



LEGAL ASPECTS OF PERSONAL DATA PROCESSING FOR SCIENTIFIC PURPOSES

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Role of the Directorate for Personal Data Protection

- supervising lawfulness of personal data processing by data controllers
- establishing violation of the right of citizens if personal data are disclosed
- Imposing fines



Relevant legal framework

- Law on Personal Data Protection from 2005
- By-laws (Rulebook on technical and organizational measures, Rulebook on video surveillance, Rulebook for notification of data collections in the Central registry, Rulebook for notification of transfers to other countries, Rulebook on inspection supervisions)



New Law on personal data protection transposing GDPR

- New draft Law on Personal Data Protection prepared, not enacted yet !
- 20 new By-laws (transparency of data processing, notification of high risk processing, transfer of personal data in other countries, certification and accreditation, video surveillance, training of DPO's etc.)



Legal ground for the data processing, art. 6 Law on Personal Data Protection

- Informed consent of data subject
- Execution of contract
- Legal obligation
- Vital interests of data subjects
- Public interest
- Legitimate interests of data controllers



Principles of data protection
Article 5, Law on Personal data protection North Macedonia

- Lawfulness, fair and transparent processing
- Purpose limitation principle
- Data minimization
- Accuracy principle
- storage limitation principle (long-term archiving for scientific, historical and statistical research purposes is allowed, respecting the privacy of data subjects and data should be anonymous as early as possible)



Article 5 Law on personal data protection North Macedonia

Compatible use of personal data with the primary purpose

- Further use of personal data for historical, statistical, scientific research is allowed if necessary safeguards are taken



**article 81, new draft
Law on personal data
protection**

Personal data processing for public interest archiving, scientific and historical research and statistical purposes

Data controllers are obliged to take adequate safeguards

- Technical and organizational measures to ensure data minimization
- Pseudonymization
- Anonymization

Exemptions of data subject rights must be provided in special law

Right of access, right of limited processing, right to object if they seriously impede research



**New developments
with the transposition
of the GDPR**

Privacy by design

Privacy impact assessment for high risk processing

Data breach notification

Higher fines !!!



Identifying higher legal and ethical risks in research proposals

- Types of personal data (especially sensitive data)
- Data subjects (children, vulnerable groups)
- Scale and complexity of data processing (large scale processing, systematic monitoring, big data)
- Data collection or processing techniques (surveillance, AI, profiling, data mining, automated decision making)
- Involvement of non-EU countries

“Ethics and data protection” European Commission, November 2018



Data subject rights

Right to be informed

Right to object

Right to access, rectify and erase data



Data sharing

Relations with other research partners (agreement between joint data controllers)

Agreement with data processors

- obligation to follow the instructions of data controller
- ensures appropriate security safeguards



Prior approval of data processing by DPA

- Unique identification number
- Racial and ethnic background
- Biometric data
- Genetic data

Except if there is a legal ground for the processing



Transborder flow of personal data

Notification to the DPA for the transfer in EU/EEA

- data controller submits application and the transfer is only registered

Authorization by DPDP for the transfer of personal data in third countries (non EU/EEA)

- the director issues a decision



Technical and organizational measures for preventing unauthorized access, disclosure

Anonymization

- Anonymization of data sets before disclosure
- Mitigating the risk of re-identification of physical persons

Pseudonymization of data

"Anonymization decision-making framework", UK Anonymization Network

Data security



Recommendations

Developing special guidance's for personal data processing for scientific research

Enhancing the role of data protection officers in the research community

Regular trainings