European Transport Network Alliance

Webinar on GDPR & Ethics in Transport Research

Thursday, May 16, 2019 | 11.00 – 12:00 CET

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Moderator: Vassiliki Kalodimou, NCP for Transport FORTH/PRAXI Network
Purpose of today’s webinar

• Background
• Familiarisation with GDPR
• GDPR in Research
• How GDPR and ethics relate in H2020 project obligations
• Ethical considerations in Transport
About me...

• Electrical & Computer Engineer
• Technology transfer consultant and NCP
• DPO for PRAXI Network
• Co-founder of Enterprise Risk Management, Whistleblowing and Data Protection SME “Fraud Line”
• Certified DPO and Certified Privacy Professional– IAPP CIPP/E
• Member of the Ethics Committee of National Centre for Scientific Research "Demokritos"
A little history

• Legislation in relation to personal data has been in place for several decades.
  • An example of doctor-patient, lawyer-client confidentiality

• With the advancement of technology, we have the ability to easily collect and process personal data on a large scale.

• Artificial intelligence has changed the way data is processed, results are not always repeatable.

• Although the positive effect of technology is enormous, problems also arise, e.g. cyber security / criminal activity
Why

• Legislation over the years has gradually adapted as needs changed and increased.
• The rapid changes in technology, the trend towards digitization, the great data and the advancement of the Social Media have brought changes.
• Earlier European legislation was in the form of a directive and was interpreted differently by European countries, creating a heterogeneous mosaic.
• The current needs for the protection of personal data and the need for free movement of data within the EU led to the creation of GDPR.
• Specifically transport is becoming data rich and data from Intelligent Mobility (transport users), such as journey data although intangible, are now considered as infrastructure*

* Open Data Institute: Personal data in transport: exploring a framework for the future.
When

• Voted on April 14, 2016.
• Applied May 25, 2018.
• Automatically applies to all European countries.
• In anticipation of the Greek law.
• It looks at the risk from the subject's side.
• Carrot - whip
  • It creates a unified landscape with respect to personal data and their protection.
  • It provides fines of 2-4% on the turnover.
Personal data

• **Personal data** is anything that can directly or indirectly identify the identity of a natural person (GPS, IP address, car plate, etc)

• General Personal Data (demographics, contact information)

• Personal Data related to the subject of the activity (eg educational or research profile)

• Special categories (eg health, political beliefs, ethnic origin, biometric data)
GDPR Principles

• **Lawfulness, fairness and transparency**
  • Data processing is done in a legal, fair and transparent manner.

• **Purpose limitation**
  • The data collection is for defined, explicit and legitimate purposes, and the data is not further processed in a way incompatible with these purposes.

• **Data minimisation**
  • Data is **appropriate, relevant and limited to what is necessary** for the purposes for which it is processed.

• **Accuracy**
  • The data must be accurate and up-to-date while at the same time all reasonable steps must be taken to immediately delete or correct personal data which are inaccurate with the purposes of the processing.
GDPR Principles (continued)

• **Storage limitation**
  • Data shall be retained in a form which permits the identification of data subjects only for the time required for the processing of personal data.

• **Storage limitation**
  • Data shall be processed in such a way as to guarantee the appropriate security of personal data.

• **Accountability**
  • The controller is responsible for demonstrating compliance with the above principles.
Rights

• to be **informed** about the processing of your personal data;
• to **access your** personal data;
• ask for the **correction of** incorrect, inaccurate or incomplete personal data;
• request a **deletion** of personal data when it is no longer necessary or if processing is illegal;
• **oppose** the processing of your personal data for marketing purposes or for reasons related to your particular situation;
Rights (continued)

- request a **restriction on** the processing of your personal data in specific cases;
- to **receive** your personal data in a machine-readable format and send it to another controller ("data portability");
- to make a request that decisions based on **automated processing** concern you or affect you to a significant extent and are based on your personal data to be made by natural persons and not just by computers.
GDPR in Research and Innovation

• **Strengthening** privacy rights

• A central element of the **Digital Single Market** and the promotion of **digital innovation** within the EU

• It seeks to **reconcile** the competing values of **privacy** and **innovation**
Research as a Legal Basis for PD processing

- **Legal basis** for any processing activity.
  - Consent
  - Legal interest of an organization
- Data **may** be processed for **secondary research purposes**
- The search is not explicitly defined as a legal basis for processing, but in some cases it **can be considered as a legitimate interest**.
- It is permissible to collect PD for research purposes **without requiring the consent** of the subject.
- The basis of legitimate interest raises a balancing test with the rights of the subject of the data which prevail.
Further processing of personal data for research purposes

- **Clear consent** of the data subject for a specific purpose
- **It is not possible to determine the purpose** of the processing of personal data for scientific research **at the time of collection**
- **Later processing operations** that are "**compatible**" are allowed.
- "Further processing for archiving purposes which is of public interest, for purposes of scientific or historical research or for statistical purposes, shall be considered to be a compatible legal act of processing."
Broad consent

• Consent and information are **challenges** because of the **difficulty of identifying research purposes in advance**, especially in the context of big data.

• If consent is sought for the processing of personal data for scientific research, it **does not need to be as specific as for other purposes**.

• However, the GDPR requires that the **general research areas** be identified and, where possible, given to people detailed **options** for consent only to specific research stages of the research process or parts of research projects.

• So a person can **limit** his consent:
  • the specific and direct processing envisaged,
  • the next level of research that could be predicted
  • the use of their data for general research issues / topics within the general research scope that have been identified and which can not be considered at this time.
Information requirements

• The controllers **are obliged to provide the information** in a concise, transparent, comprehensible and easily accessible form, in clear and simple language, about the nature of the processing activities and their rights in all circumstances, **regardless of whether consent is the basis for processing**.

• **Up-to-date information** should be provided when the controller **intends to process further data** for a different purpose, including for research. Subsequent information should include both the **new research objective** and the **rights of the data subjects**.
Information requirements (continued)

Information **at the time of data collection** includes

- the identity and contact details of the controller
- the purposes of the processing activities
- that the data is transferred to another entity or other third country
- the right to access, correct, delete and protest the data subject
- information on the period during which personal data will be stored or, if that is not possible, the criteria used to determine that period.
Exemptions

• A researcher may be **exempted from the obligation to provide information** if
  • received the personal data from someone else, such as when the data came from a publicly available source
  • The subject has already received information
  • the provision of such information would prove **impracticable** or would entail **disproportionate effort** in the investigation
  • could make it **impossible** or **seriously harm** the achievement of research objectives

• Under the condition:
  • there are **appropriate safeguards** to protect the rights and freedoms and the legitimate interests of the data subject
  • making the information available to the public
  • **justifying and justifying** the options
Pseudoanonymisation

• One way of complying with the mandate for technical and organizational measures is the development of "Pseudoanonymisation".

• Pseudoanonymisation is "the processing of personal data in such a way that data can no longer be attributed to a particular data subject without the use of additional information, provided that the additional information is kept separate and subject to technical and organizational measures".

• Pseudoanonymisation is not always required, but its use is encouraged.

• Anonymity occurs when the subject can not be identified in any way.

• Therefore, even if a researcher no longer has the ability to redefine a set of data, such a set of data may still be set up within the GDPR if it can be redefined with reasonable effort.
Rights Exception - Deletion

• The GDPR gives any data subject the right to delete his or her personal data when it withdraws its consent or when the data is no longer needed for the purpose for which it was first collected.

• Compliance with this right may threaten the integrity of a researcher's dataset.

• The Regulation exempts research from the right of remission if it is likely to make it impossible or seriously harm the achievement of its objectives.
Rights exception - Opposition

• Data subjects reserve the right to oppose processing, even for research purposes.

• However, a researcher may override the opposition if processing is necessary to fulfil a duty performed in the public interest.

• In order to justify the public interest, processing should be based on the law of the Union or of a Member State.
Research on sensitive personal data

• GDPR allows researchers to process sensitive data when:
  • the data subjects explicitly consent or publish their own data
  • for research purposes when processing is necessary for research purposes under Union or Member State legislation
  • At the same time, they are subject to appropriate safeguards to respect the essence of the right to data protection and to provide for appropriate and specific measures to safeguard the fundamental rights and interests of the data subject.

• Thus, research serves as a basis for the processing of sensitive data only when provided for by Union or Member State law.
Profiling

Any form of **automated processing of** PD consisting of the use of personal data to identify certain characteristics relating to an individual, in particular to **analyse** or **predict** aspects relating to the **performance** of the individual in the **workplace**, the **financial situation**, **health**, **personal preferences**, **interests**, **reliability**, **behaviour**, **location** or **movements**.
Profiling

• GDPR eliminates existing restrictions, thus allowing further processing of PD for research that affects individuals but requires additional safeguards.

• It requires an privacy impact assessment (PIA) for systematic and extensive evaluation of personal aspects relating to individuals, based on automated processing, including profiling, which produces legal effects for them or can affect them.

• It is forbidden to subject the person to a decision based solely on automated processing, including profile profiling, as a result of the processing of sensitive data except in limited circumstances.
Conditions for research exceptions

• They should be **appropriate safeguards** to protect fundamental rights and interests of the data subject.

• "**Technical and organizational measures**" should be put in place.

• The controllers should act "in accordance with the **recognized ethical standards of scientific research**".

• In the context of data research and big data, unlike traditional research, **moral standards are still under discussion**
Summarising

• The GDPR creates **increased obligations** for entities that process personal data
• Creates **new exceptions for research** in the context of facilitating a **digital single market** across the EU.
• **Frees** research from the **principles of storage limitation** and **purpose limitation** to allow researchers to further process personal data beyond the purposes for which they are originally collected.
• Research may provide a basis for processing **without the consent** of the data subject.
• Allows researchers to process **sensitive data** and, in limited circumstances, transfer personal data to **third countries** that do not provide an adequate level of protection.
• In order to benefit from these exceptions, researchers should apply **appropriate safeguards**, in accordance with **recognized ethical standards**, reducing the risks of human rights research.
Open data considerations in H2020 projects

- Open data contribute to open innovation→Intelligent Mobility, mobility as a service, etc
- Anonymised personal data can be treated like non-personal data
- Can anonymized open data be useful?
- Can big open data really be anonymised?

Q: How does GDPR relates to the Data Management Plan?
GDPR & H2020 Research & Innovation Actions in H2020 in Transport

When does GDPR becomes relevant in the Transport?

- When research concerns:
  - Human beings
  - Data relating to human beings
  - Processing
  - Data transfer

Examples: Socio-economic research for transport users, social groups’ appropriation of connected mobility, inclusiveness in transport.
What is at stake regarding ethics in Transport Research.
Ethical considerations in H2020 transport theme

• Socio-economic component of transport research involving
  ✓ Human participant
  ✓ Interviews, focus groups, observation.
    ✓ Are they able to give their consent
    ✓ Are there any vulnerable groups?

Read more on http://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/ethics_en.htm
Self-driving cars will have to decide who should live and who should die
Whom should self-driving cars protect in an accident

The moral machine experiment, E. Awad et al Nature 2018
Surveillance
Free will
 Discrimination
Loss of jobs
Environmental
Cybersecurity
Recommendations

- Human agency and oversight
- Technical robustness and safety
- Radical transparency
- Privacy by Design and data governance
- Simplicity by Design
- Security by Design
- Diversity, non-discrimination, and fairness
- Environmental and societal well-being
- Accountability

Thank you!

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