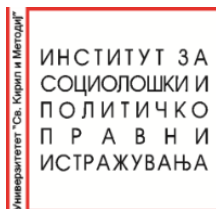


REGIONAL ROUND TABLE: LEGAL AND ETHICAL ISSUES IN RESEARCH DATA MANAGEMENT AND OPEN SCIENCE IN SEE COUNTRIES

LEGAL AND ETHICAL ISSUES REGARDING DATA COLLECTION AND SHARING IN RELATION TO OPEN ACCESS: Perspective of the Social Science Data Archive of North Macedonia

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Ethical principles in social research

Researchers are obliged to protect the integrity of respondents using the ethical principles in four key areas:

- **Protection against harm to participants.**
- **Informed consent** - voluntary participation and consent for data sharing; research staff and subjects must be informed fully about the purpose, methods and intended possible uses of the research data; what their participation entails and what risks, if any, are involved.
- **Invasion of privacy** - ensuring anonymity and confidentiality in relation to the recording of information and the maintenance of records relates to all methods of social research.
- **Protection against fraud or deception of respondents.**

Law on Scientific and Research Activities



- **The Law on Scientific and Research Activities** (2008) is based on a number of principles, and some of which address ethical issues in research data management:
 - ethics;
 - transparency of the work and dissemination of results;
 - application of international quality standards in science; and
 - inviolability and protection of human personality and dignity.



Law on Scientific and Research Activities

- The Law provides for the **establishment of an Ethics Board**. Board members should be appointed by the government.
- **The task of the Board** is to monitor and evaluate the application of ethical principles and values in scientific research; the protection of human integrity in scientific research; and the ethics of business relations between the subjects performing research activity.
- The Board adopts a **Code of Ethics** that sets out ethical principles: in scientific and research work; when publishing the results of the scientific research activity; in the relationships among researchers; in actions and activities related to competition and in public relations and the media.
- To our knowledge, no Ethics Board has been formed so far, and no Code of Ethics has been adopted.



Regulation of ethical issues in research data management within the universities

- **At the university level**, ethical norms and values related to research data management are very general addressed in Codes of Ethics
- For example: ***Code of Ethics of the “Ss. Cyril and Methodius” University in Skopje***
- ***Section 5. “Ethics in Science and Higher Education”*** states that the “Ss. Cyril and Methodius” University in Skopje implements all ethical norms of developing scientific knowledge; respects the status of the research subject and the authenticity and originality of the findings; provides linking of the research with other research and scientific institutions in the country and abroad; enables data availability and information to all concerned, primarily to the scientific community.



Research ethics committees

- Depending on the nature of the research, or when the topics are highly sensitive, **the funding organization may sometimes require from researcher to submit proposed research to an ethics committee** of the university or the research institution.
- **The role of an ethics committee is to oversee the implementation of the specific research.** This practice has been adopted and applied by Macedonian universities and research institutions.



Legal aspects of data protection and dissemination

- **Law on personal data protection** (Official gazette of the R. Macedonia No.7/05, 103/08, 124/08, 124/10, 135/11, 43/14 and 153/15)
- **Law on free access to information of public character** (Official Gazette of the R. Macedonia N. 13/06)
- **Law on copyrights and related rights** (Official gazette of the R. Macedonia No. 115/10, 140/10 и 51/11)
- **Law on archival material** (Official gazette of the R. Macedonia No. 95 from 26.7.2012)

Law on personal data protection



The Law regulates the protection of personal data through the discourse of protection of personal liberties and freedoms of individuals, and the right of privacy in connection with the usage, secrecy and protection in processing the personal data of citizens of the RN Macedonia.

- **Article 2 determines the meaning of certain terms used in this law:**

- **"Personal data"** shall be any information about an individual whose identity may be determined directly or indirectly.

- **"Personal data processing"** is every operation performed on personal data, automatically or otherwise, such as: collection, recording, organizing, storing, adjusting or altering, withdrawing, using, revealing through transmitting, publishing or making them otherwise available ...

- **"Special categories of personal data"** are data that reveal racial or ethnic origin; political, religious, philosophical or other beliefs; trade union membership; health condition, as well as genetic, biometric or sexual life data.

- **The secrecy and protection of the processing of the subject's personal data** is provided by applying "proper technical and organizational measures for protection of accidental or illegal damaging of the personal data, or their loss, change, unauthorized disclosing or approach, especially when the processing includes transmission of data over a network" (Article 23, paragraph 1).

- Regarding the **provision of personal data**, article 34 prescribes that: "The personal data processed in scientific, research and statistical purposes may not be revealed to the user in a form which enables identification of the person to whom the personal data refer".

Law on free access to information of public character



- **Provides transparency in the work of the state and public bodies and free access to information that are produced and/or possessed by such entities.** The **information holder** can be “public institution or service, legal and physical person that have public duties and their activity is in public interest” (Article 1- 3). **Information requester** is any legal or natural entity without any discrimination, which includes domestic and foreign entities (Article 3 and 4).
- The law defines that a **document is any information regardless of its physical form or nature, which includes texts on paper, any type of audio and video material and records**, but also moveable equipment for data processing, including equipment or parts of equipment, where the data are stored (Article 3).
- The main logic of the law is that any **information is under “free access”** if it is in the public interest and especially if it is produced and held based on public money.



Law on copyrights and related rights

- This Law regulates the **copyrights of authors over their work**, among others, the rights of authors of data sets over their works, as well as the practicing and protection of copyrights and related rights (Article 1).
- According to this Law, **related rights can also be “data bases and their authors”**. Related rights are regulated in Part 6 - The rights of authors of data bases (Article 118-122).
- The law **includes the following aspects**: definition of data base authors; contents of the rights of the authors of data bases; the scope of protection; rights and obligations of the legal users; restriction of the rights; and duration of the rights of authors of data bases.



Law on archival material

- The Law regulates the protection, storage, processing and use of archival material.
- **Archival material** is defined as “documentary material of permanent value for R. N. Macedonia, the science, culture, its possessors, as well as for other needs.” (Article 3)
- **Research data bases** are defined as “nonconventional archival and documentary material”, as “data kept/noted in data bases which can serve as a basis for creation of conventional documents...”.
- Also regulates **the right of access and use of the data**. The electronic archival and documentary material is regulated separately by the law (Article 8 - Article 15) where provisions with regard to “electronic archive” and “electronic data” exist, concerning their preservation, accessibility, security, confidentiality and authenticity.