



Privacy in research, not just a hiding game

Responsible conduct of research,
data management and privacy

e.hoorn@rug.nl

In 2027 what will the most likely excuse be for not having verifiable results?

- a. Somebody stole the laptop with all the data.
- b. All European participants used their right to be forgotten.



Present danger for integrity when using personal data for research

schizophrenia
between perceived requirements on openness and responsibilities for personal data of participants



Programme

- General Data Protection Regulation
- 3 steps in a learning model for transparency on legal and ethical issues
- Open data in Horizon2020 and the Data Protection Impact Assessment



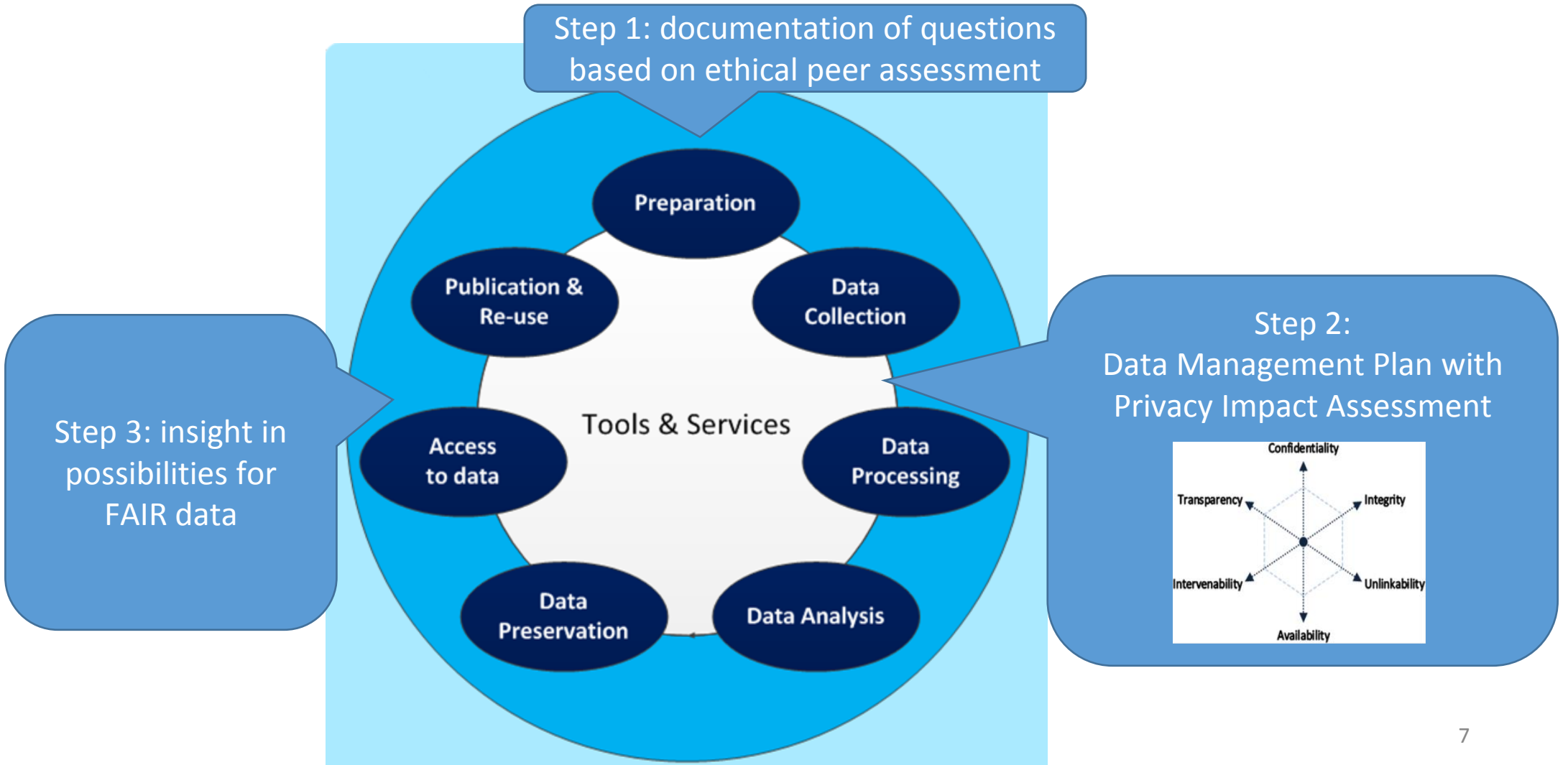
GDPR

- **General** Data Protection Regulation: May 2018...big fines!
- Controller has to be able to demonstrate compliance
- Transparency for participants more important
- Derogations for research
- Challenges for research:
 - Harmonization in Europe and worldwide
 - Responsibilities of the board, support and researchers
 - In keeping with ethical standards

Instruments in the GPDR

- Needed at all times: technical and organisational protection measures to balance the rights and freedoms of the participants.
- How?
- Privacy by design
- Privacy Impact Assessment: an **'early warning instrument'** to speak the same language in a multi-stakeholder assessment to design relevant measures.

Process: Asking the right questions...



Horizon 2020

FAIR Data Management Plan

- Findable
- Accessible
- Interoperable
- Reusable

And as open as possible...

Open access to research data

Open access as the default setting

But... projects can opt out **at any stage** if (among others) they are incompatible with:

- the need for confidentiality in connection with security issues
- rules on protecting personal data

Don't opt-out, do a PIA!



A German method to do a PIA

- Preparation stage
 - Projecting the assessment: goals and scope
 - **Standard data protection model**
 - Target, actors, relevant legal requirements
- Evaluation stage
 - Identification of protection goals **with stakeholders**
 - Attacks and evaluation criteria
- Report and safeguards stage
 - Technical and organisation **measures**



Standard Data Protection Model

Typical measures to guarantee transparency:

- Documentation of:
 - procedures
 - **data flows** and the IT systems used
 - **contracts**
- **Internal responsibility assignments**



Thank you!



Read more:

- <https://www.knaw.nl/nl/actueel/publicaties/ethische-en-juridische-aspecten-van-informaticaonderzoek>
- <http://www.privacy-regulation.eu/en/35.htm>
- SDM handbook https://www.datenschutzzentrum.de/uploads/SDM-Methodology_V1_EN1.pdf See chapter 7.
- Felix Bieker, Michael Friedewald, Marit Hansen, Hannah Obersteller and Martin Rost "A Process for Data Protection Impact Assessment under the European General Data Protection Regulation" DOI: 10.1007/978-3-319-44760-5_2 <http://friedewald.website/wp-content/uploads/2016/06/apf2016.pdf>
- Lilian Edwards, Derek McAuley, Laurence Diver, "From Privacy Impact Assessment to Social Impact Assessment", 2016, doi:10.1109/SPW.2016.19
- M. Bar-Sinai, L. Sweeney and M. Crosas, "DataTags, Data Handling Policy Spaces and the Tags Language," *2016 IEEE Security and Privacy Workshops (SPW)*, San Jose, CA, 2016, pp. 1-8. doi: 10.1109/SPW.2016.11
- Omer Tene & Jules Polonetsky, *Beyond IRBs: Ethical Guidelines for Data Research*, 72 Wash. & Lee L. Rev. Online 458 (2016), <http://scholarlycommons.law.wlu.edu/wlulr-online/vol72/iss3/7> Wilkinson, M. D. *et al.*
- The FAIR Guiding Principles for scientific data management and stewardship. *Sci. Data* 3:160018 doi: 10.1038/sdata.2016.18 (2016).
- http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-pilot-guide_en.pdf
- http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-data-mgt_en.pdf