Responsibility and Accountability under the GDPR

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GDPR is catching up with us...
— GDPR: General Data Protection Regulation

GDPR
• Became effective on 25 May 2018
• Is directly applicable as law
• Considerable consequences for processing of personal data
• Defined scope of opening clauses for national specifications to further complicate the situation
First things first...

The messenger requests that she please not be shot.
The axiom of Article 5
Art. 5.2 The controller shall be responsible for, and be able to demonstrate compliance with, paragraph 1 (‘accountability’).
Understanding the GDPR
— The most important principles

**Lawfulness**
- Art. 6 Legal Basis
- Art. 9 Special categories of data
- Art. 44-49 Transfer to third countries or international organisations

**Fairness**
- Art. 5.1 (b) purpose limitation
- Art. 5.1 (c) data minimisation
- Art. 5.1 (d) accuracy
- Art. 5.1 (e) storage limitation
- Art. 5.1 (f) integrity and confidentiality
- Art. 16-21 data subjects’ rights

**Art. 5.1 Personal data shall be:**
(a) **processed** lawfully, fairly and in a transparent manner in relation to the data subject

('lawfulness, fairness and transparency')

**Transparency**
- Art. 12-15 data subjects’ rights, Art. 30 Records of processing
What you need to know
— Processing

- Any operation [...], 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;[...] Art. 4 (2)
The heart of the GDPR
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Lawfulness, fairness and transparency

→ Sarion Bowers
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GDPR Art. 5
Purpose limitation
— Stick to your promise!

Beware:

• Stay within scope of your communicated purposes at the time of collection

Further processing

• Should be “not incompatible” according to Art. 5.1
• May not be available under consent in all countries (See statements preparations for Swedish Research Act / p32: https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2017/06/sou-201750/ )
• Requires advance information (independent of the legal basis)

Data Sharing

• Responsibility to ensure by contract the adherence to the purpose limitation
Data minimisation
— What is minimal enough?

Collection
• Collect only what is needed
  — which can be a lot considering the determinants of health and disease are unknown

Purpose
• Where no directly identifying data is needed
  ➔ pseudonymise or anonymise data
• Data analysis plans should specify which data types are needed

Access
• Access only on a need basis, not by default

Retention
• Delete data if no longer needed
  — avoid data graveyards!
Accuracy
— Data needs to be accurate

• We all aim for that!!!
Storage limitation
— Nothing lasts forever!

• Defined time point to be given
• Alternative: criteria how long data will be kept
• Independent of choice: needs to be told to the study participants
• Beware: don’t forget your archiving obligations in the communication with the study participants

What do you mean, we need to delete the data right after the project? What about archiving?
Integrity
— Avoid data corruption or data loss

• Use checksums to test for corruption

• Backups are important
  — we know that anyway! 😊
Confidentiality
— Art. 25 & 32: Organisational and technical measures

• Technical security measures (pseudonymisation, encryption, access restriction, event logging, compliance monitoring, ... )

• Policies

• Training

• Security clauses
Data subjects’ rights: Articles 15 – 21
— Actions to be taken on demand of the data subject

- Give access to data
- Inform about every user and every project
- Have data deleted or rectified – even from subsequent recipients
- Withdrawal of consent or objection to processing
- Portability - transfer data to another processor or controller
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Art. 13 - 15: Information provision
— “The data subject should never be surprised...”

- Inform about:
  Identity and contact of controller, legal basis, purpose of processing, recipients, transfers outside the EU, source of the data, automated decision making, rights of the data subject

- Important guidance from European Data Protection Board (EDPB)

- Beware: EDPB states that ethics information must be separate from data protection information

- Keep in mind: information obligation applies in the same way to your website privacy notes!!
Record keeping following Art. 30.1 — Documentation is key under GDPR

Content of processing records
• Contact details of controller: representative and data protection officer
• Purposes of the processing
• Categories of data subjects and categories of personal data
• Categories of recipients, in particular: recipients in third countries or international organisations
• Transfers outside the EU including safeguards
• Envisaged time limits for erasure of different categories of data
• Description of technical and organisational security measures

Problem for most institutions
• Registries need to cover a wide field of activities: Personnel administration, teaching, research, ...
DAISY – a GDPR registry for research data

MitoPD omics data
Local custodians: Enrico GLAAB
Source Type: From collaborator
Generated from samples: no
Has special subjects: no
Datatypes: Genomics variant array, Transcriptome array

Samples location: University of Tuebingen
Subjects Category: Case-Control
Added on: May 31, 2018, 10:25 a.m.
Last edit: May 31, 2018, 10:25 a.m.

Source projects and collaborations
MitoPD (collaboration with University of Tuebingen)

Data files
hpc gaia work /work/users/eglaab/gwas/ueb /work/users/2zhang/non_public_hum_list/mitoPD
Other: automatic gaia backup

Use restrictions
PUB: Acknowledgement required.
DAISY – a GDPR registry for research data
DAISY: metadata about our data...

— What is collected about the datasets

• Responsibilities
  - Internal principal investigator
  - Role as processor or controller
  - Where external controller: PI, legal representative, DPO

• Study type
  - E.g. Case / control, cross-sectional / longitudinal

• Confirmation of ethics approval for collection and sharing

• Data subjects
  - E.g. Minors, subjects not able to give consent

• Data types and size

• Retention information

• Use conditions
  - Processing of data for certain diseases / health research in general
  - Homogeneity / heterogeneity of consent
  - Other, e.g. data sharing
DAISY: Processing information
— To become audit proof

• Reference to data locations

• Documentation
  - Legal and ethics documents (e.g. contracts, ethics approvals)
  - Data protection management plans (reference)
  - Data protection impact assessment (reference)

• Processing information
  - Projects (description, publications)
  - Legal basis of processing (e.g. consent, public interest, ...)
  - Access rights with duration and purpose
  - Upload / download
  - Changes to data set (e.g. pseudonymisation) or metadata
DAISY: Additional features
— Support responsible processing

- Monitoring tool
  - Data storage duration
  - Ethics approval renewal

- Automated request tool
  - Data use expiry (request for renewal or confirmation of erasure)
  - Request information on publication on data

- Consent management
  - Match Access Request with Use Restrictions from Consent

→ Automated features to comply with responsibility requirements
Accountability is more than transparency! — How to document your compliance with the GDPR
Accountability is more than transparency!
— How to document your compliance with the GDPR

Transparency
- Document what you do

Accountability
- Document why you believe what you do is enough

Data Protection Impact Assessment
- Assess if your information provision and processing will not pose a risk or violate the data subjects’ rights and freedom
  - Affects security measures, bridging situations, ambiguities (e.g. profiling), ... 
  - Involve your Data Protection Officer

Audits
- Where documentation demonstrates a responsibly performed assessment → no fines to be expected
THANK YOU!

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