GPDR, a broad conception for research

Fundamental & applied research

Research involving technological development

Privately funded research

Studies conducted in the public interest, in the area of public health

Governance and policy of research in the European Union are clearly for facilitation of sharing, e.g Open AIRE, European Science Cloud, Data Governance Act, Luxembourg national platform exchange project, etc.

GDPR
E-privacy
New
regulations*

Data protection in research

Processing
& Sharing
in research

* e.g Data Governance Act, AI Act, etc.

How to combine efficently these elements?

Some **challenges** & **pitfalls** for research in GDPR perspective

Not always easy as the **definition of personal data is large. Data in research means**

Various datasets, e.g direct identifiers, indirect identifiers, regular & sensitive data

Use of pseudonyms

Combinaison & analysis of different datasets

Pseudonymisation versus anonymisation

Pseudonymisation

- Priviledged in research
- Guidance from EDPB or EU bodies would be appreciated
- Missing of national third trust party

Anonymisation

- Old guidance from 2014
- Must be priviledged if feasible in research
- Anonymisation of personal data in research can be difficult/impossible

EDPB guidelines about access right will be published soon for consultation

- Clarification of the **scope**

- **Information must be provided** to the data subject

- **Format** of access request

- **Main modalities** for providing access

- The notion of **manifestly unfounded or excessive request**

Guidelines

- Clarification of the access right **scope**:

  - What about the data produced by the research activities themselves/confidentiality & IP?

- **Which information** must be provided to the data subject? How to chase ambiguous answers?

- **Format** of access: which electronic means accepted?

- Assessment & criteria of requests manifestly unfounded or excessive

Science and research have no borders

Collaboration with partners located outside the EU & EEA

Online apps, solutions, services, etc. (providers located outside the EU & EEA)

Clarification of the notion of international transfer

Etablissement in the EU

- Potential application to non EU institutions having establishment and link in the EU: case by case
- Applicable to controller and processor established in EU even if processing takes place outside EU

Data subjects in the EU

- Data subject being located in the Union at the moment of offering goods or services or when the behaviour is being monitor

Montoring the behaviour

- Health & lifestyle app developed by a US company
- Personal data indicators (sleep time, weight, blood pressure, heartbeat) can be recorded by the app from users
- App making available to individuals in the EU

1. Clarify that transfer is not only transmission

2. Disclosure by transmission or **otherwise making data available** to another institution (controller or processor)

3. Data importer is geographically in a third country or is an international organisation

4. No disclosure where the data is disclosed directly by the data subject to the recipient as data subject is neither controller nor processor
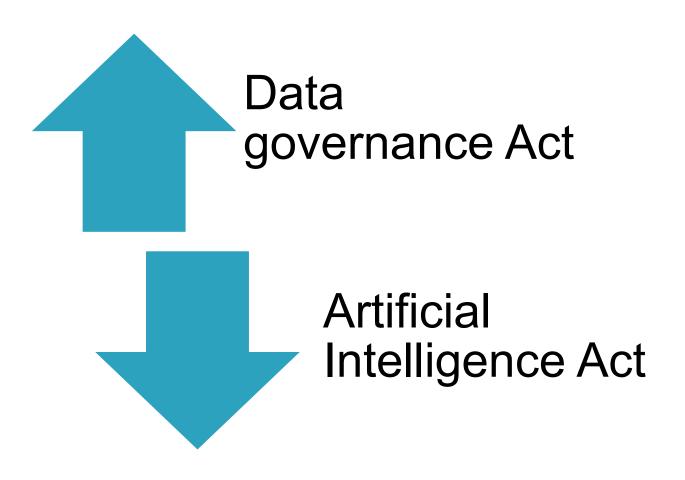
- How to interprete "*otherwise making data available to another institution*"?

- Examples provided by EDPB mentioned "sending", "providing"

- What about giving access to a data importer located outside Union to a database located in the EU?

- Clarify how an institution located outside EU with an establishment or a link with EU will apply the rules of international transfers

Recent initiatives regarding data

Data governance Act

Artificial Intelligence Act

DATA GOVERNANCE ACT AT A GLANCE

- **Provisional agreement by European Council & Parliament in December 2021**

- **Wide reuse of certain types of protected public sector data**
  - Personal data must be protected
  - The EC will set up a searchable electronic register of public sector data, accessible via national information points
  - Future initiative in Luxembourg

- **Data altruism for the common good**
  - E.g medical research collecting data serving general interest may apply to be listed in a national register of recognised data altruism organisations
  - Encourage individuals to donate data to these organisations in a regulated & safe way

- **Definition of AI**: attempt to differentiate AI from other information technology

- **Wide scope of application:** application where the output of the system is in the EU (even if an organisation has no commercial presence within the EU)

- **Risk-based approach**:

  - *Unacceptable risk-activities* which are prohibited under the act, e.g social scoring

  - *High risk activities*, e.g. those related to medical devices, biometric systems, education & vocational training (Annex III)

  - *Low risk activities*, like chatbots

- **Legal requirements for high-risk AI:**

  - Transparency & information of users

  - Security

  - Rules taken from recognised Ethics guidelines

- Activities not mentioned in the Act seem to be of **minimal risk** and are not regulated

- AI systems used solely for the purpose of **scientific research** are included?

Questions?

Remarks?