

Personal Data Protection in Social Sciences in Big Data Era

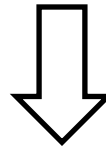
BIG DATA: NEW CHALLENGES FOR LAW AND ETHICS

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- Data in Social Sciences
- Ethical Framework
- Legal Framework
- Social Media Data in Research
- SERISS
- CESSDA
- Activities

- Data about individuals and other potentially sensitive and disclosive data
 - New forms of data in scientific research:
 - ✓ Big data
 - ✓ Social media data
(content is user generated and actively shared)



- **Legal and ethical challenges**
 - ✓ Protection of privacy
 - ✓ Informed consent
 - ✓ Data confidentiality

Ethical Framework

How to protect the privacy of research subjects throughout the whole research lifecycle?

Research community **ethical codes:**

- Protect participants against possible harm and distress
 - Assure participation by obtaining informed consent
 - Respect disciplinary methodological standards
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- ✓ Consider data use, results presentation, data access and data management
 - ✓ Inform participants
 - ✓ Apply safeguards (direct/indirect identifiers, different level of protection)

Legal framework (1)

The new General Data Protection Regulation (GDPR) will replace the former EU Data Protection Directive in May 2018

Objectives:

- To protect fundamental rights and freedoms of persons, in particular their *right to protect personal data*
- To allow for the *free movement of personal data* without restrictions and prohibitions for reasons connected with the protection of persons with regard to the processing of personal data.

Introducing new responsibilities of controllers and processors, while strengthening data subject rights, but still believed to be research friendly.

Legal framework (2)

Data protection is ensured through the **consent**:

→ GDPR defines consent as „any freely given, specific, informed and unambiguous indication of the data subject’s wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her.“(Article 4 (11))

However, its requirements are not absolute – exemptions for scientific and historical research

- The processing of sensitive personal data is allowed if the data subject has given explicit consent **or** the processing is necessary for research purposes (Article 9 (a) and (j))

Legal framework (3)

“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 ('purpose limitation'). (Article 5(b) and Recital 50).



Secondary use of data collected from administrative registers or the internet

- ✓ For scientific research purposes without having to obtain further consent from the individuals
- ✓ If appropriate safeguards are in place (Article 89(1)):
 - *anonymisation* (removing personally identifiable information where it is not needed),
 - *pseudonymisation* (replacing personally identifiable material with artificial identifiers),
 - *encryption* (encoding messages so only those authorised can read it).

GDPR and Research Community

The GDPR contains special provisions on processing of personal data for health purposes as well as for historical, statistical and scientific research purposes.

It gives member states a mandate to grant research interests a special status and to allow them guarantees within the scope of data protection.

But:

following Article 6 “Lawfulness of processing”, member states may also introduce additional conditions to processing personal data, which in turn might pose challenges for scientific research!

Social Media Data

Public or private?

If private → seek consent:

- massive data
- re-use of data (consent too specific for the initial research purpose)

Legal:

- Information made publicly available is exempted both from the Directive and the new GDPR (Article 9, 2 (e)).

Social media data can be legally used without consent (but not archived!)

Ethical:

- Although it might be legal, it does not necessarily mean that it is ethical as well

“People may operate in public spaces but maintain strong perceptions or expectations of privacy. Or, they may acknowledge that the substance of their communication is public, but that the specific context in which it appears implies restrictions on how that information is -- or ought to be -- used by other parties” (AoIR 2012).



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

(Marianne Høgetveit Myhren, Norwegian Social Science Data Services)

6.1 Legal and ethical challenges related to the use of social media data and related data

- How social media data is used in social scientific research
- Legal and ethical challenges related to the use and re-use of social media data
- How is administrative data used in social scientific research
- Legal and ethical challenges related to the use and re-use of administrative data
- Legal and ethical challenges regarding preservation/archiving
- Dissemination
- Legal and ethical challenges related to cross-national transfer
- Quality assessment

Consortium of Social Science Data Archives



- Permanent research infrastructure for delivering better access to data, regardless of data location and researchers' location.
- 15 members (+ 1 observer)
- Each member is represented by a national institution – a Service Provider (appointed by the Ministry)

Arhiv družboslovnih podatkov (ADP) – Social Sciences Data Archives

- ✓ CESSDA Member (representing Slovenia)
- ✓ National repository for social sciences (the only research data repository in Slovenia)

CESSDA Members Activities

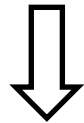
Nordic cooperation project in relation to the implementation of the new GDPR

- Project partners: Norwegian Centre for Research Data, Swedish National Data Service, The Danish National Archive, Finnish Social Science Data Archive (legal advice provided by Nordforsk)
- Aiming to strengthen the Nordic research community by making it *easier to share data* (including register data) among themselves and across national borders
- Exploring and highlighting *the impact of GDPR* on existing and new possibilities and barriers for data sharing and research collaboration in the Nordic countries
- Expected output: recommendations to the Nordic ministries with regard to the *implementation of the research and archiving provisions in the GDPR*

Source: Nordic cooperation project in relation to the implementation of the new GDPR; New data protection rules in the EU open doors to Nordic research in [NSD News](#) - 1/2017.

ADP Activities

Research communities across the member states should monitor the implementation process as well as communicate their research interest in order to protect it.



Round table conference: “Ethics in Science with a special focus on the New General Data Protection Regulation”

Faculty of Social Sciences, University of Ljubljana, 12 January 2017

Proposal to set up a *working group*, gathering researchers and other relevant stakeholders, aiming to protect research interests by actively engaging in the implementation process at a national level as well as by raising awareness of the importance of scientific research to society.

Why Call to Action?

Countries have common vision, objectives, activities to support long term curation and sharing of research data and to tackle main challenges of society.

But:

- Research interests and data protection interests should be *balanced* (Kvalheim, 2016)
 - Protection is needed both for participants in research as well as for the researchers
 - Information **privacy** vs. **legitimate interest of research** to access and use personal data
- Data sharing rules should be *clarified* (Litton, 2017)
 - Society needs access to data
 - **Transparency** and **replicability** of research

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