



# seriss

SYNERGIES FOR EUROPE'S  
RESEARCH INFRASTRUCTURES  
IN THE SOCIAL SCIENCES

[www.seriss.eu](http://www.seriss.eu)  
@SERISS\_EU

## WP6 - New forms of data: legal, ethical and quality issues & Perspective on the GDPR implementation

### 3<sup>rd</sup> SERISS Survey Experts Network Workshop London 19<sup>th</sup> June 2018

Marianne Høgetveit Myhren  
NSD, CESSDA ERIC

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



This project has received funding from the *European Union's Horizon 2020 research and innovation programme* under grant agreement No 654221.



# seriss

SYNERGIES FOR EUROPE'S  
RESEARCH INFRASTRUCTURES  
IN THE SOCIAL SCIENCES

[www.seriss.eu](http://www.seriss.eu)  
@SERISS\_EU

## A collaboration between:

- European Social Survey (ESS ERIC)
- Survey of Health, Ageing and Retirement in Europe (SHARE ERIC)
- Consortium of European Social Science Data Archives (CESSDA ERIC)
- Generations and Gender Programme (GGP)
- European Values Study
- WageIndicator Survey



This project has received funding from the *European Union's Horizon 2020 research and innovation programme* under grant agreement No 654221.



## Designed to:

- Strengthen social science research across Europe and beyond by overcoming fragmentation and fostering interoperability, harmonisation and innovation
- Equip social science infrastructures to play a major role in addressing key societal challenges and ensure that national and European policy making is built on a firm socio-economic evidence base
- Promote the value of the social sciences to the wider research community, and policymakers





## Objectives WP6 - New forms of data: legal, ethical and quality issues

- Determine and provide guidance related to the legal and ethical issues when using traditional and new forms of data in the social sciences
- Ensure social scientists can work effectively when handling personal data within an evolving legal and ethical framework whilst retaining the confidence of the public
- Increase the range and depth of the CESSDA infrastructure to ensure that new forms of data can be shared and reused





## WP6 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**





## List of deliverables:

- **Three submitted**

- **D6.10 – Synopsis of policy-rules for collecting biomarkers in social surveys – T6.4**
- **D6.11 – Biomarkers consent analyses – T6.4**
- **D6.7 Generic high-level workflows for the curation of different forms of 'Big Data' – T6.3**

- **Five due in June 2018**

- **6.1: Work-shop on use of social media data in social surveys – T6.1**
- **6.4: Work-shop on use of administrative data in social surveys - T6.2**
- **6.8: Versioning requirements for curation and access to new forms of data - T6.3**
- **6.9: Appraisal/selection requirements for new forms of data – T6.3**
- **6.12: Report on practical strategies to include biological samples in population-based social surveys – T6.4**

- **Two due in December 2018**

- **6.3 Guidelines on the use of social media data in survey research – T6.1**
- **6.5 Guidelines on the use of administrative data in survey research – T6.2**

- **Two due in April 2019**

- **6.2 Report on legal and ethical framework and strategies related to access, use, re-use, dissemination and preservation of social media and related data – T6.1**
- **6.6: Report on legal and ethical framework and strategies related to access, use, re-use, dissemination and preservation of administrative data - T6.2**

- **One due in June 2019**

- **6.13: Report on the feasibility of a “broad consent” strategy with regard to the storage and use of biological samples – T6.4**

Task 6.1 = Green
Task 6.2 = Blue
Task 6.3 = Purple
Task 6.4 = Red





Legal and ethical issues affect all stages of the research data lifecycle.





## 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 offer goods/services or monitor behaviour 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:**

- Individuals get more rights e.g. right to data portability
- New requirements for information to be provided to data subjects
- New requirements for consent
- Broad consent to certain areas of scientific research possible
- Broad definition of scientific research
- Code of conducts for various sectors encouraged
- 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
- Privacy by design and default
- Data protection officers mandatory for many institutions





# What are personal data?



<https://www.cessda.eu/Research-Infrastructure/Training/Expert-Tour-Guide-on-Data-Management/5.-Protect/Ethics-and-data-protection>



This project has received funding from the *European Union's Horizon 2020 research and innovation programme* under grant agreement No 654221.



## What are 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)





## 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



# 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

## **Processing of 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 (Article 89. 2 and 3)





# Consent

Wikimedia Commons

**Definition:** any freely given, specific, informed and unambiguous indication from a person that affirms that his/her personal data may be processed (art.4)

- **Freely given:** must be a genuine choice, be able to refuse/withdraw without consequences, not be in a dependent relationship
- **Specific** - 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
- **Unambiguous:** "opt in" - silence, pre-ticked boxes, and inactivity are not valid (Recital 32)







## Consent (2)

- ❖ The controller must be able to demonstrate that consent has been given
- ❖ 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, e.g. 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 –





## GDPR compliant participant information sheet

### ESS round 9 as use case

- both personal data and special categories of personal data
- both respondents and non-respondents
- Legal basis – consent, public interest or legitimate interest?

### Consent and information requirements in the GDPR:

- Article 4,7,8, and Chapter III, especially Article 12,13 and 14 GDPR
- Relevant preambles
- WP29 consent and transparency guidelines

### Challenges:

- How to documents that consent is given?
- As long as it is possible to identify someone, people can exercise their rights
  - How to facilitate the demand for «it should be as easy to give consent/withdraw consent

### Disadvantages when not using consent as legal basis?

- Use of public interest in requires national law – may differ in different European countries
- Possibilities to link survey data to new forms of data might be challenging

Information sheet will be used to make a specific and generic informed consent/information sheet template that will include guidance on linkage to social media data and administrative data.





## Example from ESS

### 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 EU's 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.





## 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 process personal data?
- 2) Will you process special categories of data?
- 3) What is your legal basis for processing personal data?
- 4) Have you provided the necessary information for participants to exercise their rights?
- 5) Have you ensured that appropriate safeguards are in place - requires appropriate technical and organisational measures:
  - Principle of data minimisation
  - Pseudonymisation/anonymization/encryption
- 6) Is it necessary to derogate from any of the data subject's rights?
- 7) Are there issues related to ownership/terms of use/ other legal issues?
- 8) Have you planned for archiving/re-use of data?





## Thank you for listening!

