Q 2016
European Conference on Quality in Official Statistics

NEW FORMS OF DATA – LEGAL AND ETHICAL ISSUES



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seriss SYNERGIES FOR EUROPE'S RESEARCH INFRASTRUCTURES IN THE SOCIAL SCIENCES

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New forms of data





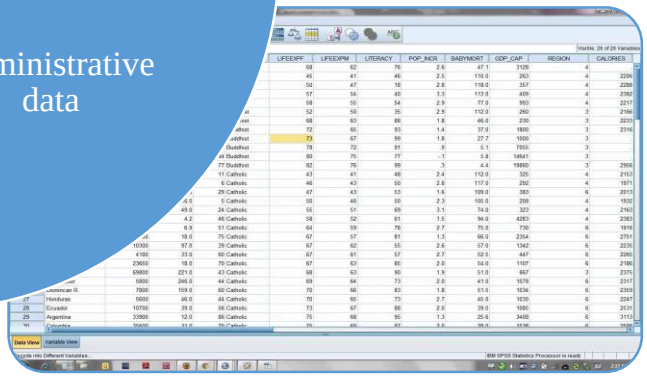
Big Data

Social media data

Biomarkers

Administrative data





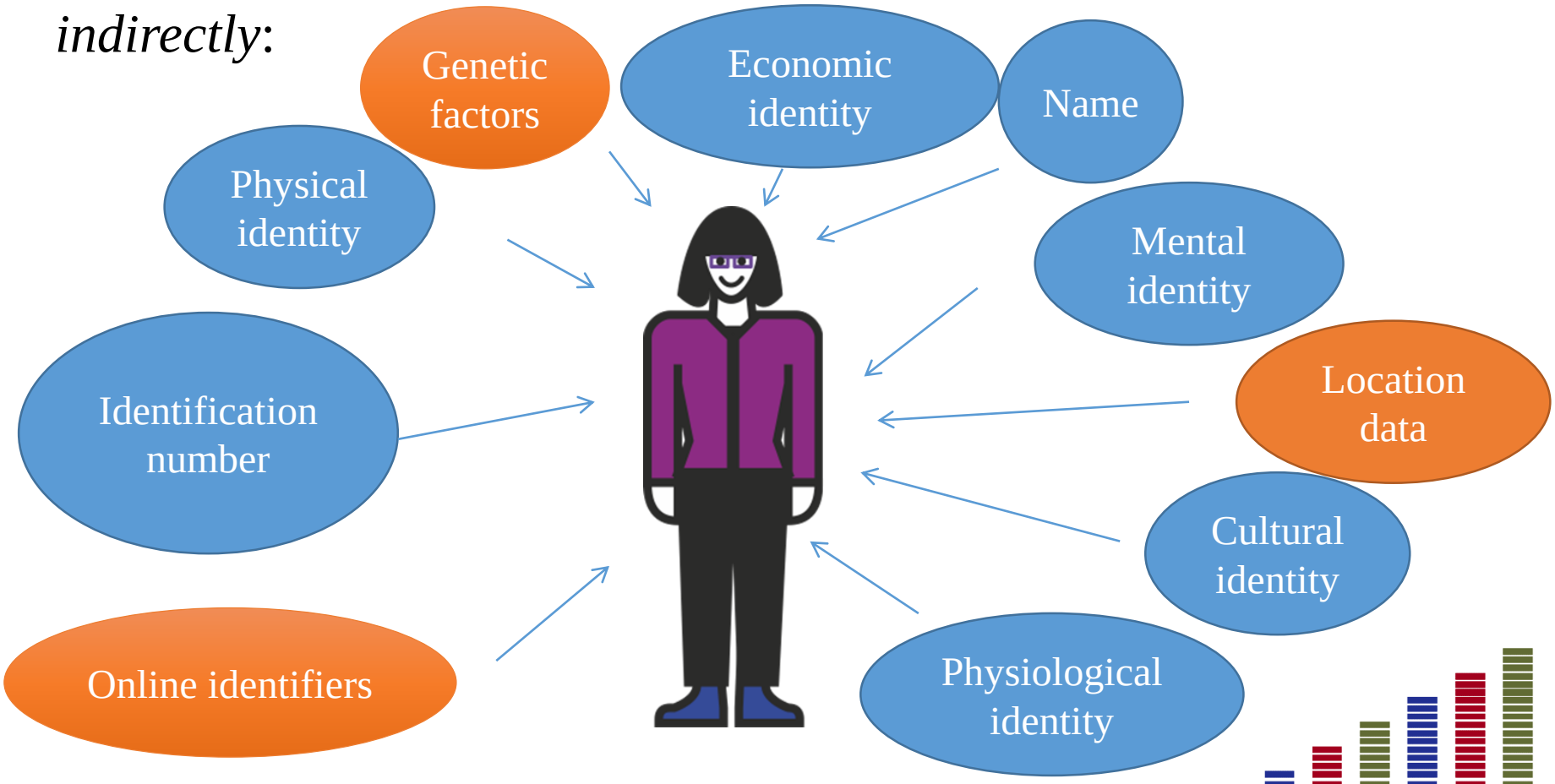
Key goals of the General Data Protection Regulation (GDPR)

- Make Europe fit for the digital age
- Harmonise the rules across Europe
- Remove barriers to facilitate cross border data flow
- Ensure a high level of data protection in order to provide legal certainty and trust
- Put citizens in control of their data



What is personal data?
The scope of the GDPR

Any information that can be used to identify a person *directly* or *indirectly*:



Implications for research and statistical agencies

- Research and statistical agencies occupy a privileged position in the GDPR
- Consent still a key mechanism for protecting privacy
- Consent requirements are not absolute; *(...) further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall, in accordance with Article 89(1),* ***not be considered to be incompatible*** *with the initial purposes (Article 5 (b))*
- Important exemptions: right to object, right to be forgotten, and also for storage of personal data

Appropriate safeguards
Article 89 (1)

- Data must be adequate, relevant and limited to what is necessary
- Use of techniques such as: **Anonymisation**, **pseudonymisastion** and **encryption**
- Provide **information** in clear and plain language
- Strengthening of **data protection officer** arrangement



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New forms of data - a challenge for the data subjects' confidentiality?



"Privacy as we have known it is ending, and we're only beginning to fathom the consequences" (Enserink and Chin 2015).

Four essential principles to retain trust:

- Transparency
- User control
- Privacy be design
- Accountability

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The fine line between private and public



Vox SCIENCE & HEALTH

Researchers just released profile data on 70,000 OkCupid users without permission

Updated by Brian Resnick on May 12, 2016, 6:00 p.m. ET @B_resnick brian@vox.com

TWEET SHARE (4,095)



People may operate in public spaces but maintain strong perceptions or expectations of privacy (AoIR 2012).

Concluding remarks

- GDPR is research friendly and safeguards the interests and the needs of scientific research institutions and statistical agencies

- The legal basis for using new forms of data is largely in place, but the possibility for member states to introduce conditions for certain types of data may pose a challenge.

- Ethical issues requires a dynamic approach

- Increased risk of re-identification creates a need for greater transparency to retain public trust

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Thank you for listening!

