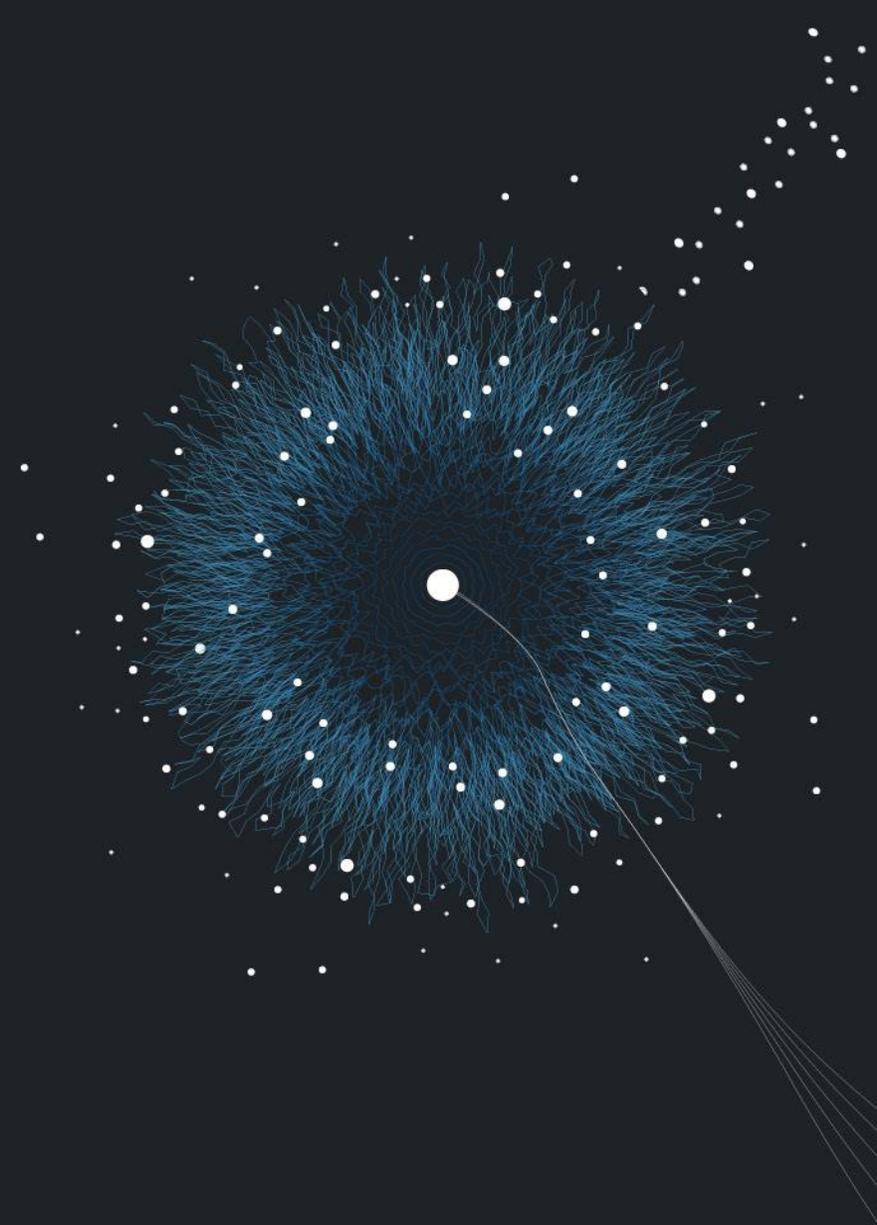


DCC thematic session 28-09-2022

PERSONAL DATA IN RESEARCH

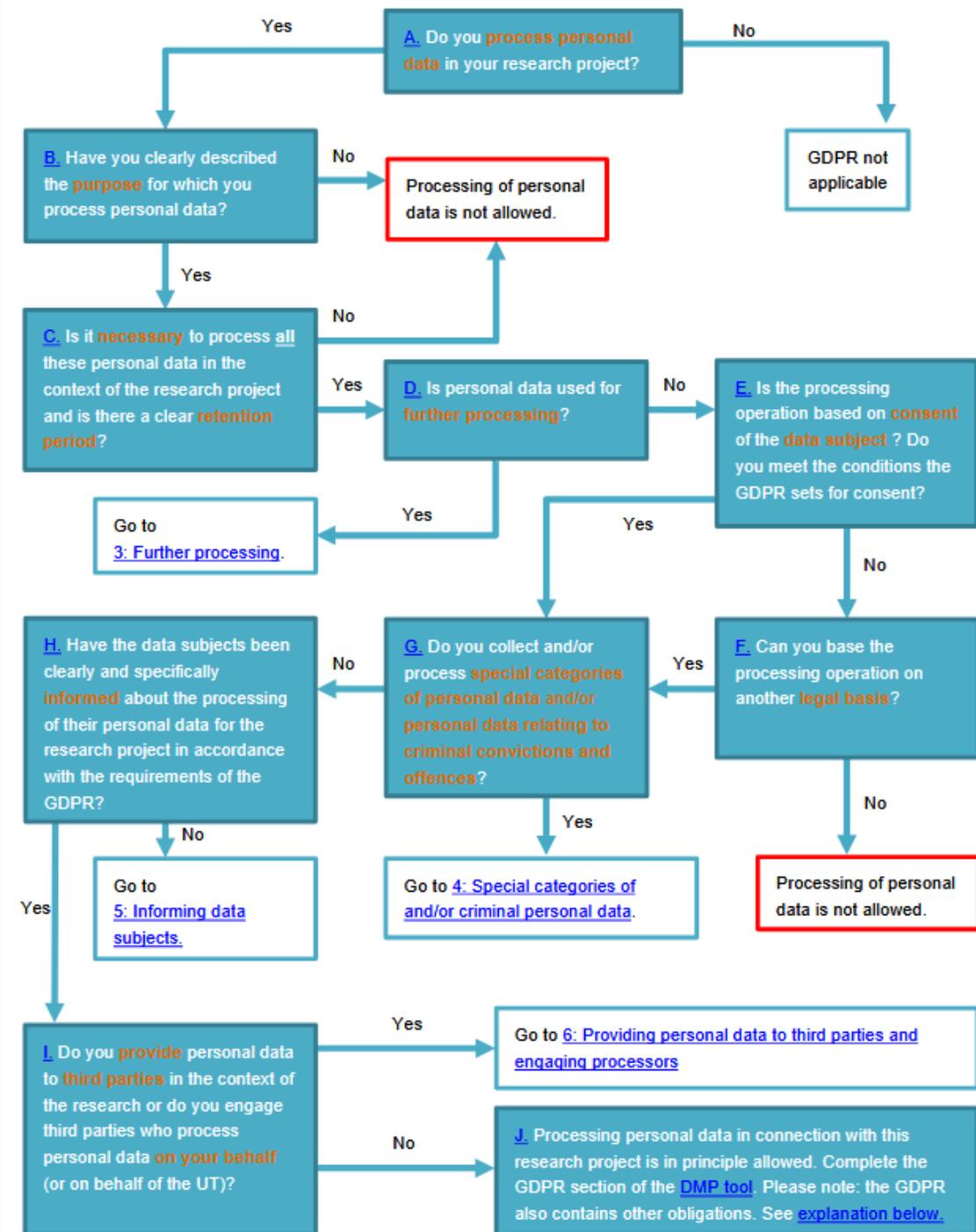
PETRI DE WILLIGEN
RESEARCH SUPPORT SPECIALIST EEMCS



FLOWCHART ([LINK](#))

APPROPRIATE USE OF PERSONAL DATA IN SCIENTIFIC RESEARCH ACCORDING TO THE GDPR

- Purpose
- Legal Basis -> Consent
- Informing participants
- Secondary data
- Special categories of personal data
- Data sharing



DO YOU PROCESS PERSONAL DATA

ANONYMIZATION VS PSEUDONYMIZATION

- Pseudonymization is a security measure
- Can someone else still identify the data subjects (secondary data)
- Is identification possible by combining the data with other sources

Necessary actions:

- GDPR registration -> [link](#)
- Ethics review -> [link](#)
- Possible DPIA (*Data Protection Impact Assessment*) -> [link](#)

CONSENT AS LEGAL BASIS

- Consent forms:
 - What data do you collect/process
 - Who has access
 - How is it stored
 - For how long is it stored
 - How to ask for your data to be removed
- Templates available on ethics committee website
- Think about where and how to store your consent forms

GDPR vs Scientific integrity

- Possibility for data subjects to have their data removed

DATA SECURITY

- Data minimization
- Storage -> [Storage decision tree](#)
- Do not use portable storage, encrypt your hard drive
- Encryption/pseudonymization ->store keys separate from data
- Data breach

GDPR vs Scientific integrity

- Retention period

SHARING DATA

DEPENDS ON CONSENT (OR OTHER LEGAL BASIS)

- Data agreements
 - File transfer: [SURF filesender](#) (use encryption)
 - Data processing agreement
 - Data transfer agreement
 - Joint controller agreement
 - (flowchart coming soon)
- > ask your PCP for support!

FAIR DATA

- Fully anonymize (possibly after retention period)

OR

- Consent
 - Ask consent for the use in future research
 - Cannot make purpose too broad, because consent needs to be specific
- Data agreement will probably be necessary

QUESTIONS ???

Website: [Personal data in research](#)

Privacy contact persons:

<https://www.utwente.nl/en/cyber-safety/contact/#privacy-contact-persons>