

# GDPR from a researcher's point of view

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# NSD

- A national research infrastructure and data archive established in 1971
- From 2003 owned by the Norwegian Ministry of Education and Research
- Data protection official for research for 132 Norwegian research and educational institutions



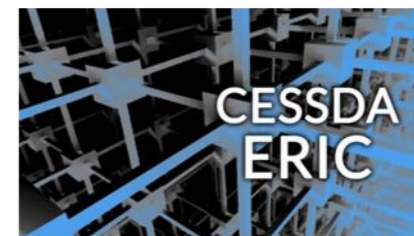
## Objective

Facilitate empirical research that primarily depends on access to relevant and high quality data



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SYNERGIES FOR EUROPE'S  
RESEARCH INFRASTRUCTURES  
IN THE SOCIAL SCIENCES



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NORWEGIAN CENTRE  
FOR RESEARCH DATA



## WP6 – New forms of data – legal, ethical and quality issues

### Tasks:

- T6.1. - Legal and ethical challenges related to the use of **social media data and related data**
- T6.2. - Legal, ethical and quality challenges related to the use of **administrative data**
- T6.3.- Connected **curation and quality**
- T6.4.- Consent and **biomarkers**

Partners: CESSDA ERIC, ESS ERIC, SHARE ERIC, KNAW



# The General Data Protection Regulation (GDPR)

- Implemented 25 May 2018 in all EU countries
- Applies to personal data and data of living persons
- Applies to any controller or processor:
  - **in the EU** who processes personal data regardless of whether the processing takes place in the EU or not
  - **outside the EU** if they process personal data of EU citizens
- will be supplemented by national laws
- repeals Directive 95/46/EC

# Key goals of the 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



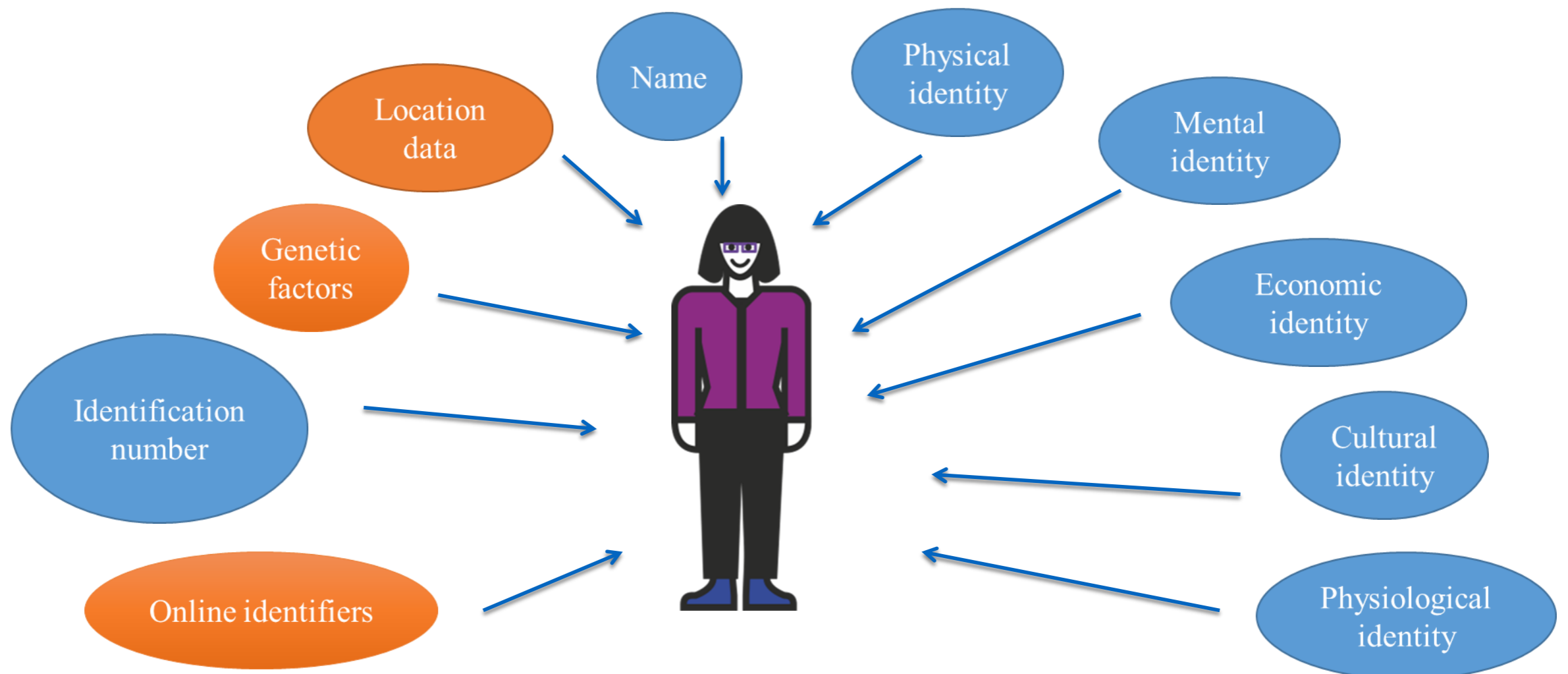
# GDPR – implications for research

## **More continuity than change, however:**

- GDPR has a limited flexibility, but leaves room for national supplementary provisions, including derogations, and this possibility applies especially to the field of research.
- Individuals get more rights i.e right to data portability
- Institutions will be held more responsible for the data they hold and process – “accountability”
- Increased fines for breaching GDPR and the misuse of personal data
- Broad definition of scientific research
- Privacy by design and default
- Data Protection Impact Assessment (DPIA)
- Code of conduct for various sectors encouraged
- New requirements for information to be provided to data subjects
- New requirements for consent
- Broad consent to certain areas of scientific research possible

# What is personal data?

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



# What is pseudonymous data?

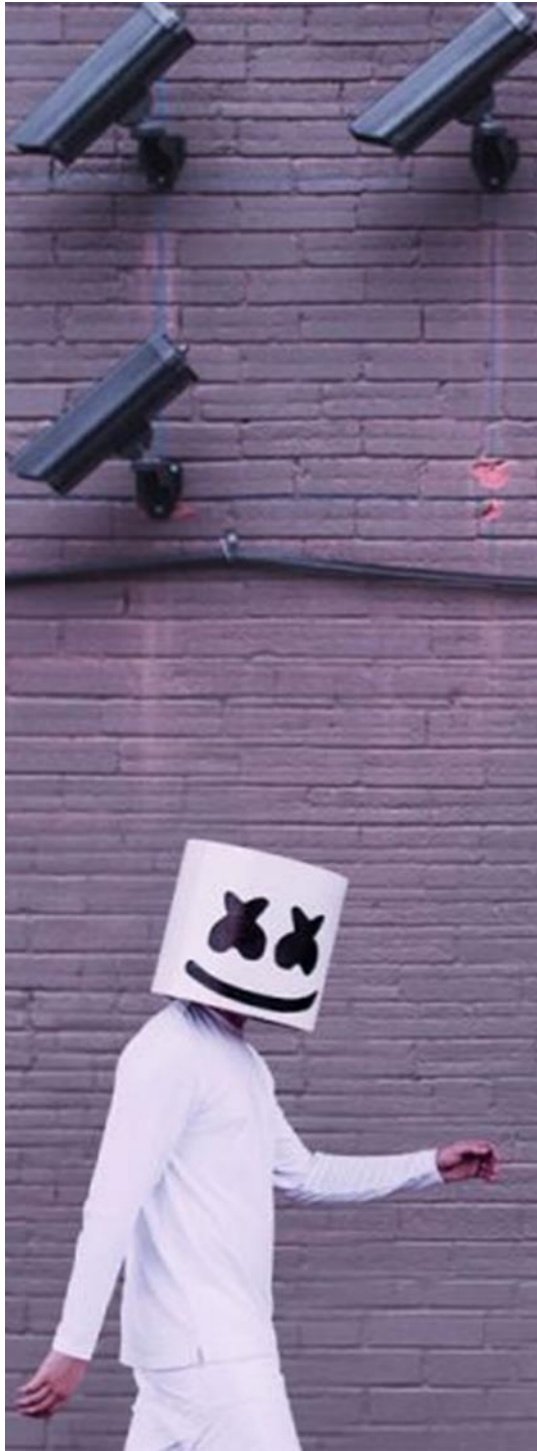
- The handling of personal data in such a way that no individuals can be identified from the data without a “key” that allows the data to be re-identified
  - Involves removing or obscuring direct and indirect identifiers
  - The key must be kept separately and secure
- Explicitly encouraged as a security measure in the GDPR
- Pseudonymised data or encrypted data are personal data





# What is Anonymous data?

- information which does not relate to an identified or identifiable natural person or
- personal data rendered anonymous in such a manner that the data subject is not or no longer identifiable.
- anonymisation of data should be irrevocable, but should also be checked at regular intervals in light of new technologies
- GDPR does not apply to anonymous data (Recital 26)



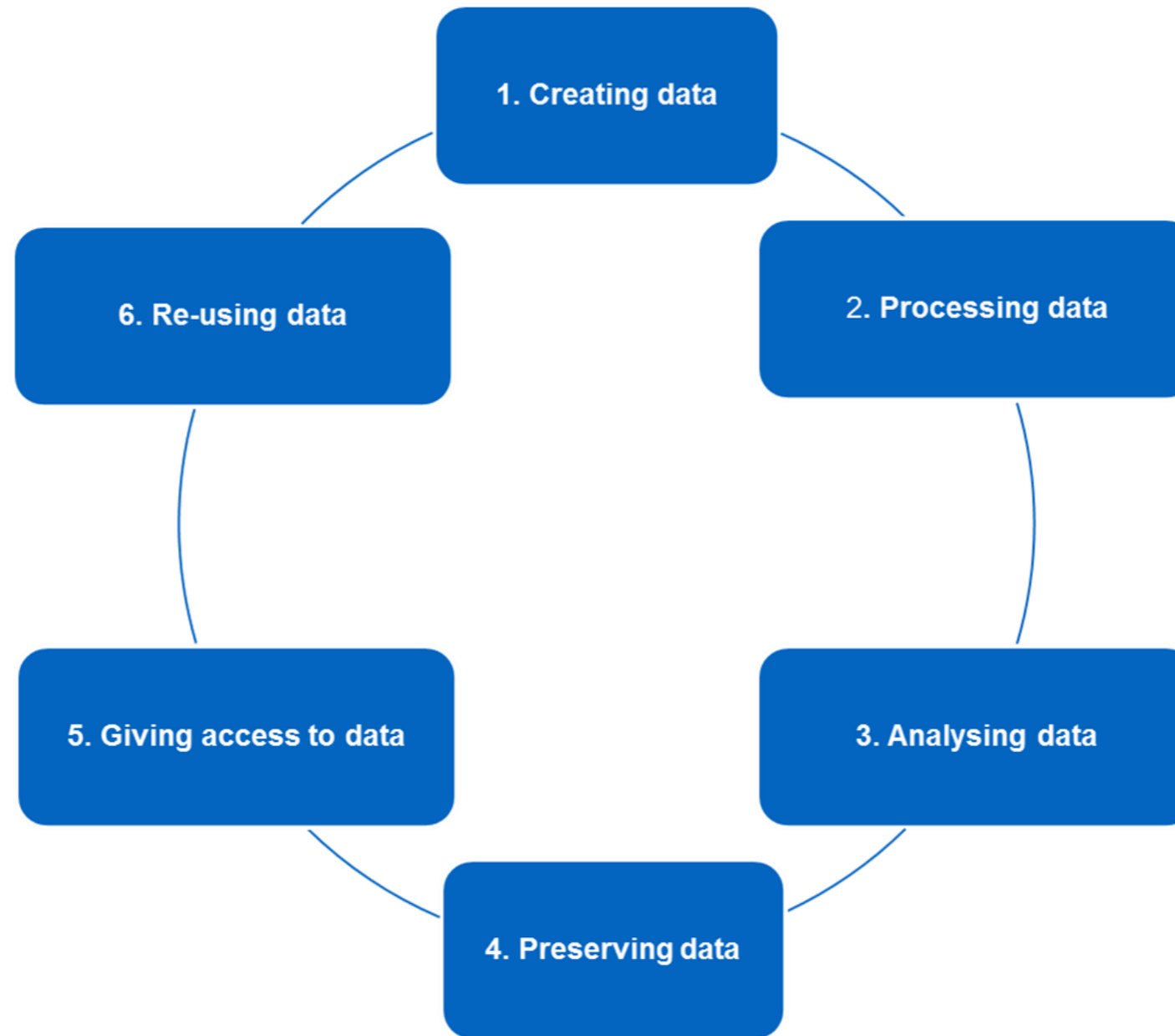
# Special categories of personal data

Special categories of personal data are subject to additional protection:

- racial or ethnic origin,
- political opinions,
- religious or philosophical beliefs,
- trade-union membership;
- data concerning health or sex life and **sexual orientation**;
- **Genetic data or biometric data** (Art. 9(1)).

EU/EEA states may maintain or introduce further conditions, including limitations for the processing of genetic, biometric and health data (Article 9,4)

# Law and legal practice affect all stages of the research data lifecycle.



# Six principles (Article 5)

## **Personal data must be:**

- a) Processed lawfully, fairly and in a transparent manner
- b) Collected for specific purposes and not processed further for incompatible purposes (purpose limitation) –  
exemption for research/archiving purposes in accordance with art.89 (1) – further processing not incompatible with original purpose
- c) Adequate, relevant and limited to what is necessary – (Data minimisation)
- d) Accurate and where necessary up to date
- e) Kept in identifiable form no longer than necessary (Storage limitation) - exemption for research/archiving purposes in line with art.89 (1).
- f) Processed with appropriate security – integrity and confidentiality

**The controller shall be able to demonstrate compliance - Accountability**

# Legal grounds for processing

All processing of personal data requires legal basis. The most common for research are:

## **Lawfulness of processing (Article 6):**

a) consent

e) necessary for the performance of a task carried out in the public interest

f) necessary for a legitimate interest pursued by the controller

## **Special categories of data (Article 9)**

Prohibited unless:

a) explicit consent

e) personal data are manifestly made public by the data subject

j) necessary for archiving, scientific or statistical purposes in accordance with Article 89.1 **and** based on Union or Member State law

# Special provisions for archiving and research purposes

When in accordance with Article 89 (1):

- Further processing is **not considered to be incompatible** with the initial purposes (Article 5(1)(b)).
- Personal data **may be stored for longer periods** (Article 5 ,1 (e))
- Exemptions from data subjects' rights:
  - "right to be forgotten" (Article 17.2 (d))
  - "right to object" (Article 21.6)
  - "right to information" (Article 14.5 (a,b))
- Union and Member States may create further derogations from the data subjects' rights

# Possibilities for Union and Member states

## **Derogations for scientific purposes - Art. 89 (2):**

- A.15 - right of access
- A.16 - right to rectification
- A.18 - right to restrict processing
- A.21 - right to object

## **Derogations for archiving purposes – Art.89(3) same as above and:**

Art.19 – Notification obligation (for rectification/erasure/restriction)

Art.20 – right to data portability (only when based on consent)

# Appropriate Safeguards

## Article 89 (1)

The use of derogations presupposes appropriate safeguards to protect the rights and freedoms of the data subjects.

### These include:

- Appropriate technical and organisational measures to respect the principle of data minimisation – i.e.
  - safe data and safe environments,
  - data protection officer involvement,
  - remote access solutions
- May include pseudonymisation and anonymisation, provided that the purposes can be fulfilled in that manner





# 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

# Consent

(Article 4 and 7)

**Definition:** any freely given, specific, informed and unambiguous indication from a person that affirms that his/her personal data may be processed

- **Freely given:** must be a genuine choice, be able to refuse/withdraw without consequences, not be in a dependent relationship
- **Specific** - not explained in the GDPR, but guidance from WP29 (2011) - clear information on extent and consequences
- **Informed:** Content and form requirements, should be easily understood, easily accessible, clear and simple language, especially when the information is given to children
- **Active:** “opt in” - silence, pre-ticked boxes, and inactivity are not valid (Recital 32)

# Consent (2)

- ❖ May be given in writing, orally or electronically
- ❖ The controller must be able to demonstrate that consent has been given
- ❖ Must be distinguishable from other matters.
- ❖ It should be as easy to withdraw consent as to give it
- ❖ Explicit consent when processing special categories of data for one or more specified purposes
- ❖ Can be used as legal basis to transfer data outside of EU (art.49)
- ❖ National legislation may impose more requirements for consent, i.e. within health

**Broad consent for certain areas of scientific research when in keeping with recognized ethical standards for scientific research (Recital 33)**

# Information to data subjects

(Article 13 and 14)

## **An information sheet should provide information about:**

- Name and contact details of the controller
- Name and contact details of DPO
- Purpose of research
- Legal basis – if use of legitimate interest - what legitimate interest
- Who you will share personal data with
- Possible transfer to countries outside of Europe
- Period of storage or criteria for determining the time period
- Data subjects' rights (access / correction / deletion / limitation / reservation / data portability)
- Right to withdraw consent
- Right to complain to the Data Inspectorate
- Occurrence of automated decisions
- Planned usage of data during the whole research data lifecycle
- Procedures for safeguarding personal information

## **Extra requirements where personal data are not collected from the data subject**

- From which sources the data originate
- Information must be provided within one month
- information must be given before commencing when processed for new purposes –

# Example from SERISS



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## Your privacy - safe storage and further use of the data

- We will treat all the information about you with strict confidentiality and in accordance with EUs General Data Protection Regulation (GDPR) and national data protection laws.
- Your name and contact information will be replaced by a code. Only the national team, that collects data, will have access to the code list.
- When the survey is finished, the national team will send the data, without your name or contact details, to the Archive (NSD - Norwegian Centre for Research Data, Bergen, Norway).
- Your name and contact information will be deleted by [mm/yr] .
- The rest of the collected data will be securely stored for an indefinite period. They are made available for use in scientific studies by researchers, students and others interested in Europeans' social attitudes.
- **There is a slight possibility that some background information** (such as citizenship, age, country of birth, occupation, ancestry and region <expand>) **may identify you**. In such cases, access will only be given to researchers after approved applications and confidentiality agreements are in place.
- The results will be published on our website in [month/year]. **We will make every effort to ensure** that no participant will be recognisable in any publications (scientific papers, website etc.) based on the study.



NORSK SENTER FOR  
FORSKNINGSDATA

## Your rights

As long as we are certain that we can identify you in the data material, you have the right to:

- object to the processing of your personal data, and to access, modify and erase any information about you. If you wish to make use of these rights, please contact the national team <insert name of fieldwork agency>.
- ask us what information we hold about you. See our website or <contact our Data Protection Officer, see below for details.>
- You also have the right to lodge a complaint with the supervisory authority for data protection, the Information Commission's Office (<https://ico.org.uk/global/contact-us/>) or to your national supervisory authority: [insert contact details]

# Some important considerations

- 1) Will you handle personal data?
- 2) Will you handle special categories of data?
- 3) Does the data contain information about third persons?
- 4) Is some of the data likely to be considered sensitive to the person in question?
- 5) Might the research lead to unwarranted stigmatisation or discrimination against a group?
- 6) Do any of the data subjects constitute/represent vulnerable groups (i.e. children, vulnerable adults)?
- 7) What is the legal basis for collecting data?
- 8) Is it necessary and/or possible to inform the data subjects?
- 9) Is it necessary to derogate from any of the data subject's rights?
- 10) Are there issues related to ownership/terms of use/ other legal issues
- 11) Archiving/re-use issues

# OECD recommendations for researchers

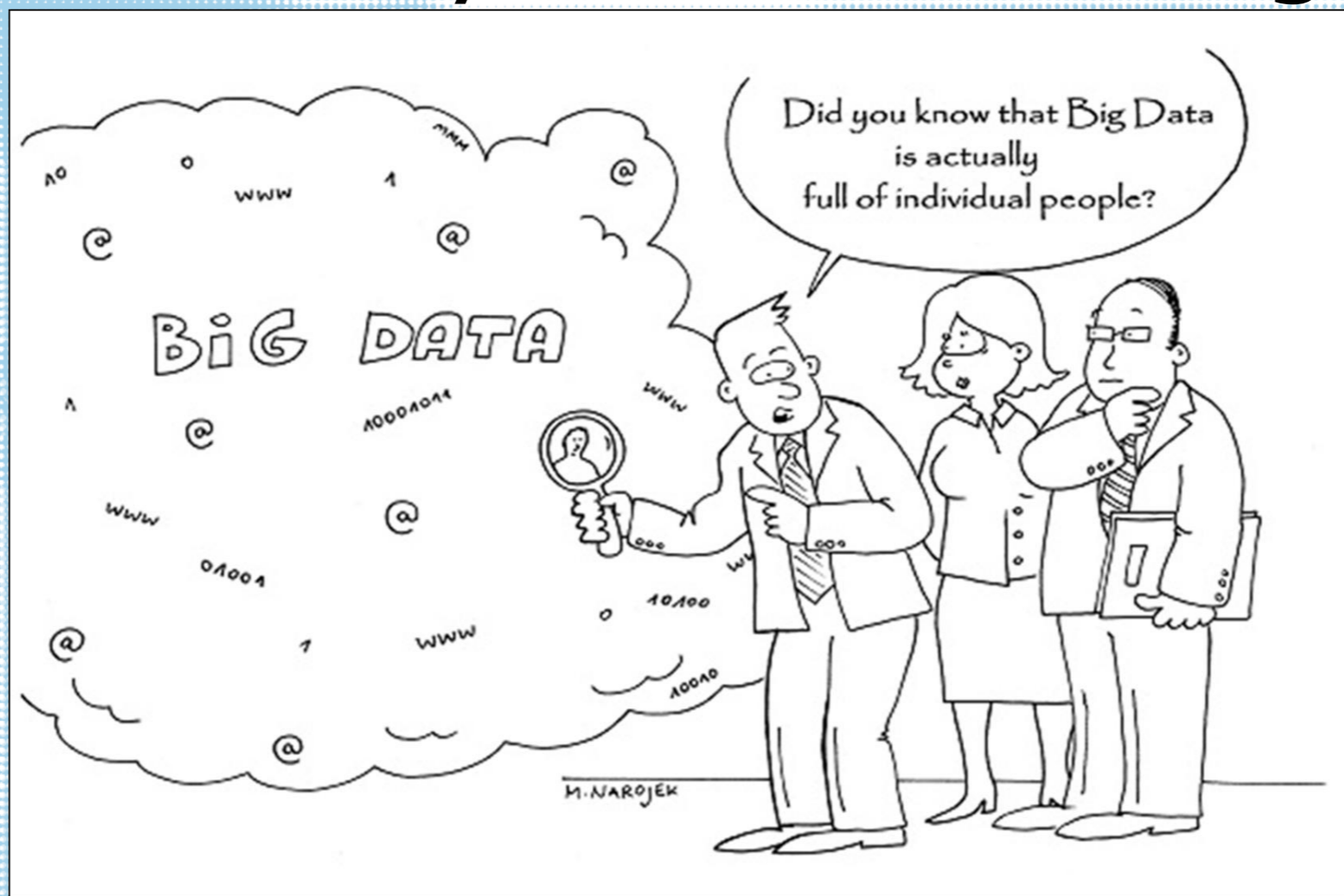
- Make a plan for clear communication to relevant audiences on how their privacy will be protected in research.
- Make a brief statement understandable to non-experts, explaining the general purposes and motivations for the research, together with an assessment of the potential risks and benefits;
- consider the means of obtaining, and wording of, the consent sought for new data collection with a view to future-proofing' the consent to enable future research projects to use the data
- where possible, offer research participants the means to receive updates about the progress of the research, including previously unanticipated uses of data and opportunities to reaffirm consent for use, where applicable.



# Concluding remarks

- GDPR is research friendly and safeguards the interests and the needs of scientific research institutions
- The legal bases for processing data for research purposes are largely in place, but the possibility for member states to introduce conditions for certain types of data may pose a challenge.
- Increased risk of re-identification creates a need for greater transparency to retain public trust
- New requirements for information to be provided
- New requirements for consent
  - Must be able to document that consent has been given
  - As easy to give as to withdraw

# Thank you for listening!



# NSD

NORWEGIAN CENTRE  
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- GDPR - [http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L\\_.2016.119.01.0001.01.ENG&toc=OJ:L:2016:119:TOC](http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L_.2016.119.01.0001.01.ENG&toc=OJ:L:2016:119:TOC)
- Guidelines from Article 29 WP - [http://ec.europa.eu/newsroom/just/item-detail.cfm?item\\_id=50083](http://ec.europa.eu/newsroom/just/item-detail.cfm?item_id=50083)
- OECD (2016), "Research Ethics and New Forms of Data for Social and Economic Research", OECD Science, Technology and Industry Policy Papers, No. 34, OECD Publishing, Paris.
- <http://dx.doi.org/10.1787/5jln7vnpxs32-en>