

# Data Bites

## Privacy and Ethics

### in Research

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30/04/2026

Please note that this webinar will be recorded. The presentation part of the webinar (excluding the Q&A and open discussion parts) will be made available on Zenodo. In case you would like to ask a question during the presentation without having your voice recorded, please use the chat to type your question. Thank you!



### DATA ARCHIVING

All research data related to a published peer-reviewed article is archived in a curated data package for 10 years (15 years for medical data).



### DATA MANAGEMENT PLAN

A Data Management Plan (DMP) is created and regularly updated for all research projects.



# TU/e RDM policy

BEST PRACTICES

### FAIR DATA

Final research data must follow the FAIR (Findable, Accessible, Interoperable, Reusable) principles and when possible, published in a data repository.



### ETHICAL APPROVAL

Research (in)directly involving human participants requires approval from the ethical review board.



### LAWFUL DATA USE

All research data are obtained and used in a lawful manner.



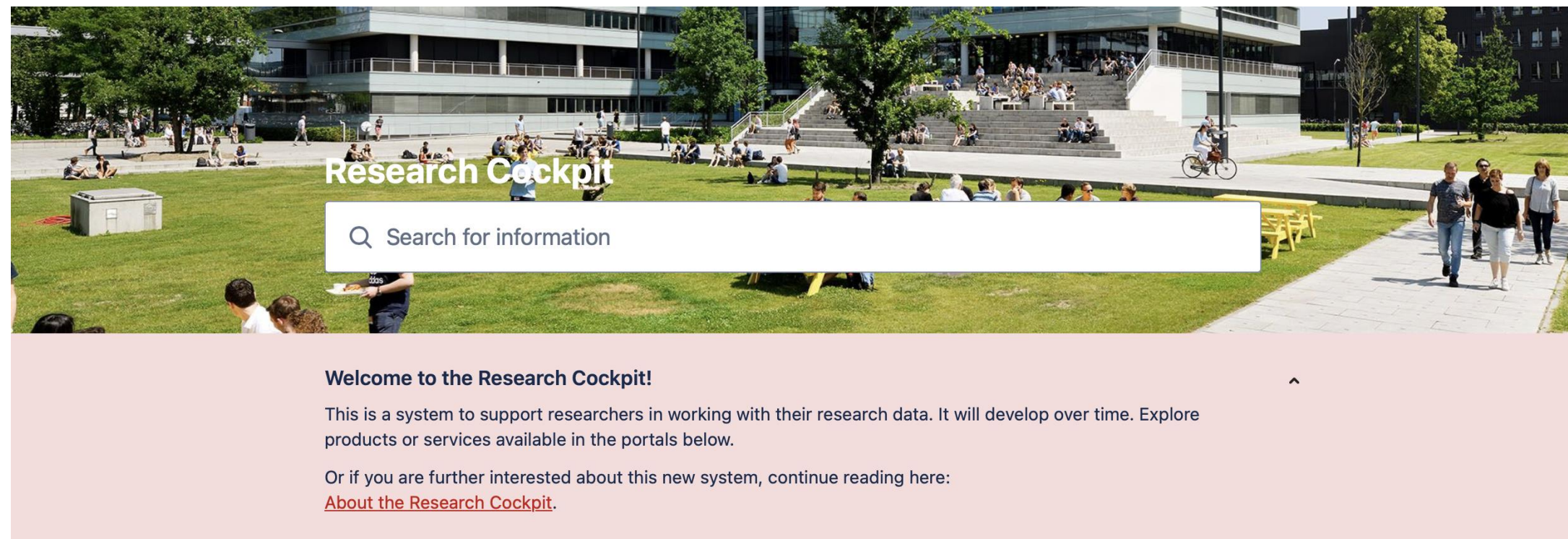
### STORAGE

All research data processed at TU/e are stored in TU/e-supported storage solution (exceptions may apply).





# Take Control: Research Cockpit



## RDM Policy: for BSc, MSc, & EngD

DMP & ERB is required for research projects that includes data from humans



## Why would I need it?

For educational purposes  
(thesis, internship projects)



## Any advantages?

Timely guidance from your department's Data Steward



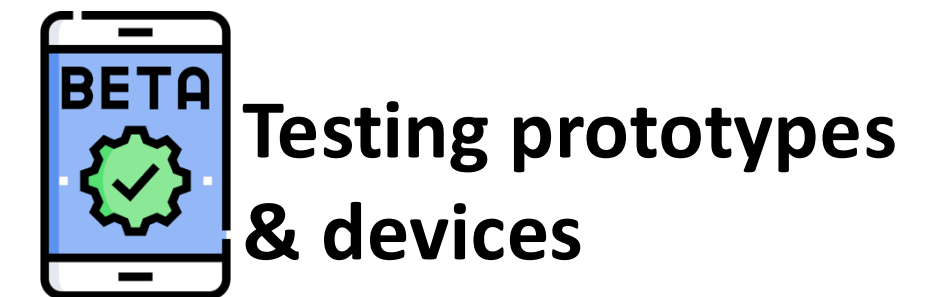
# Why bother about Ethics & Privacy?



**Do you have  
Human Participants?**

- TU/e Regulations – RDM Framework Policy
- Scientific Code of Conduct for Research Integrity
- Funders and publishers' requirements
- Law – GDPR (AVG)

# Examples of Research with Human Participants



5



# What is Personal Data?



*“Any information relating to an identified or identifiable natural person”*

## REGULAR

### Identifying



### Education



### Location



### Physical Characteristics



## SPECIAL

### Health Data



### Biometrics



### Gender Identity



### Beliefs



# GDPR Principles in Short

1 Lawfulness, fairness,  
& transparency

2 Accuracy

3 Integrity &  
confidentiality

4 Purpose limitation

5 Data minimization

6 Storage limitation

7 Accountability



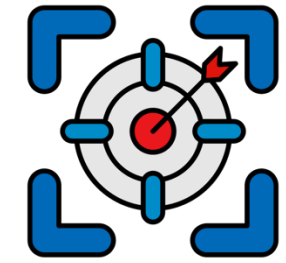
Regulatory  
Compliance



Informed  
Consent



Safeguard &  
Security



Scope  
Limitation



Control &  
Responsibility



Anonymization/  
Pseudonymization



Data at  
Minimum



Data  
Retention

*What does it mean for you?*

# De-identification Techniques



## Anonymization

- ✓ Permanent deletion of information to make re-identification impossible

e.g., Public data sharing in articles or in repositories, esp with sensitive dataset



## Pseudonymization

- ✓ Replacing or altering information with artificial identifiers

e.g., Longitudinal studies that needs multiple contact with participants

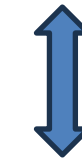




# High-Risk Research Activities

- Studies with vulnerable subjects
- Large (geographical) scale studies <10,000
- Innovative use of new technology
- Systematic monitoring of persons
- Subjects cannot exercise rights
- Scoring, ranking, or profiling
- Blacklist activities
- Automated decision making
- Linking or combining datasets

**Pre-DPIA check**  
*Research Cockpit*



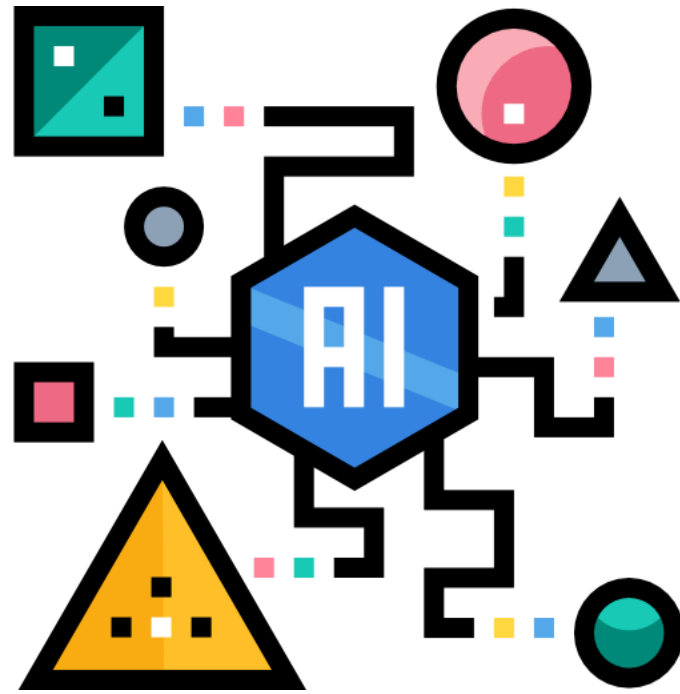
## Data Protection Impact Assessment

When processing of personal data poses a high risk to the rights and freedoms of the subjects

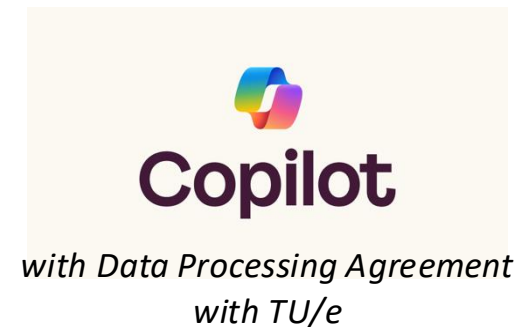
- ✓ Description of the processing activities
- ✓ Security & legal assessments
- ✓ Necessity and proportionality
- ✓ Mitigation measures



# Research/Education with AI



By default, must be used locally



*\*\*These solutions are not yet vetted by TU/e in general*



# A walk through the Ethics Review Process



Mandatory for research involving  
**HUMAN PARTICIPANTS**

- ✓ Protects the subjects from harm
- ✓ Aims for minimal risk
- ✓ Address & mitigate ethical issues
- ✓ Ask support for advice

## Integrated in the Research Cockpit



Create your DMP (data management plan)



Data stewards reviews for  
RDM, privacy, & ethical red flags



Prepare ERB application



Attach all relevant research documents  
(ICF, protocol, sample stimulus)



Ethics review & decision



Healthy adults  
(non-medical research)

Voluntary  
(no pressure or coercion)

Anonymous or only regular  
data

Not burdensome

No harm or discomfort

No compensation

Covert observation only in  
public space

No sensitive topics

Non-invasive procedure

CE/non-CE certified device  
for un/intended with 18V

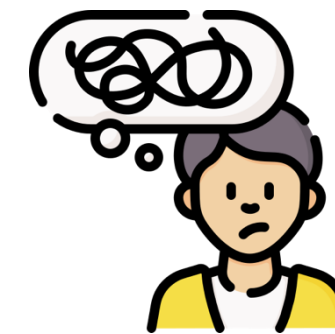


Checklist for a  
*Minimal Risk Study*

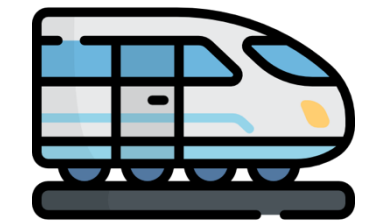
# Informed Consent Forms

- What are expected of their participation
- How their data will be used and processed
- Who can access their data
- How their confidentiality is kept
- Where and how long will it be stored
- Their rights to withdraw their data
- Explicit consent for specific purposes (e.g., quoting)

## Special Cases



Personal limitations



Time constraints



Settings constraints



# Some functional RC tips:

## How to generate an extra ERB



Notifications on



Duplicate DMP



**Reuse DMP for other projects**



Update my DMP



**Update if changes occur**

**New  
ERB**



# Some functional RC tips: How to amend your ERB

## Activity

All

Comments

History

Work log

Approvals

 Summarize 2 comments



[Add internal note](#) / [Reply to customer](#)



Pro tip: press **M** to comment



Jonathan Gerona April 30, 2026 at 11:38 AM

Dear @Maartje Mulder ,

I would like to make the following amendments in this approved ERB:

- Add another session of user testing for the design protocol developed during the co-creation session
- Revise the existing consent form to accommodate the new research activity I want to add
- Increase the target subjects from 10 to 20 participants

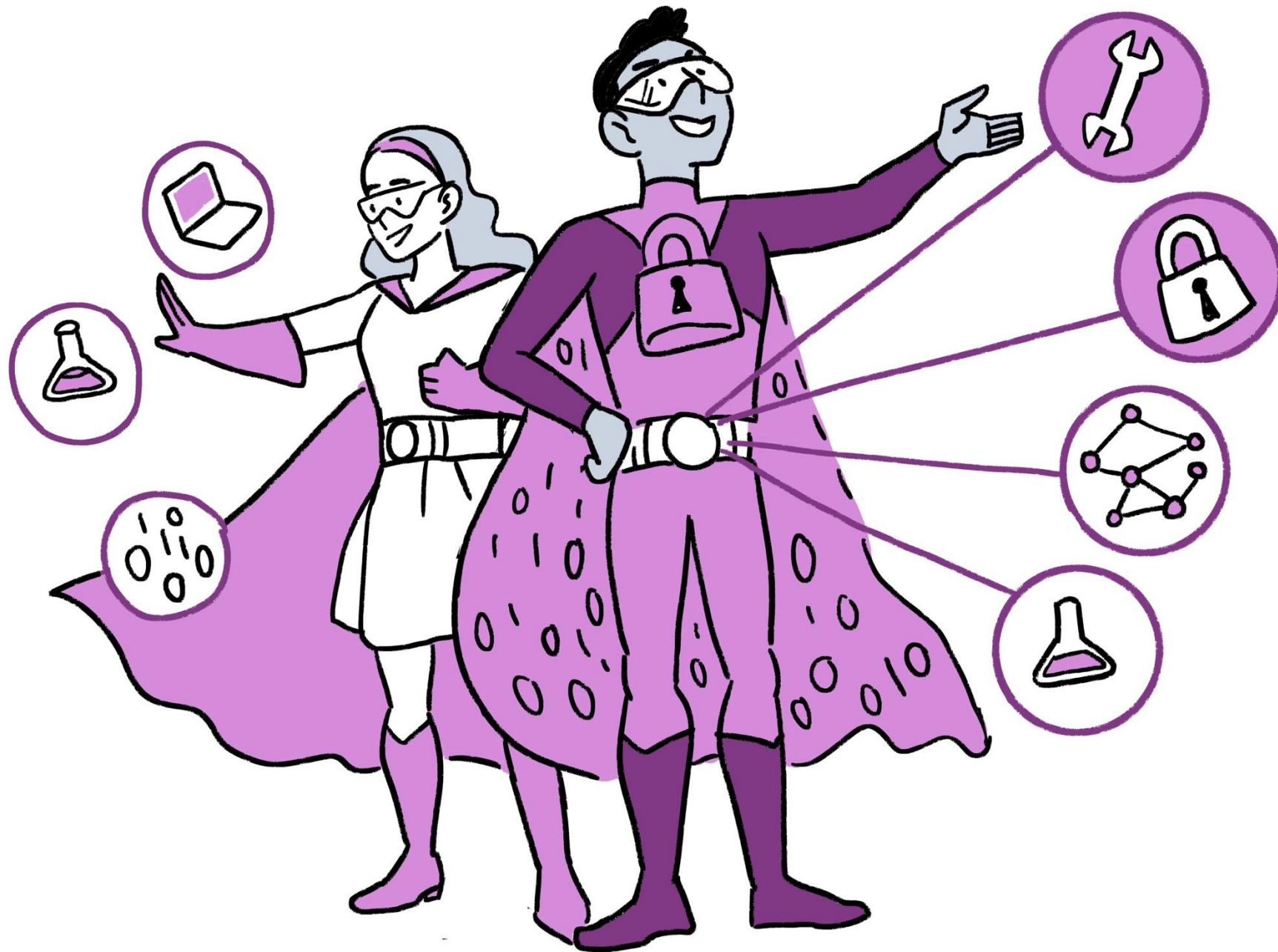
Many thanks and looking forward to your approval.

Best regards, Jonathan



· Edit · Delete

# 1<sup>st</sup> Responders: Data Stewards



✓ Research Data Management

- Privacy Concerns

- Ethical Considerations



# **Any questions?**



# Before we go

# Evaluate this session.



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the link in the chat**

<https://forms.office.com/e/19e6pgWFQ4>

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the link in the chat



Upcoming



**DATE**  
28/05

## How to create data package



**DATE**  
25/06

## Version control in action



**TIME**  
13:00 – 13:30



**LOCATION**  
ONLINE – TEAMS



RDMSUPPORT@TUE.NL

# Connect with us.

Email

**j.gerona@tue.nl**

RDM support

**rdmsupport@tue.nl**

**Thank you for joining this  
session!**