Privacy in research: asking the right questions

Ethical and Legal Aspects of research, data management and privacy
- 30,000 students
- 2000 PhD students
- 3,314 FTE academic staff
- 11 faculties
- ERC grants: 70
“the biggest civil rights issue of our time.”
(Alistair Croll, O’Reilly Radar, Aug 2, 2012)
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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
German model supports a multi-stakeholder approach which results in state of the art measures.
Process: Asking the right questions...

Step 1: ethical peer assessment

Step 2: Data Management Plan with Privacy Impact Assessment

Step 3: Insight in re-use and goal of verifiability: Roles and responsibilities
**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
  • Indentification of protection goals with stakeholders
  • Attacks and evaluation criteria

• Report and safeguards stage
  • Technical and organisation measures
Process: Asking the right questions...

Step 1: ethical peer assessment

Step 2: Data Management Plan with Privacy Impact Assessment

Prepare Step 3: insight in measures for re-use and goal of verifiability: Clear roles and responsibilities
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
- Consent of minor
- Data collection tools for new waves
- Linkage to personal data Pseudonymisation
- Research portal tool

Tools & Services

- Preparation
- Data Collection
- Data Processing
- Data Analysis
- Data Preservation
- Access to data
- Publication & Re-use

Publication management
Link with persistent identifier

Set authorisation and access
Make data findable

Long term data archiving
• 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
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!
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