



# Privacy in research: asking the right questions

Ethical and Legal Aspects of research,  
data management and privacy



university of  
groningen



- 30,000 students
- 2000 PhD students
- 3,314 FTE academic staff
- 11 faculties
- ERC grants: 70







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# Programme

- General Data Protection Regulation
- 3 steps in a learning model for ethical & legal issues
- Assessments mapped on the data lifecycle
  - Ethical assessment: **example**
- Open data in Horizon2020
  - Privacy Impact Assessment: **example**

# Our inspiration

Jeanne Mifsud Bonnici, STEP

*'Ethics? 80% is privacy'*



José van Dijck, president of the Royal Netherlands  
 Academy of Arts and Sciences

*'Ethics & legal issues need a learning model'*



Marit Hansen, Datenschutzzentrum

*'A Privacy Impact Assessment to be able to  
 demonstrate compliance'*





# A learning model



# 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:
  - Harmonization
  - Responsibilities board, support, researcher
  - In keeping with ethical standards
- Needed anyway: State of the art technical and organisational protection measures...instruments:
  - Privacy by design
  - Privacy Impact Assessment as 'early warning' design instrument





## Art. 35 GDPR

Where a **type of processing** in particular using **new technologies**, and taking into account the **nature, scope, context and purposes** of the processing, is **likely to result in a high risk to the rights and freedoms of natural persons**, the controller shall, prior to the processing, carry out an assessment of the **impact** of the envisaged processing operations on the protection of personal data.

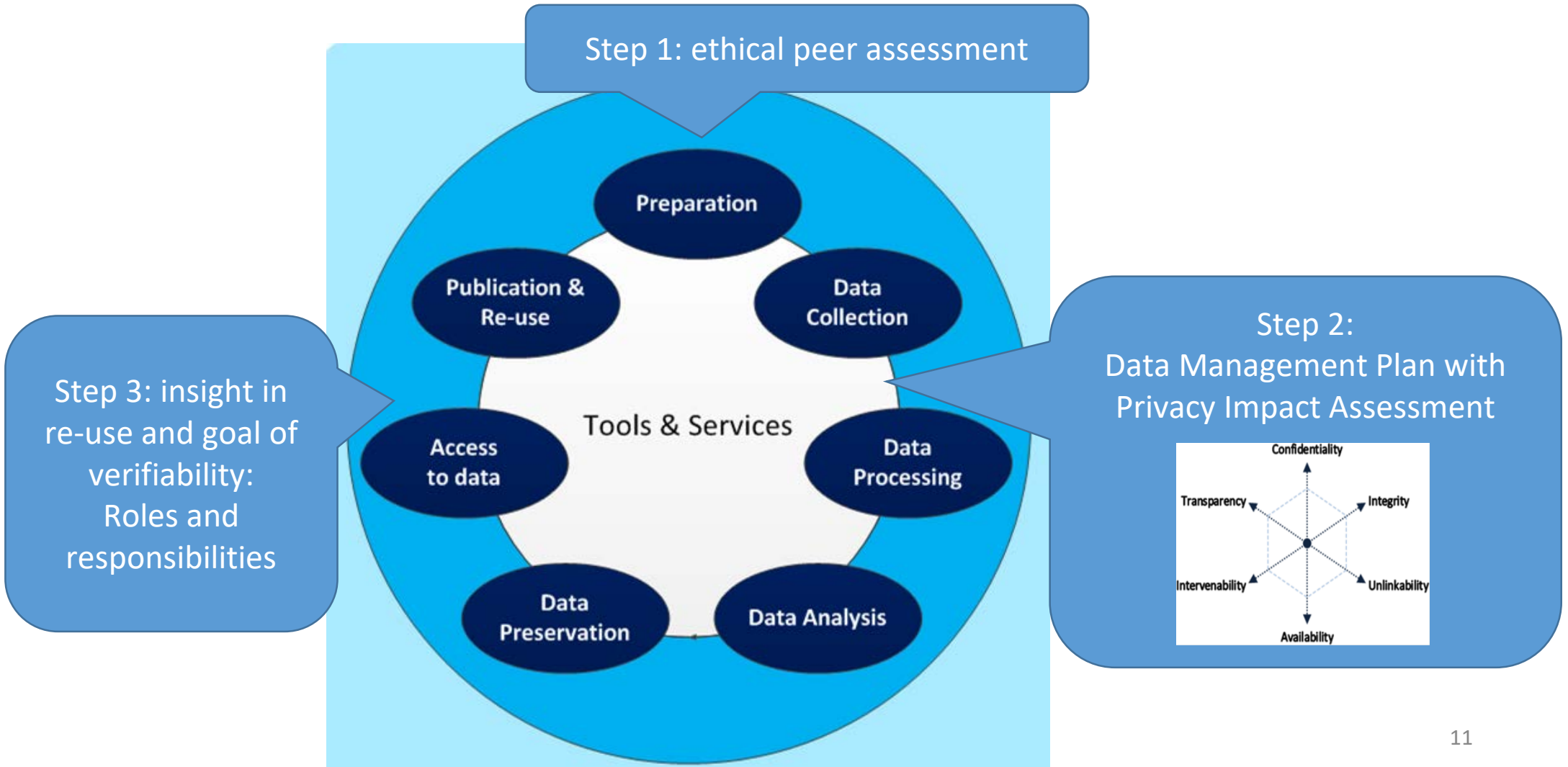
Different perspective from IT security: individual, not organisation

# Data Protection Impact Assessment



German model supports a multi-stakeholder approach which results in state of the art measures.

# Process: Asking the right questions...



# Ethics issue table



- Does your research involve human participants?
- Does your research involve personal data collection and/or processing?
- Do you plan to import any material - including personal data - from non-EU countries into the EU?
- In case your research involves low and/or lower middle income countries, are any benefits-sharing actions planned?

# ERC Consolidator Grant

- Transcripts from interviews
- Research notes

Countries: Mauritius, Ethiopia

## **Exportation/importation personal data outside/inside a non-EU country requires:**

- Ethics approval/data protection authorisation
- Local authorisation for export/import

# Ethics self-assessment

- Show awareness of the local legal rules / procedures
- Describe the necessity of collecting the data
- Describe the process of collecting / storing personal data
- Refer to previous research with similar ethical issues
- Get approval from your faculty ethical committee
- Describe the trade-off

# 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!

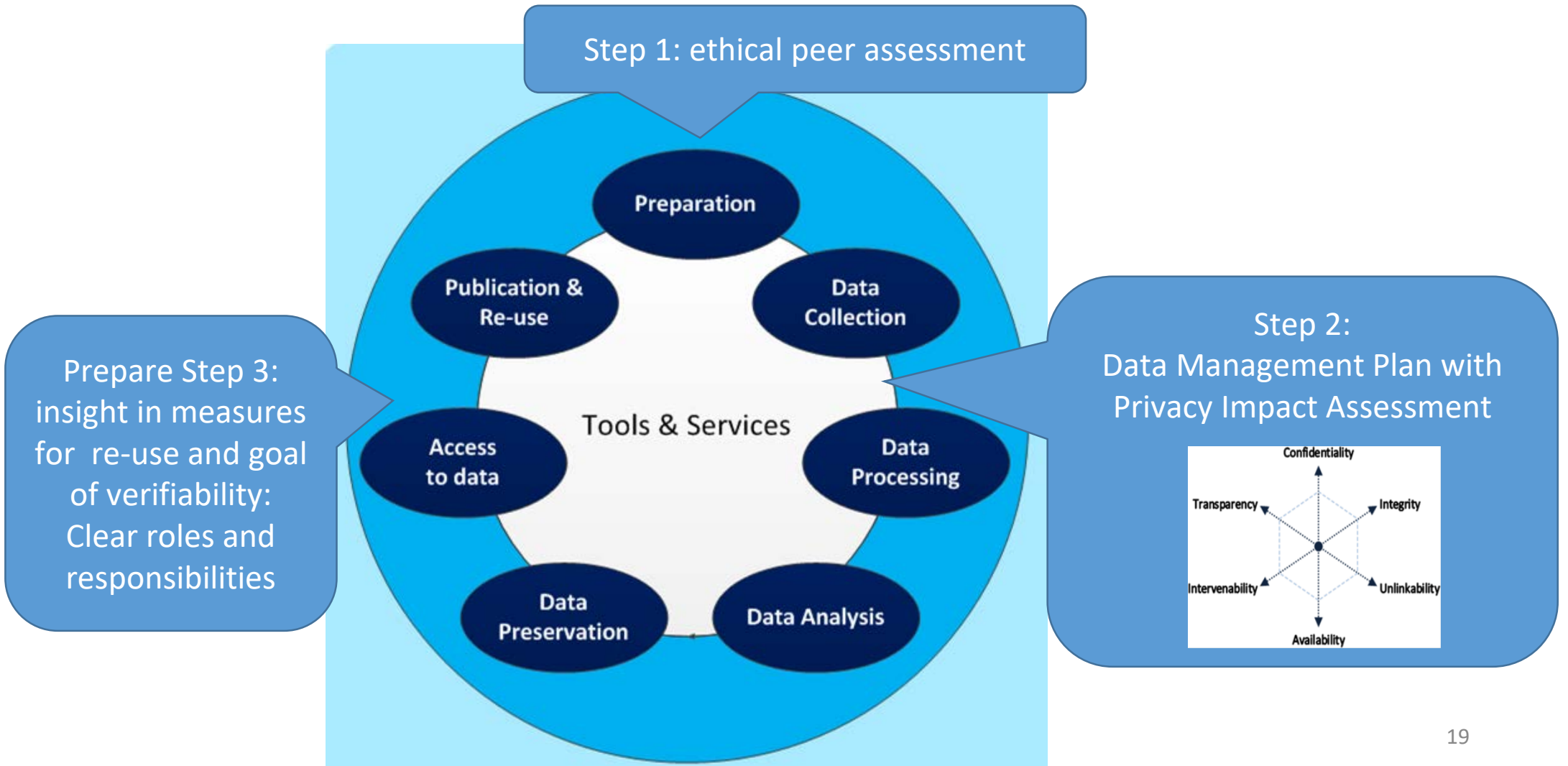


# A multi-stakeholder method to do a PIA

- 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**



# Process: Asking the right questions...





## KiVa: Anti-Bullying programme

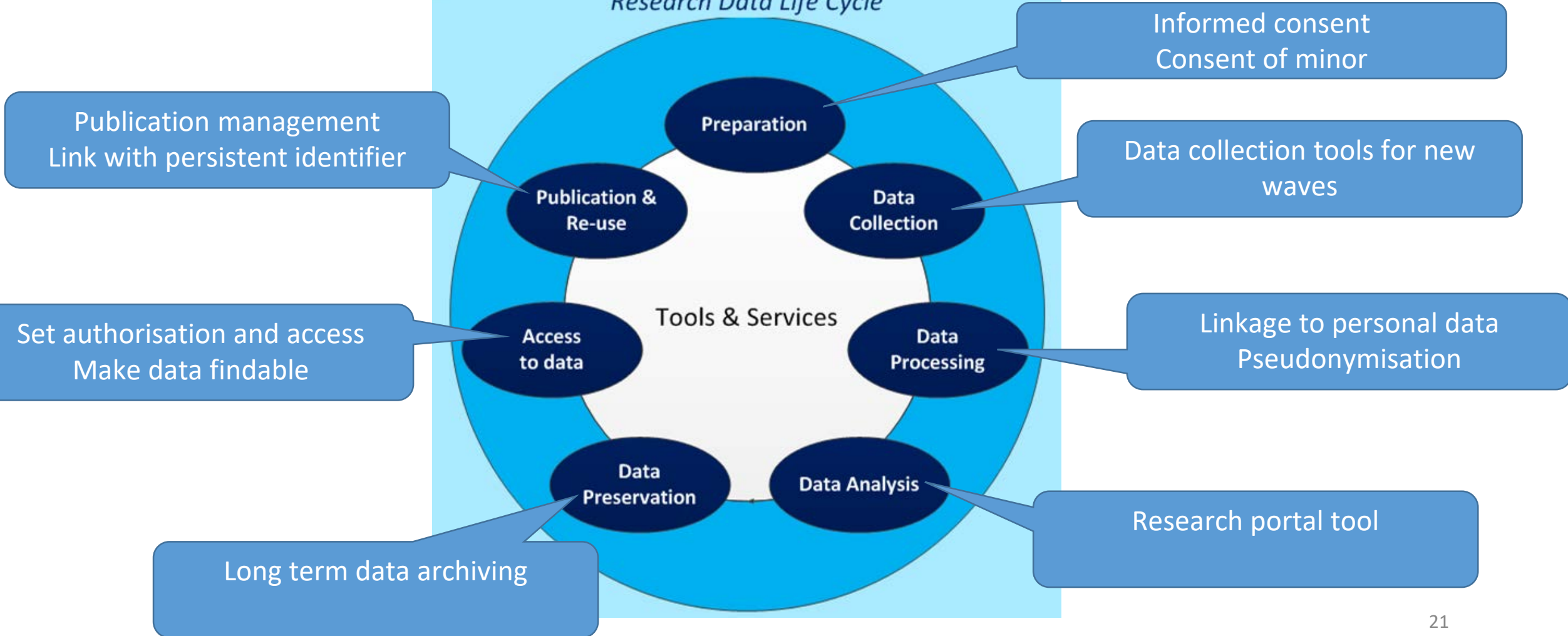
### Stakeholders:

- University of Groningen
- Turku University, Finland
- KIVA BV
- Schools
- Parents
- Children



# Measures for KiVa

*Research Data Life Cycle*





- Informed consent
- Privacy regulations ↔ law on safety in schools
- Open-ended questions

# Resuming....



# Standard Data Protection Model

## Typical measures to guarantee transparency:

- Documentation of:
  - procedures
  - **data flows** and the IT systems used
  - **contracts** with internal employees
  - data processing agreements
- **Internal responsibility assignments**





# Asking the right questions together



**EU GDPR  
Compliance  
Toolkit**

# Negotiating the public case for privacy compliance

- Apply PIA method to identify research scenarios with
  - Multidisciplinary groups of students
  - Members of ethical boards
  - Research projects
- Identify where standards measures can be adopted and where specific measures are needed for citizens involvement in research
- Harmonize....GDPR article 40: Codes of conduct



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](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-pilot-guide_en.pdf)
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