

Addressing legal and ethical dimensions of the processing of personal data in research contexts: The DARIAH ELDAH Consent Form Wizard

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Schedule

- 10:00-10:10 Welcome, short introduction of speakers, process and context
- 10:10-10:20 General view at importance of data protection and ethics in research and short introduction of WG ELDAH (Koraljka)
- 10:20-10:35 Introduction to GDPR principles and research exceptions (Walter)
- 10:35-10:50 Introduction to prevalent personal data processing scenarios in research contexts and the Consent Form Wizard (Vanessa)
- 10:50-11:20 3 Breakout sessions for testing the tool (moderated by Koraljka, Vanessa and Walter)
- (A) Gather data/consent for hosting academic events
 - (B) Gather data/consent for communication purposes, e.g. mailing list, newsletter
 - (C) Gather data/consent from and/or about living people for research purposes
- 11:20-11:30 Summary and wrap-up



Ethics & Legality in Digital Arts & Humanities ELDAH

- a working group of DARIAH-EU (Digital Arts & Humanities Research Infrastructure) - <https://www.dariah.eu/>
- established with the aim to address the needs of the DH research and education community regarding the topics of legal issues and research ethics
- Scope of expertise:
 - Intellectual Property Rights and Licensing
 - Data Protection and Privacy
 - Research Ethics and Scholarly Conduct
- Outputs:
 - recommendations, training and information materials
 - workshops to scholars



Ethics & Legality in Digital Arts & Humanities ELDAH

- **Some facts:**
 - established in 2017
 - 40 + members
 - 18 countries
 - 2 projects
 - 3 co-leads

- **Collaborations**
 - DARIAH Research Data Management WG
 - DARIAHteach
 - CLARIN-ERIC (CLIC)
 - CESSDA-ERIC
 - EUROPEANA (Copyright Community)
 - ICARUS (Ethical Board)
 - OANA (Open Science Network Austria)

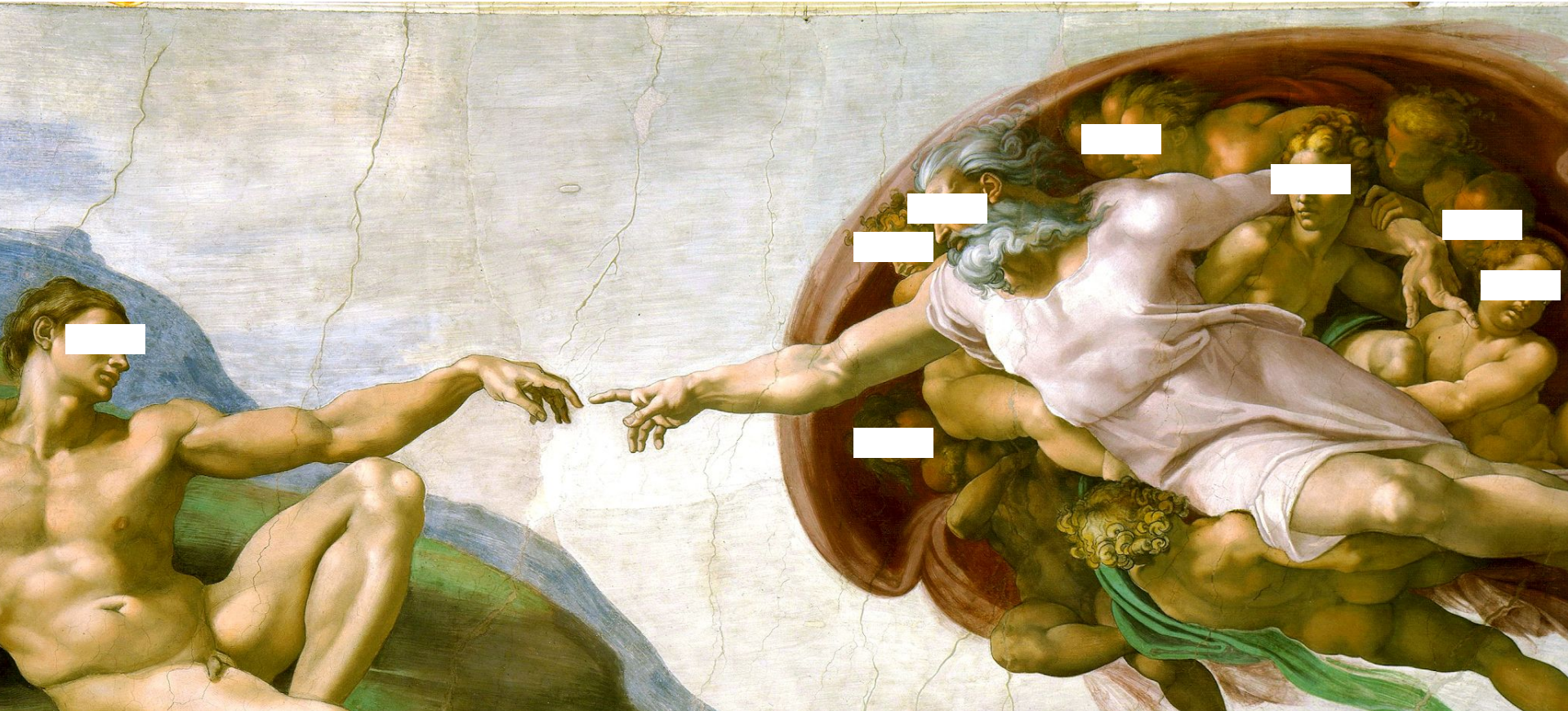


Data protection & ethics in research

- Open access to cultural heritage content and research data held by publicly funded institutions
- Ethical and legal issues in open access
- **WHY** data needs to be protected?
- **WHAT** data needs to be protected?



The General Data protection Regulation (GDPR)



CHARTER OF FUNDAMENTAL RIGHTS OF THE EUROPEAN UNION

Article 8 - Protection of personal data

(1) Everyone has the right to the **protection of personal data** concerning him or her.

(2) Such data must be **processed** fairly **for specified purposes** and on the basis of the **consent of the person** concerned or some **other legitimate basis** laid down by law. Everyone has the **right of access** to data which has been collected concerning him or her, and the **right to have it rectified**.



GENERAL DATA PROTECTION REGULATION (GDPR)

- Regulation ≠ Directive
- in force since 24 May 2016
- directly applicable EU law as of 25 May 2018
- also implemented in national Data Protection Acts amendments
- GDPR Website (EU): <https://gdpr-info.eu/>
- GDPR on EURLEX (all EU official languages):
<https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679>



APPLICABILTY

... applies to the **processing of personal data** wholly or partly **by automated means** and to the processing other than by automated means of personal data which form part of a filing system.

Not applicable for data processing:

... by a natural person in the course of a purely personal activity

... by authorities for the purposes of the prevention, investigation, detection or prosecution of criminal offences, execution of criminal penalties and safeguarding against threats to public security.



PROCESSING

... means any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction.



PERSONAL DATA

... means **any information relating to an identified or identifiable natural person** ('data subject')

An **identifiable natural person** is one who can be identified, directly or indirectly, by reference to an identifier such as a name, an identification number, location data or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

Anonymization = not identifiable = **not subject to the GDPR!**



ROLES IN THE GDPR

Controller

... the natural or legal person, public authority other body which, determines the purposes and means of the processing

Processor

... a natural or legal person, public authority or other body which processes personal data **on behalf of** the controller

Data Subject

... a natural person, whose data is processed



PRINCIPLES OF DATA PROCESSING (ART 5)

- lawfulness, fairness and transparency
- purpose limitation
- data minimisation
- accuracy
- storage limitation
- integrity and confidentiality
- accountability



LAWFULNESS

- With the consent of the person concerned (for sensitive data: express consent!)
- Contract with data subject
- Compliance with legal obligations (e.g. social security)
- Safeguarding the legitimate interests of the person responsible or of a third party, provided that the interests of the person concerned do not outweigh each other.
- In "good faith" (What should the data subject reasonably expect in the case of lawful processing?)
- Transparency (information duties)



PURPOSE LIMITATION

Processing only for clearly defined and legitimate purpose

DATA MINIMISATION

Only collect the data necessary for processing.

ACCURACY

Data must be factually correct and up-to-date.



STORAGE LIMITATION

Storage as long as necessary for the achievement of purpose (legal retention periods, internal reporting, archivability)

INTEGRITY

Ensure “security by design” (i.e. through appropriate technical and organizational measures like access control)

ACCOUNTABILITY

Information and training (of employees)



RIGHTS OF THE DATA SUBJECT (ART. 12-23)

- Information (at data collection)
- Access
- Rectification
- Erasure (right to be forgotten)
- Restriction of processing
- Data portability
- Objection



RIGHT TO INFORMATION

- the processing **purposes**
- the **categories of personal data** to be processed
- the **recipients** (in particular recipients in third countries)
- if possible, the **envisaged duration** for which the personal data will be stored (or criteria for determining this duration)
- the existence of a **right to rectify or erase personal data** relating to them,
- the existence of a **right of appeal** to a supervisory authority
- a **copy** of all data!



GDPR EXCEPTIONS: ARTICLE 85

For processing carried out for **journalistic purposes** or the **purpose of academic, artistic or literary expression**, Member States shall provide for exemptions or derogations [...] if they are necessary to reconcile the right to the protection of personal data with the **freedom of expression and information**.



GDPR EXCEPTIONS: ARTICLE 89

"... for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes."

Union or Member State law may provide for derogations from the rights [of access, rectification, restriction of processing or the right to object] (...) in so far as such rights are likely to render impossible or seriously impair the achievement of the specific purposes (...), providing that appropriate safeguards are applied.



ARTICLE 89 IN PRACTICE

- **broad consent**: the possibility of obtaining consents not only for specific purpose, but for one or more research areas
- **purpose extension**: research is always “compatible purpose”
- **storage extension**: no limitation for duration
- **restriction/objection limitation**: not applicable if the exercise of this right “*is likely to render impossible or seriously impair*” the achievement of the purposes of the research.

“**appropriate safeguards**”: Pseudonymisation, transparency, opt-out policies, codes of conduct, ethics commissions, ...



The DARIAH ELDAH consent form wizard (CFW)

<https://consent.dariah.eu/>



Breakout rooms

- Gather data from and/or about living people for research purposes
- Gather data/consent for communication purposes, e.g. mailing list, newsletter
- Gather data/consent for hosting academic events



Stay in touch!

- : Twitter: [@ELDAHdariah](https://twitter.com/ELDAHdariah)
 - : [YouTube](#)
 - : Join the mailing list: wg-eldah@dariah.eu
 - : E-mail us: eldah@dariah.eu
 - : Blog: <https://eldah.hypotheses.org/>
-
- : and use the tool! :-) > [DARIAH ELDAH Consent Form Wizard](#)

