NEW FORMS OF DATA – LEGAL AND ETHICAL ISSUES

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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:

- Genetic factors
- Economic identity
- Name
- Mental identity
- Location data
- Cultural identity
- Physiological identity
- Identification number
- Physical identity
- Online identifiers
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, pseudonymisation and encryption
• Provide information in clear and plain language
• Strengthening of data protection officer arrangement
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 by design
- Accountability
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
Thank you for listening!