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# Research Ethics and Data Protection Legislation

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Pravni in etični vidiki ravnanja z  
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# Disclaimer

- » The information on the GDPR in this presentation is based on our current interpretation of the legislation and its implications for research and the archiving of research data
- » This is a very fluid area and thus changes are still possible
- » This presentation **does not constitute, or should not be construed as, legal advice and / or guidance**

# Research Ethics

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# RESPECT Code of Practice

- » Ethics are an integral part of a research project, from the conceptual stage of the research proposal to the end of a research project
- » Within the EU the RESPECT project has drawn up professional and ethical guidelines (Institute for Employment Studies, 2004) for conducting socio-economic research
- » The RESPECT Code of Practice is based on three main guidelines:
  1. Upholding scientific standards
  2. Compliance with the law
  3. Avoidance of social and personal harm



# Ethical Review Process

- » Ethical review is about helping you as a researcher to think through the ethical issues surrounding your research
- » The principles of good research practice encourage you to consider the wider consequences of your research and engage with the interest of your participants
- » Ethics review by a Research Ethics Committee (REC) is typically required when (sensitive) personal data are being collected
- » The role of a REC is to protect the safety, rights and well-being of research participants and to promote ethically sound research
- » Among other duties, this involves ensuring that research complies with national and international data protection laws regarding the use of personal information collected in research



# Ethical Self-Assessment



- » Performing an ethical self-assessment:
  - » Question 1: The project's aim and method
  - » Question 2: Research involving identifiable persons
  - » Question 3: Whistle-blowing

# Ethical Arguments for Archiving Data

- » Not burden over-researched, vulnerable groups
- » Make best use of hard-to-obtain data, e.g. elites, socially excluded, over-researched
- » Extend voices of participants
- » Provide greater research transparency

*In each, ethical duties to participants, peers and public may be present*

# Data Protection Legislation

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# The General Data Protection Regulation (GDPR)

- » The GDPR will apply from the 25 May 2018
- » The GDPR applies to any data controller or data processor in the EU who collects personal data about a data subject of any country, anywhere in the world
- » A data controller or data processor that is based outside the EU but collects personal data on EU citizens will also be covered by the GDPR
- » This means that a researcher (data controller) based within the EU who collects personal data about a participant, from any other country within the EU, or the world, needs to comply with the GDPR
- » Also means a researcher (data controller) outside the EU who collects personal data about a participant in the EU will be covered when this relates to offering goods/services or the monitoring of their behaviour within the EU

# GDPR Applies to...

- » The GDPR applies only to 'personal data' and data of 'living persons'
- » Data which do not count as personal data do not fall under data protection legislation
- » Though there may still be ethical reasons for wanting to protect this information!

# Principles Relating to Processing of Personal Data

## 1. Process lawfully, fair and transparent

- » The participant is informed of what will be done with the data and data processing should be done accordingly

## 2. Keep to the original purpose

- » Data should be collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes. \*Note Article 5(1)(b), Article 89 \*

## 3. Minimise data size

- » Personal data that are collected should be adequate, relevant and limited to what is necessary

# Principles Relating to Processing of Personal Data

## 4. Uphold accuracy

- » Personal data should be accurate and, where necessary kept up to date. Every reasonable step must be taken to ensure that personal data that are inaccurate are erased or rectified without delay

## 5. Remove data which are not used

- » Personal data should be kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed. \* Note Article 5(1)(e), Article 89 \*

## 6. Ensure data integrity and confidentiality

- » Personal data are processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures

# GDPR Archiving and Research Exemption

*Processing for archiving purposes in the public interest, scientific or historical research purposes or statistical 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 that **technical and organisational measures** are in place in particular in order to ensure respect for the principle of **data minimisation**. Those measures may include pseudonymisation provided that those purposes can be fulfilled in that manner. Where those purposes can be fulfilled by further processing which does not permit or no longer permits the identification of data subjects, those purposes shall be fulfilled in that manner*

- » Principle 2. and 5. are less strict
- » 2. Purpose: further processing allowed
- » 5. Personal data may be stored for longer periods

# The Grounds for Processing Personal Data

» There are 6 grounds for the processing of personal data, and one of these must be present in order to process a data subject's personal data:

1. Consent of the data subject
2. Necessary for the performance of a contract
3. Legal obligation placed upon controller
4. Necessary to protect the vital interests of the data subject
5. Carried out in the public interest or is in the exercise of official authority
6. Legitimate interest pursued by controller

# GDPR and Consent

- » Consent needs to be **freely given, informed, unambiguous, specific** and by a **clear affirmative action** that signifies agreement to the processing of personal data
- » Consent cannot be inferred from silence, pre-ticked boxes or inactivity
- » Consent must be documented

# GDPR - Data Subject Rights

- » The right to be informed
- » The right of access
- » The right to rectification
- » The right to erasure - the 'right to be forgotten'
- » The right to restrict processing
- » The right to data portability
- » The right to object
- » Rights in relation to automated individual decision-making and profiling



# Best Practice for Legal Compliance

- » Investigate early which laws apply to your data
- » Do not collect personal or sensitive data if not essential to your research
- » Seek advice from your research office
- » Plan early in research
- » If you must deal with personal or sensitive data
  - » Inform participants about how their data will be used
  - » Remember: not all research data are personal (e.g. anonymised data are not personal)

# Strategy for Sharing Confidential Data

1. Obtain informed consent, also for data sharing and preservation or curation
2. Protect identities e.g. anonymisation and not collecting personal data
3. Regulate access where needed (all or part of data) e.g. by group, use or time period
4. Securely store personal or sensitive data

# Questions

- » Dr Scott Summers
- » Collections Development and Producer Relations team
- » UK Data Service
- » University of Essex
- » [ukdataservice.ac.uk/help/get-in-touch](https://ukdataservice.ac.uk/help/get-in-touch)