research set up 2:

- 1 What is your age ?

- 2. How many banana's do you eat per week?

- 3. In what town do you live?

- 4. What is your profession?

ODISSEI

cessda

Data Archiving and Networked Services
DANS

Is this personal data?

Questions research set up 3:

- 1 What is your age ?

- 2. How many banana's do you eat per week?

- 3. In what town do you live?

- 4. What is your profession?

- 5. What is your political affiliation?

- 6. What is your address?

Yes, personal data

Next steps: Deciding on your research set up and data protection. Your plan.

Conducting *Data protection impact assessment* (DPIA)
- DPIA is an instrument to analyse, identify and minimise the data protection risks: elaborate screening of intended plan
- For research with a "high" privacy risk
- Generally for special categories of personal data and children's data
- Similar research may be excluded
- Related: ethical review. This has a wider focus than the GDPR.

Consulting a privacy officer or DPO

Before research: how to start my research GDPR proof?

How will you handle your data
- Anonymisation: excluding data, using categories (i.e. age 20-30)
- Pseudonymisation: deidentifies, reversible
- Encryption: protection method, key management
- Storage: access control
- Organisational and technical measures in place
- Including for collaboration

Will others (processors) handle your data
- Platforms, tools etc.
- Processing agreement

Data minimisation

ODISSEI

cessda

Data Archiving and Networked Services
DANS

Before research: how to start my research GDPR proof?

Are you archiving or sharing your data

- What data do you archive or share
- Reuse: generally for (a specific) research (domain) only

Set up informed consent

- Inform participants adequately about your research, including how you will handle the data, and inform about archiving and sharing plans

- Outline their right to withdraw from the research.

➢ [Data Management Expert Guide: Protect – Informed consent](#)
➢ DARIAH ELDAH consent form Wizard: https://consent.dariah.eu/

Before research: how to start my research GDPR proof?

Writing your DMP: include the essentials of GDPR proof data management

- What is your legal basis?

- Are you transparent?

- How do you handle your data?

- What happens after your research?

During research: how to keep my research GDPR proof?

- **Stick to your plan!**

- **Be sure to:**

  - Follow what was agreed in the informed consent

  - Be critical regarding processors (properly contracted?)

  - Choose file and folder names cautiously (visibility vs access control)

  - Applying appropriate safety measures when sharing (giving access, sending data etc) data (what is safe to use? What policies apply here?)

  - Do a good data clean up whenever possible (Do you, or others, process only that what is needed? No discarded versions, no hidden data? No unintended answers to open questions)

  - Act in line with the rights of data subjects

After research: how to take care of your research data?

- Archiving & publishing
  - Options are based on informed consent
  - Possibility: a "restricted" version (not anonymous) and "open" version (anonymous)
  - Any anonymous data can be openly published (anonymised files, scripts etc). NOT pseudonymised data.

- Fulfil your responsibilities
  - To manage reuse conditions (most likely when archived)
  - To keep any data properly safeguarded (still properly protected at your institution? At a processor?)
  - To act in line with the rights of data subjects

ODISSEI

cessda

Data Archiving and Networked Services
DANS

Sharing experiences

What issues did you encounter in your own research? Or what was challenging?

- Go to www.menti.com

- Fill in mentimeter code

Wrap up

- Recap on learning goals:

  - **How to make your research data management GDPR proof?**

    - Process personal data only with a legal basis

    - Be transparent about how you process your data

    - Ensure protection of your data, wherever stored, minimise where you can and share under the right conditions

    - Act in line with the rights of data subjects

  - **What needs to be covered in your DMP?**

    - The essentials of GDPR proof data management

    - How you will process and protect personal data during and after your research GDPR proof

    ➢ Data Management Expert Guide: for more information and examples

Thank you for your attention!

emilie.kraaikamp@dans.knaw.nl