

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

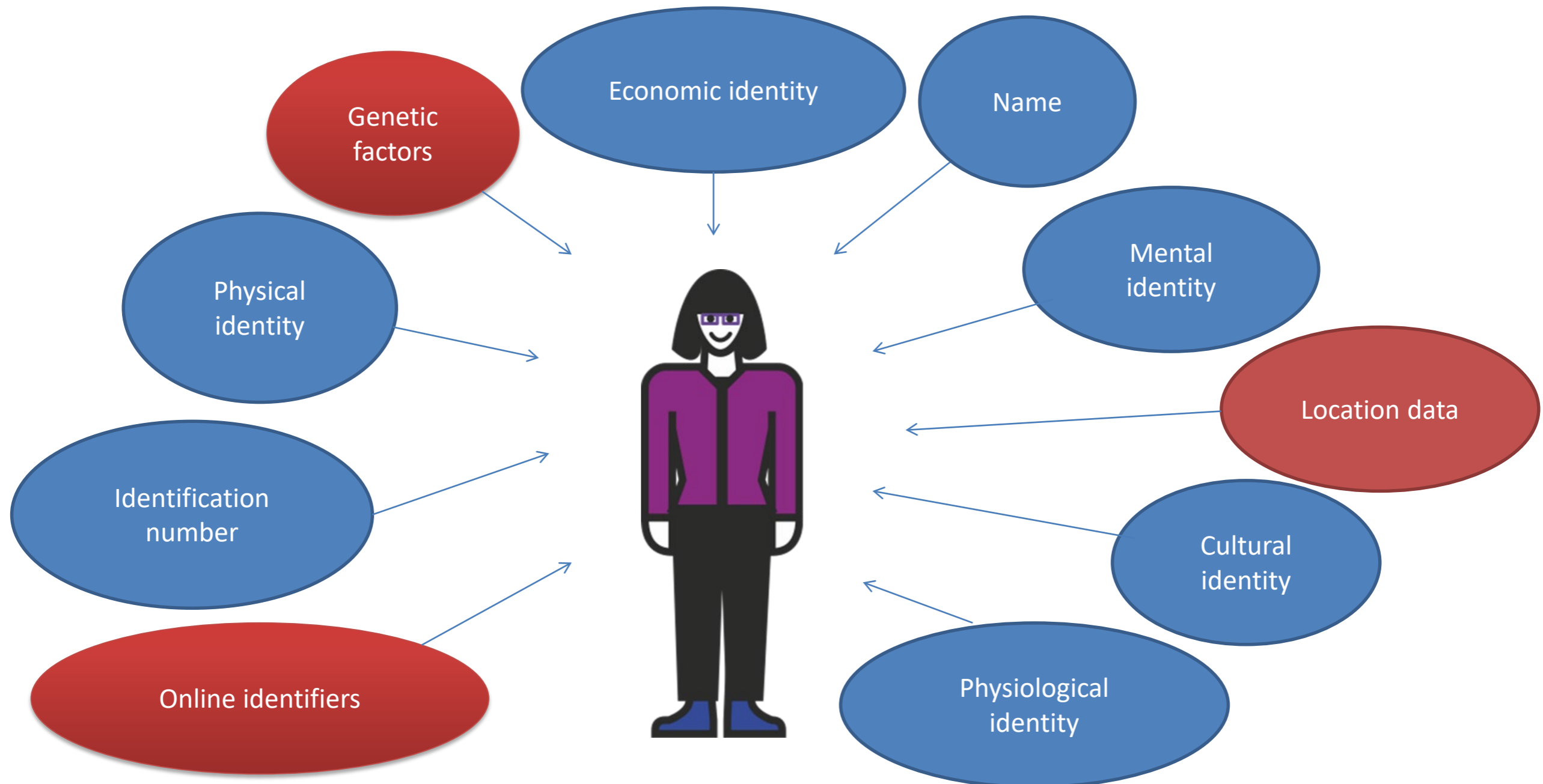
- Make Europe fit for the digital age
- Ensure a consistent and high level of data protection
- Provide legal certainty and trust
- Put citizens in control of their data
- Put an end to the patchwork of data protection rules

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!

NSD

NORWEGIAN CENTRE
FOR RESEARCH DATA