



# Efese, ethics in research

Spetses, June 2017  
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# Dataprotection in research

- > Examples:
  - > Geography: students wearing GPS trackers for a week
  - > Sociology: students performing telephone inquiries
  - > Sociology: a large project on an anti-bullying programme on primary schools



# Terms:

- > Privacy: protection of individual against control of others, personal autonomy (Art. 7 EU charter)
- > Dataprotection: organizational perspective (Art. 8 EU charter)

(In ECHR they are both protected in Art. 8)



# Ethical questions

- Does your research involve human participants?
- Does your research involve personal data collection and/or processing?
- Do you plan or are you under an obligation to publish your datacollection for re-use and/or verifiability and does it contain personal data?



# Data protection

- > Not only a legal issue
- > But largely ethical!
  
- > It should be task of ethics commission,
- > For an ex ante assessment and weighing the interests and data protection risks at stake

# 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

# GDPR

- General Data Protection Regulation: May 2018...large fines!
- Controller has to be able to demonstrate compliance
- Transparency for participants more important
- Derogations for research...challenges:
  - Responsibilities (Controller) Board University? or Faculty?, researcher? (academic freedom!)
  - 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



## Research in GDPR

- > art. 89
- > Processing for (...) **scientific** (...) purposes shall be subject to **appropriate safeguards**, in accordance with this Regulation for the rights and freedoms of the data subject. Those safeguards shall ensure the **technical** and **organisational measures** are in place in particular to ensure respect for the principle of data minimisation. (...) may include **pseudonimisation** of **anonymisation**





# PIA

→ Privacy Impact Assessment

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.



# Use a PIA to assess what is needed to protect data

- > We are experimenting with a German model, the six pointed star.
- > It contains 6 protection goals:
  - > 3 of them are classic protection goals in IT security
  - > 3 are protection goals for dataprotection and privacy
- > And all together it is called 'privacy engineering'



# Protection goals

The IT protection goals are the the so-called CIA triad:

**Confidentiality:** the need for secrecy and non-disclosure

**Integrity:** reliability and non-repudiation, the need for processing unmodified, authentic and correct data

**Availability:** the need of data to be accessible, comprehensible and processable



# Protection goals

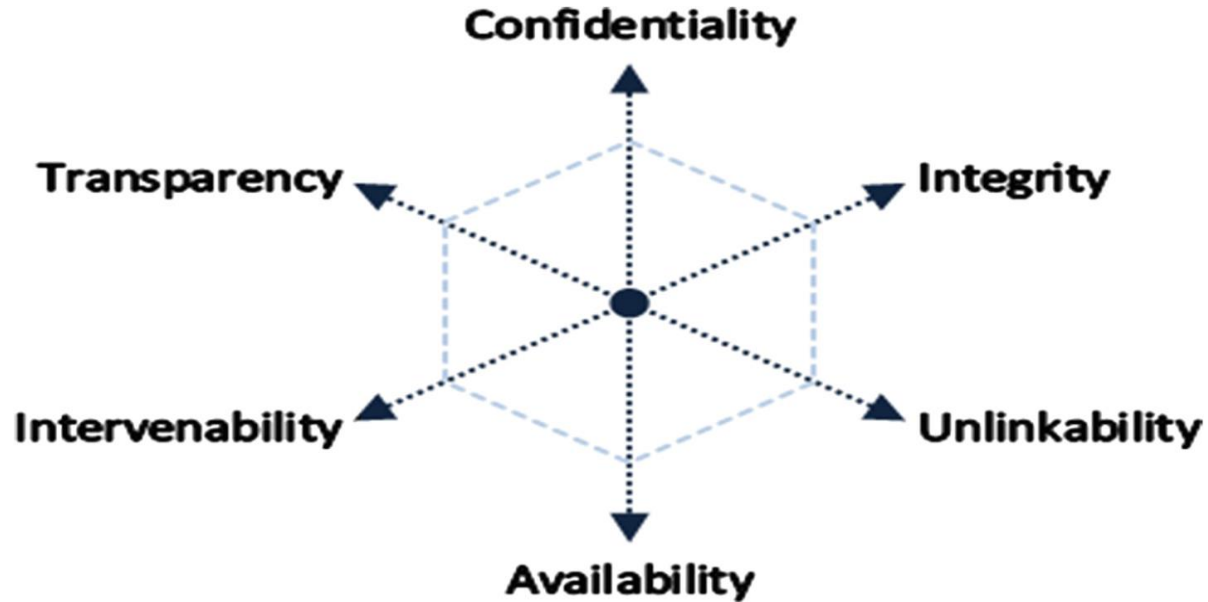
The dataprotection goals:

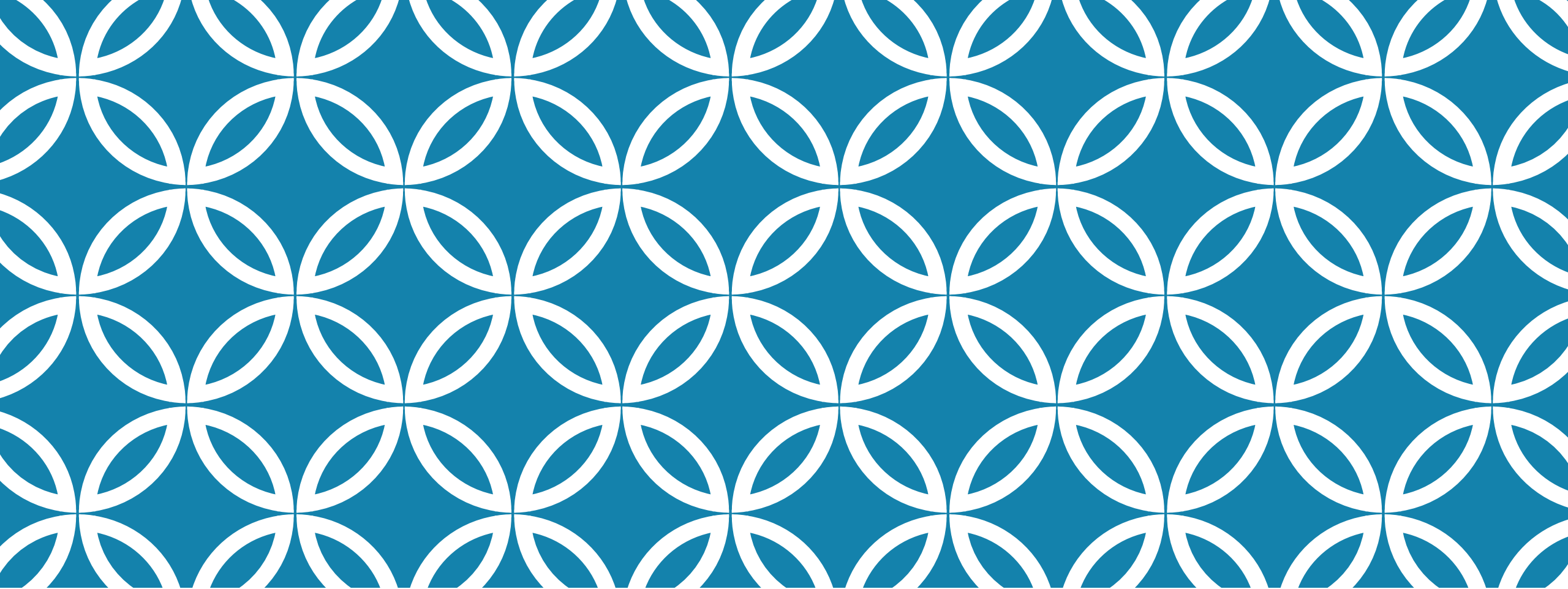
**Unlinkability:** data cannot be linked across the domain, the purpose for which they are collected

**Transparency:** privacy relevant dataprocessing can be understood and reconstructed at any time before, during and after processing

**Intervenability:** intervention is possible concerning ongoing of planned dataprocessing, it reflects the rights of individuals to rectification or erasure of data, right to withdraw consent, of lodge a claim

# Model for PIA





# RESPONSIBLE RESEARCH

Dr. Maria Mousmouti,  
CECL & IALS

# ETHICS & RESEARCH

Ethics and research go hand-in-hand - **WHY?**

**What are ethical standards ?** = values essential to collaborative work

**Main objectives:**

- Protection & safety of subjects
- Ensure that the manner of conducting research serves the interests of society
- Reliable and transparent results

**What do ethical norms cover?** = principles for authorship, copyright & policies for patenting, policies in sharing data; confidentiality

**When are ethics relevant?** = the entire life cycle of research (from design, administration, testing, implementation, dissemination and writing)

# WHY ARE RESEARCH ETHICS IMPORTANT?

1. **Fair treatment for participants** – inform the subjects what they will experience – avoid harm or deception
2. **Provide knowledge helpful to society** – decisions about moral or ethical questions
3. **Set boundaries in research for what science can and cannot do** – safeguard health, safety, and human involvement in science
4. **Safeguard safety** – safety is the basis of ethical research – research performed in a violent or detrimental way could hurt the public, such as an unsafe new drug
5. **Promote ethical conduct** – ethics set the standard of acceptable conduct and empower professionals in promoting moral values in their work



# EUROPEAN CHARTER FOR RESEARCHERS

## What is it?

- principles and requirements which specify the roles, responsibilities and entitlements of researchers, employers and/or funders of researchers
- a framework for acting responsibly and professionally

## Aim?

- to ensure that research relationships are conducive to successful performance in generating, transferring, sharing and disseminating knowledge & technological development

## Who does the Charter concern?

All researchers = “Professionals engaged in the conception or creation of new knowledge, products, processes, methods and systems, and in the management of the projects concerned”

All career stages – all research fields – public and private sectors, irrespective of appointment or employment, legal status, type of organisation – all research roles

# GENERAL PRINCIPLES AND REQUIREMENTS APPLICABLE TO RESEARCHERS

- **Research Freedom** = research for the good of mankind and expanding the frontiers of scientific knowledge – freedom of thought and expression – recognised ethical principles and practices – limitations?
- **Ethical principles** = adhere to ethical practices and principles
- **Professional responsibility** = research relevant to society – no duplication – no plagiarism – respect for intellectual property and joint data ownership
- **Professional attitude** = awareness of goals of research environment and funding mechanisms, request for approvals before starting
- **Contractual and legal obligations** = familiarity with national, sectoral or institutional regulations governing training and/or working conditions

- **Accountability** = towards employers, funders & society – efficient use of public money – sound, transparent and efficient financial management – openness to scrutiny
- **Good practice in research** = safe working practices – familiarity with legal requirements regarding data protection and confidentiality – necessary steps to fulfil them
- **Dissemination, exploitation of results** = results of research to be disseminated and exploited, e.g. communicated, transferred into other research settings or, if appropriate, commercialised
- **Public engagement** = research activities to be made known to society in a way that they can be understood by non-specialists
- **Relation with supervisors** = structured relationship with supervisor(s)
- **Supervision and managerial duties** = high professional standards in acting as supervisor, mentor, career advisor, leaders, project coordinators, managers or science communicator
- **Continuing Professional Development** = continuous improvement by updating and expanding skills and competencies

# EXAMPLE: SAS RESEARCH ETHICS POLICY AND PROCEDURES

**Ethics statement:** The School of Advanced Study at the University of London is committed to carrying out its research, teaching, consultancy and other activities within a comprehensive ethical framework.

The **purpose** of this Policy is to:

- Set out the principles applicable to all research, consultancy projects and studies;
- Provide members of the School with a clear understanding of the ethical review process operated by the School; and
- Support a culture of academic freedom and excellence by providing a framework for review, which subjects research proposals and other studies to a level of scrutiny that is in proportion to the risk of harm or adverse effect to participants, researchers, the University and to society as a whole.

This Policy is managed and monitored by the **School Research Ethics Committee**


**Procedures = Ethical Review Process** – all projects checked for ethical implications

**Scope** = all activities, all disciplines and research when dealing with human subjects or data-related to human subjects

**Who?** All staff, students and fellows of the School engaged in studies or research as well as visitors, individuals, collaborators, or agents conducting research or other studies in the name of the School and/or engaged to conduct research by the School + consultancy and enterprise activities.

# PRINCIPLES

- Studies and research should be designed, reviewed and undertaken to ensure **integrity, quality and transparency**
- Activities, undertaken by members of the School, which involve research or studies on human participants or involving data relating directly to identifiable human subjects, will always require **formal ethical consideration** and a review may be needed
- Participants must be **fully informed** about the research or study they are invited to participate in – consent must be made voluntarily, freely and without any coercion
- **Risks should be managed** so that harm and/or damage arising from the research is avoided and measures should be taken to ensure that the benefits of research outweigh potential harm or damage
- The **independence of the research/study** must be clear, and **conflicts of interest or partiality must be explicit.**
- The same high ethical standards shall apply wherever in the world the study/research is undertaken in the School or University name or in association with the School or University.
- The School is committed to upholding the Policy by communicating its standards, policies and procedures to staff through education and training

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- Look out for the research ethics policy of your University!
  - Look out for ethics self assessment checklists!
  - Consider the relevance of ethics for your research!