

# NEW FORMS OF DATA – LEGAL AND ETHICAL ISSUES



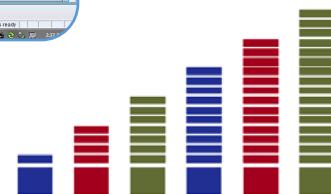
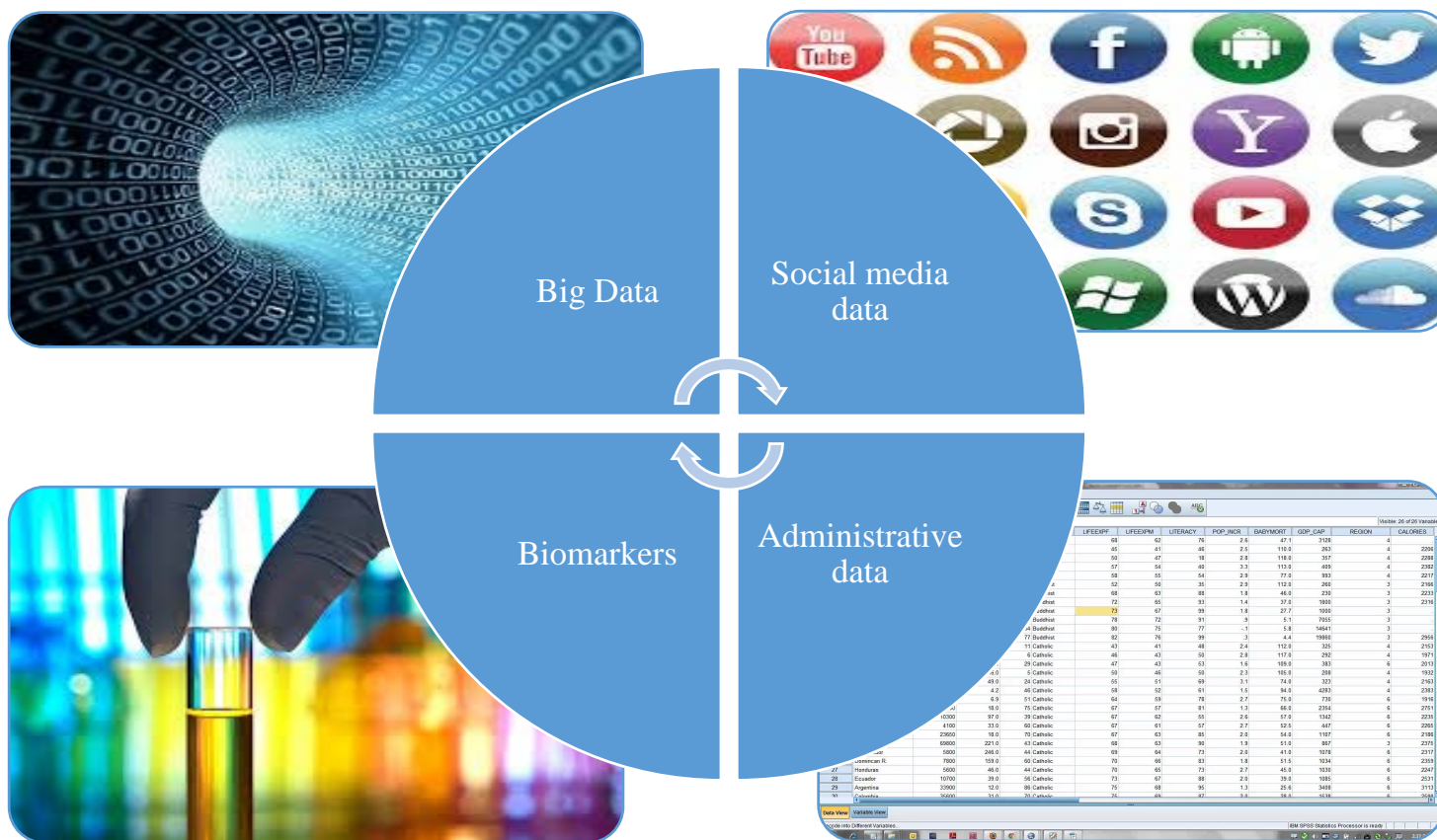
Marianne Høgetveit Myhren  
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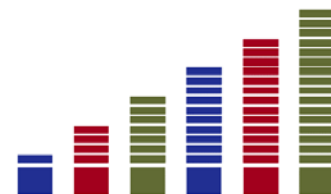
SYNERGIES FOR EUROPE'S  
RESEARCH INFRASTRUCTURES  
IN THE SOCIAL SCIENCES

# New forms of data



# Key goals of the General Data Protection Regulation (GDPR)

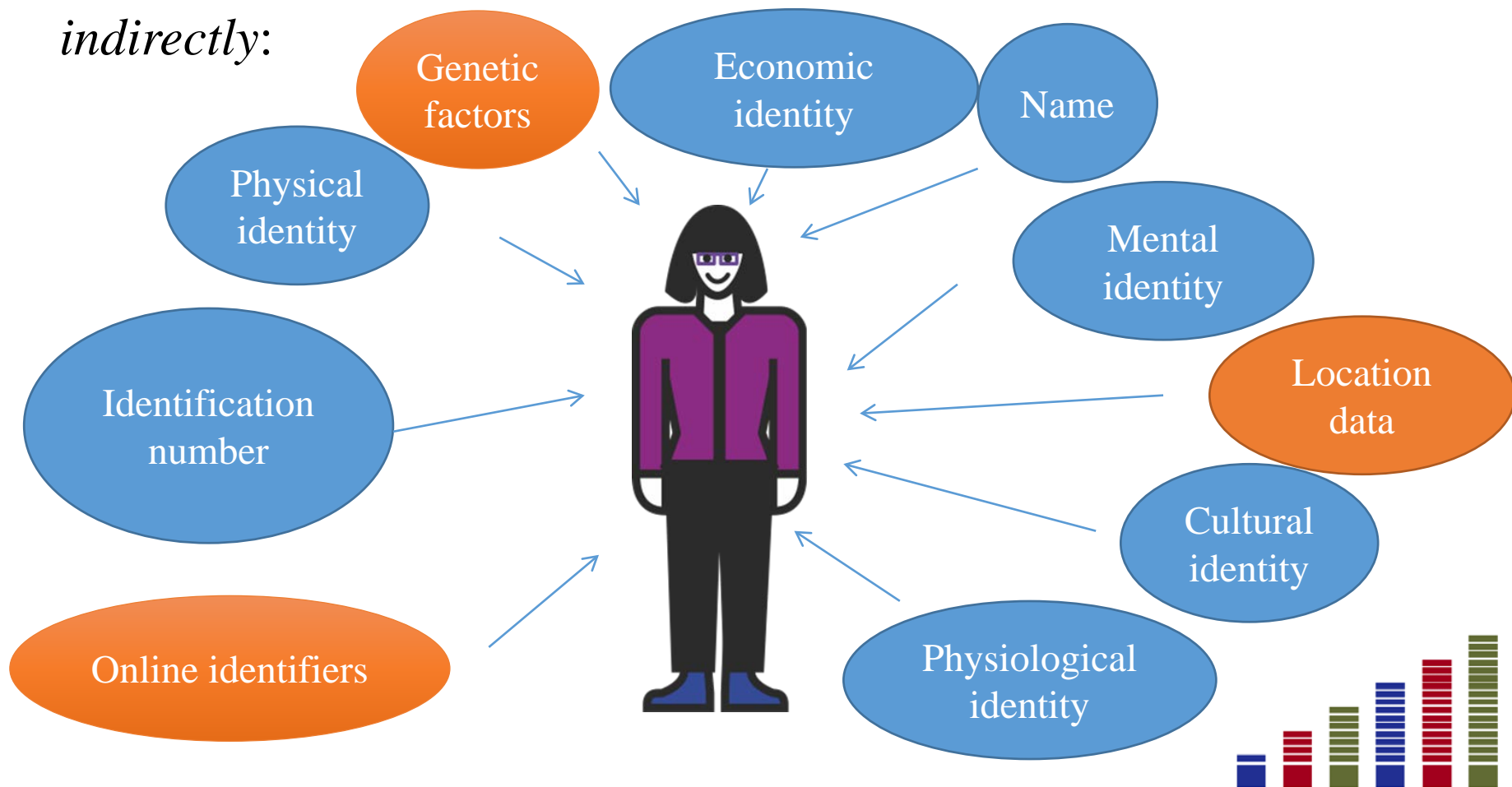
- Make Europe fit for the digital age
- Harmonise the rules across Europe
- Remove barriers to facilitate cross border data flow
- Ensure a high level of data protection in order to provide legal certainty and trust
- Put citizens in control of their data



# What is personal data?

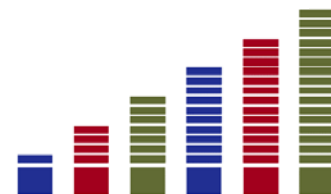
## The scope of the GDPR

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

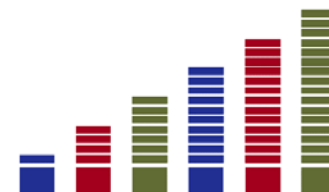




# Appropriate safeguards

## Article 89 (1)

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



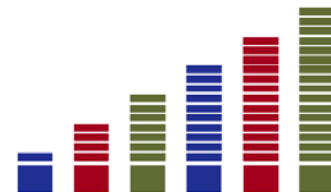
# New forms of data - a challenge for the data subjects' confidentiality?

“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



# 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](#)

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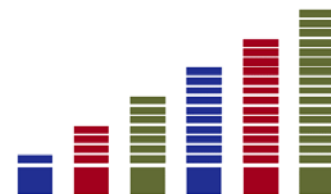
People may operate in public spaces but maintain strong perceptions or expectations of privacy (AoIR 2012).





# 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!

