Personal Data Protection in Research Involving Humans

GDPR and ethics perspective

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Personal Data Protection in Research Involving Humans

Content

- Data protection principles
- Personal data section of ERC's ethics self-assessment

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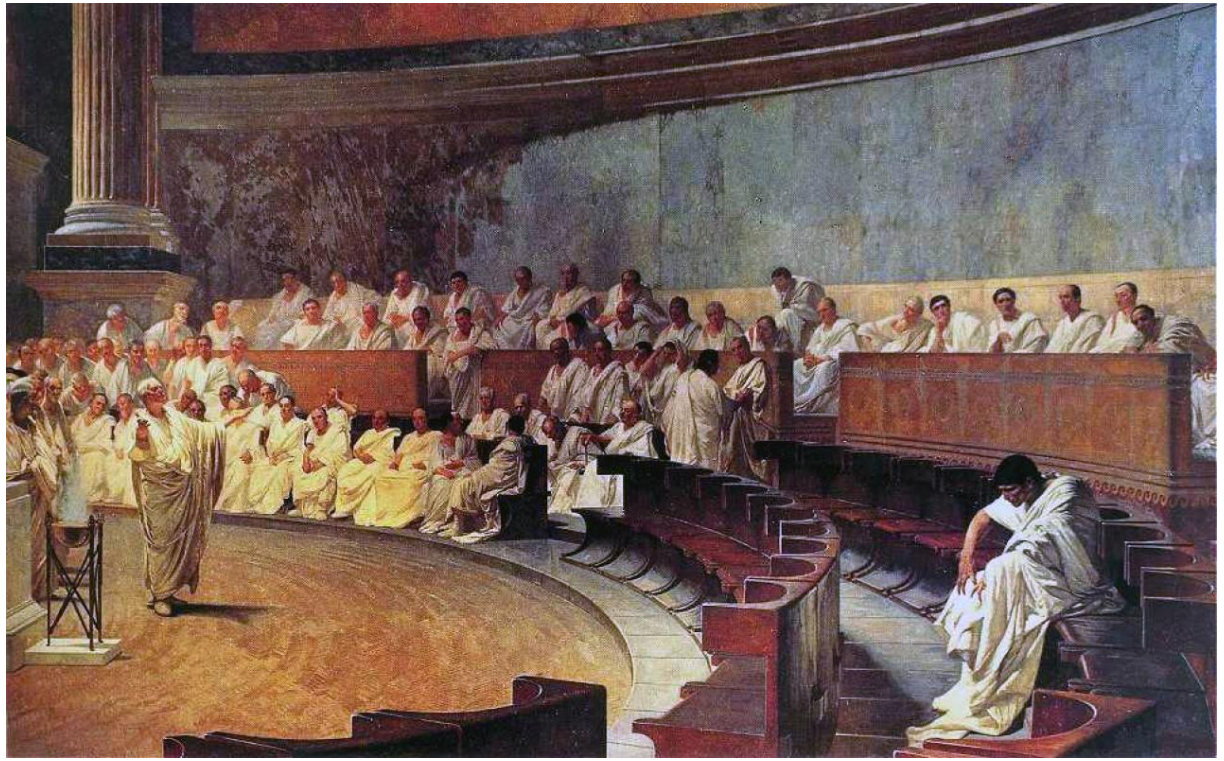
Data protection principles



Cicero denounces Catiline. Cesare Maccari - 1889
https://commons.wikimedia.org/wiki/File:Maccari-Cicero.jpg

In ancient times citizenship was about being part of social events.

The term ”privacy” didn’t exist.

Privacy **=** **Intimacy + Personal Data Protection**

Data protection principles

Personal Data
any information relating to an identified or identifiable natural person

Data ownership
Personal Data always belongs to the data subject

http://getwallpapers.com/wallpaper/full/0/8/7/540775.jpg

Data protection principles

Special categories of personal data

- Racial or ethnic origin
- Political opinions
- Religious or philosophical beliefs
- Trade-union membership
- Health, sex life, sex orientation
- Genetic, biometric data

Special consent and security measures apply

Minors

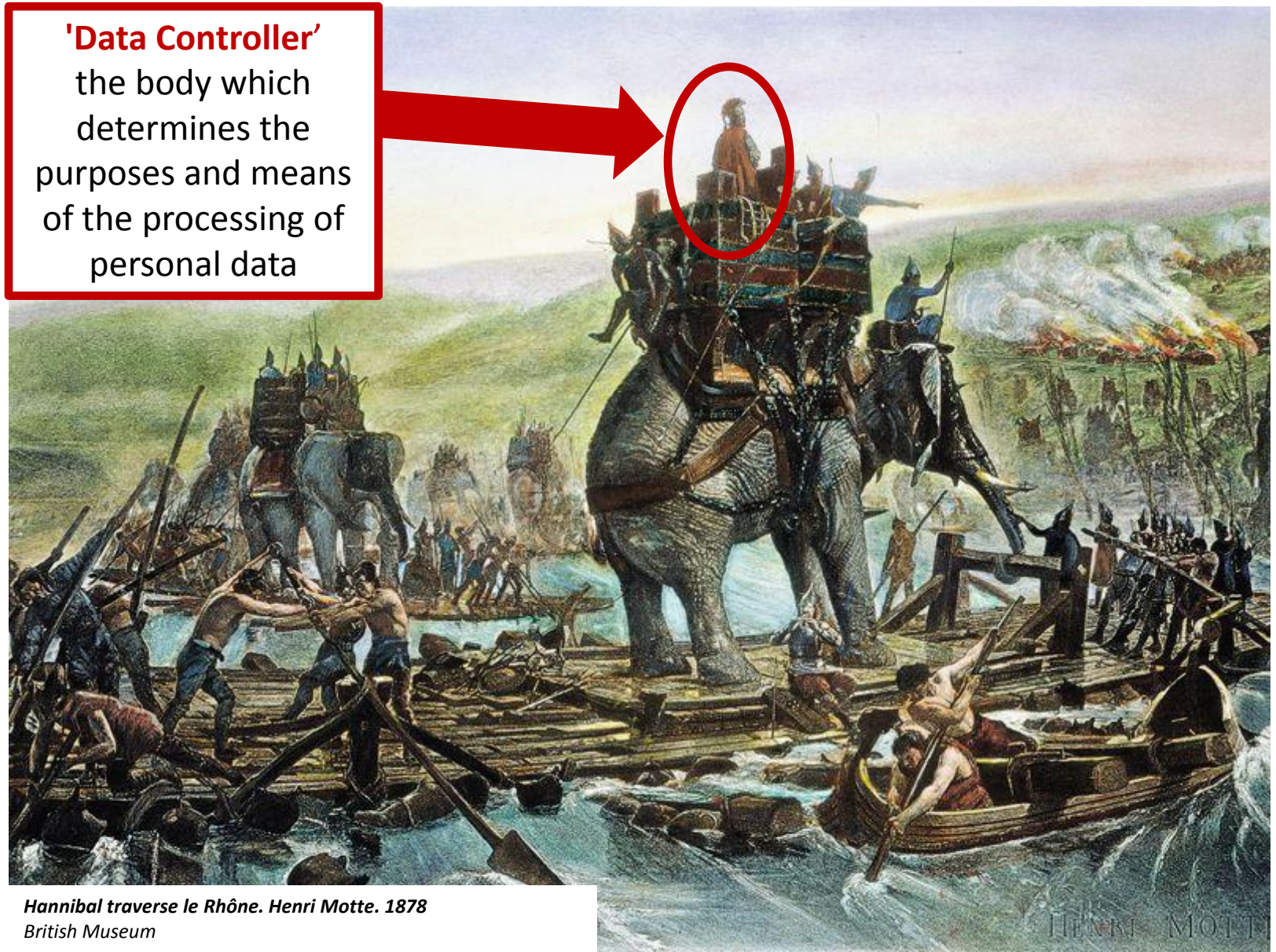
- Consent must be provided by the holder of parental responsibility
- In Spain under 14 years old
- In other EU countries may differ

No one knows why, in April last year, Tiziana Cantone sent a series of sex videos of herself to four friends, including a man she was dating.

What is certain is that events quickly spiralled out of her control. The videos -

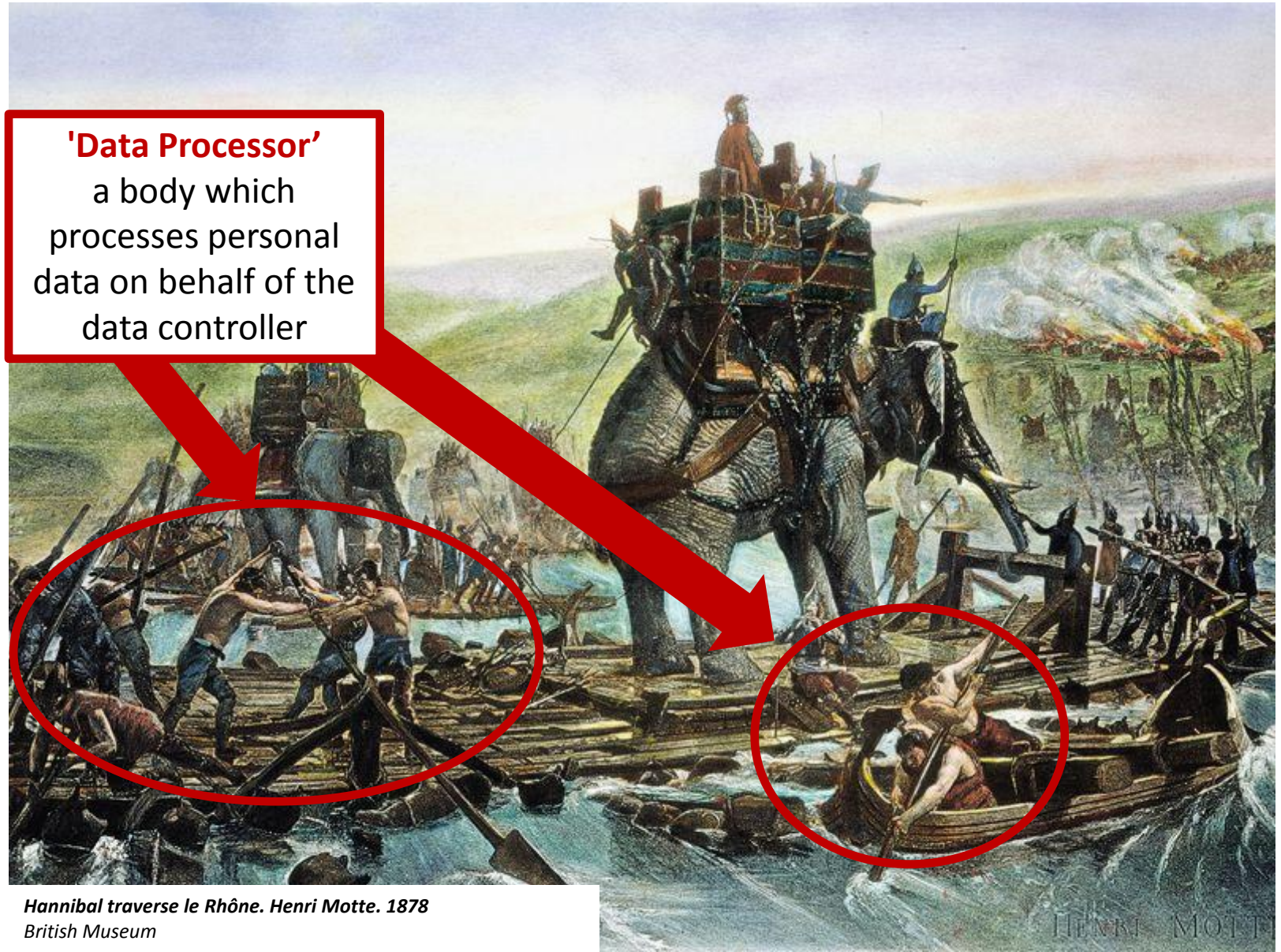
Data protection principles

'Data Controller'
the body which determines the purposes and means of the processing of personal data



Hannibal traverse le Rhône. Henri Motte. 1878
British Museum

Data protection principles



Hannibal traverse le Rhône. Henri Motte. 1878
British Museum

Data protection principles

Personal data shall be:

(a) processed **lawfully**, **fairly** and in a **transparent** manner in relation to the data subject

(b) collected for specified, **explicit** and **legitimate purposes** and not further processed in a manner that is incompatible with these purposes;

further processing for scientific research purposes, subject to appropriate safeguards for the rights and freedoms of the data subject, shall not be considered to be incompatible with the initial purposes

Data protection principles

Privacy by design
Privacy by default

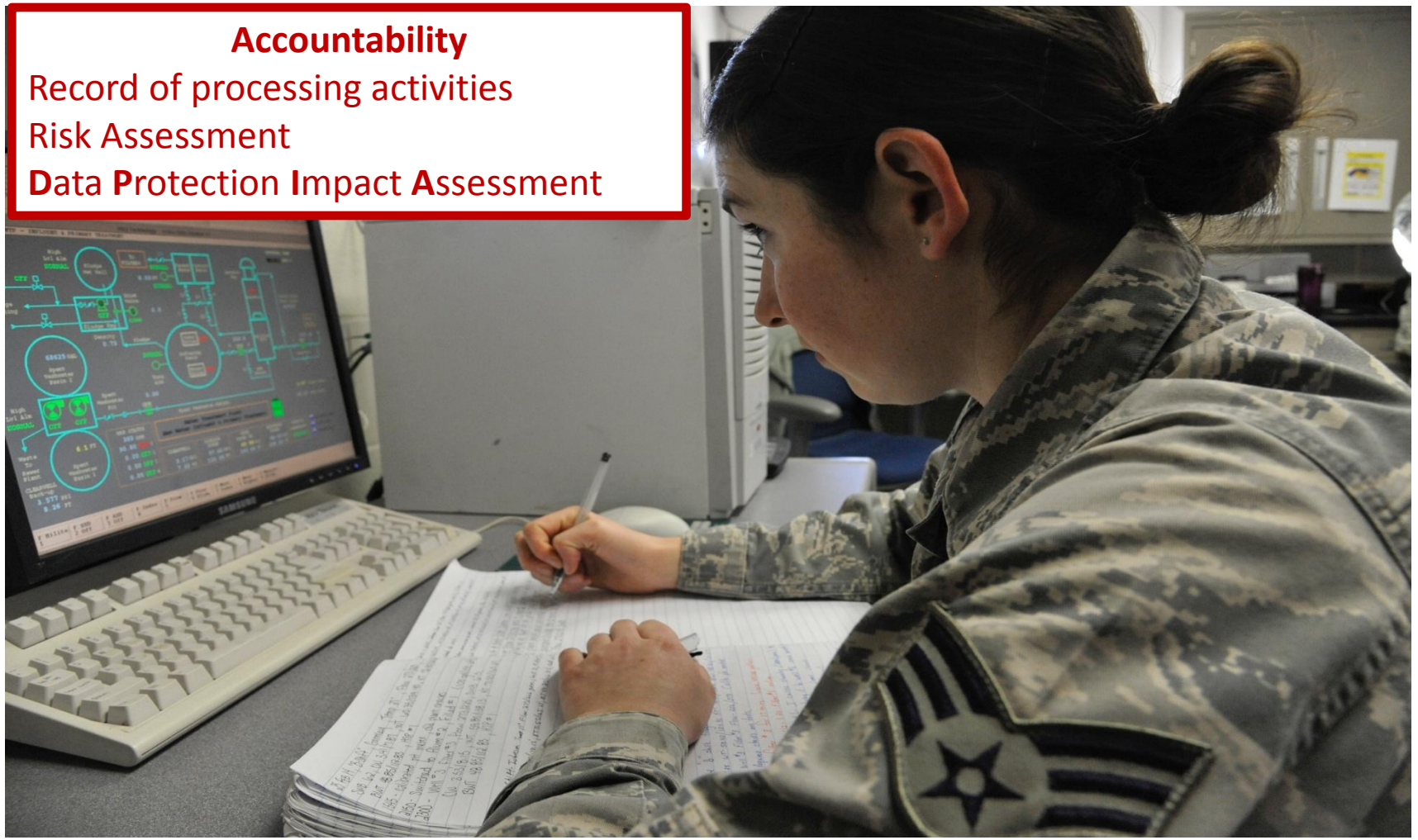
Data protection principles

Accountability

Record of processing activities

Risk Assessment

Data **P**rotection **I**mpact **A**ssessment



Data protection principles

Data minimization

Dataset size

Preservation period

Data protection principles

Technical and organizational security measures

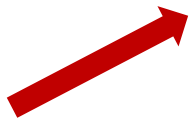
Anonimisation

Pseudonimisation

Data protection awareness

✓ Pseudonimisation

Research dataset	
Identification data	**Research data**
John	John's answers
Mary	Mary's Answers



Pseudonimisation file	
Identification data	**Id.**
John	001
Mary	002

Pseudonimized Dataset	
Id.	**Research data**
001	John's answers
002	Mary's Answers

Still Personal Data
But requirements are relaxed

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Data protection awareness

- Does your research involve personal data collection and / or processing ?

YES

NO

Data protection awareness

If your research involves personal data collection and / or processing, then you have to provide:

1. Data collection details
2. Procedures for data storage & processing
3. Data safety analysis
4. Preservation protocol
5. Dissemination of datasets expectations
6. Third party transfers projection

Data protection awareness

1. Data collection details (personal data source)

Data owner ← → **Third party**

- Legitimation
- Fairness
- Informed consent

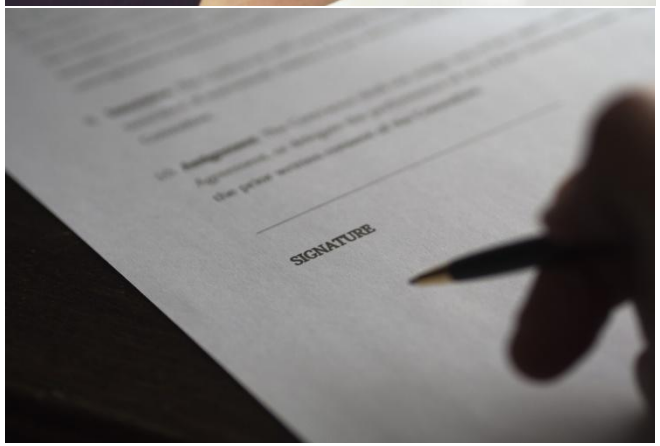
- Dataset details
- Origin and lawfullness
- Owner's permission

Data protection awareness

2. Procedures for data storage & processing
3. Data safety analysis
4. Preservation protocol

a) Organisational measures

- ✓ Non-Disclosure Agreements
- ✓ Data processing contracts
- ✓ Risk analysis
- ✓ **D**ata **P**rivacy **I**mpact **A**ssessment
- ✓ …



Data protection awareness

2. Procedures for data storage & processing
3. Data safety analysis
4. Preservation protocol

b) Technical measures

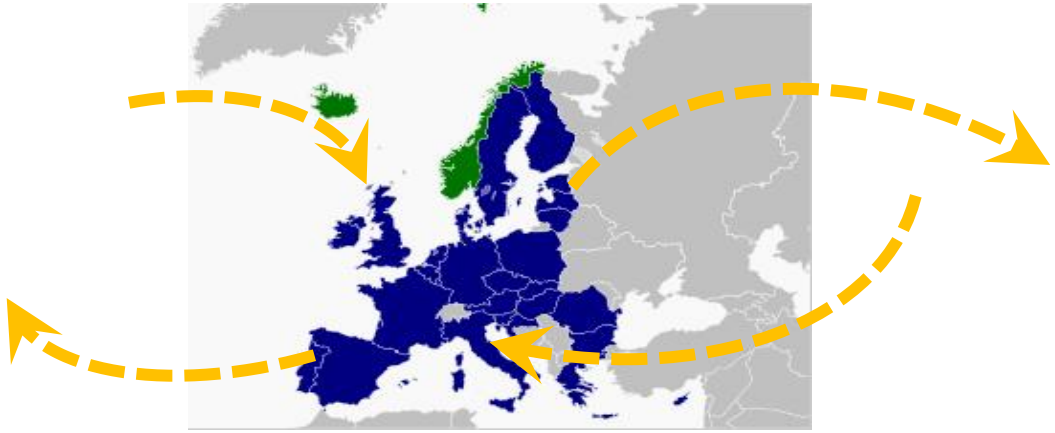
- ✓ Data access control
  (and sometimes access logging)
- ✓ Encryption
- ✓ Anonymisation
- ✓ Pseudonimisation
- ✓ Backup
- ✓ …

Data protection awareness

5. Personal data dissemination
6. Third party transfers

- ✓ Anonimisation
- ✓ Consistency with Informed consent
- ✓ Terms & conditions
- ✓ Data transfer procedures

- ✓ Special regulations in the case of transfers outside EEE



Thank you !!!

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