LINKING AUXILIARY DATA TO SURVEY DATA

ETHICAL AND LEGAL CHALLENGES IN EUROPE AND THE US

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Examples of auxiliary data

• Neighbourhood contextual information
• Geo location indicators
• Social media behavioural or attitudinal data
• Administrative records
Key goals of the new EU Regulation

• Make Europe fit for the digital age
• Ensure a consistent and high level of data protection
• Provide legal certainty and trust
• Put citizens in control of their data
• Put an end to the patchwork of data protection rules
Key goals of the NPRM to the Common Rule

- Strengthen protection of research participants
- Increase opportunity to make informed decisions
- Reduce potential for disclosure risk
- Facilitate valuable research
- Reduce burden, delay, and ambiguity
- Build public trust in the research system
EU: What is personal data?

Any information that can be used to identify a person *directly* or *indirectly* (by means reasonably likely to be used):
The Common Rule’s definition of identifiable private information:

“the identity of the subject is or may readily be ascertained by the investigator or associated with the information”
Elements of discussion in the Proposal

- Usefulness of “may be readily ascertained” in the context of modern technology
- Harmonization to the Health Privacy Rule
- A more stringent standard as greatly impeding research
Confidentiality issues

- Breach of confidentiality is the most serious risk of harm to which participants in social research are exposed
- Increased disclosure risk when linking and combining data
Protection of confidentiality

Restricting data

- Swapping, recoding, aggregating
- Restricting upper and lower ranges of continuous variables
- Adding random variation or error in the variable

Restricting access

- End user licenses/data enclaves
- Remote Data Access
- On-site data laboratories
Data security

**EU Regulation**
- Data protection by design
- Promotes anonymization, pseudonymization and encryption techniques
- Breach notification guidelines

**US Proposal**
- Increase emphasize on protection against disclosure risk
- Implement mandatory privacy protection policies
Auxiliary data: When is consent required?

Non-respondents

• Balancing of interest: societal value vs. individual disadvantages (sensitive data, data source, identifiability, safeguards)

Respondents

• Possible to make inferences?
• Enhancing information on respondents?
Consent in EU Regulation

• Expressed by statement or clear affirmative action
• Clear and plain language
• Exemption for research purposes
• Notice requirement

Consent in US Proposal

• Significantly tightening of consent rules
• No longer “unduly long documents”
• Fewer rights for data subjects than in Europe
Thank you for listening!