

GDPR - PRACTICAL IMPLICATIONS FOR RESEARCHERS

Examples and solutions from brain research

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Personal data handling and sharing: Do you need all the data?

- GDPR: a great opportunity to reflect on data collection
- As researchers we are allowed to handle personal data, but are they needed to answer our research questions?
- Ask yourself:
 - 1. Which bits are **direct/indirect identifiers** of the data subject?
 - Do I need to store them after data collection is over?

Goal: Remove all direct identifiers so that data can be "As open as possible, as closed as necessary" (EU Guidelines on FAIR data management in Horizon 2020)

For each collected data type, see if it is a direct/indirect identifier

- See full table at:

 http://www.fsd.uta.fi/aineistonhal
 linta/en/anonymisation-andidentifiers.html
- Not all data types are listed: discuss with your peers and follow best practices in your field

Identifier type	Direct identifier	Strong indirect identifier	Indirect identifier	Anonymisation method
Personal identification number	x			Remove
Full name	×			Remove/Change
Email address	x	x		Remove
Phone number		x		Remove
Postal code			x	Remove/Categorise
District/part of town			x	Categorise
Municipality of residence			x	Categorise
Region			x	(Categorise)
Major region			x	
Municipality type			×	
Audio file	x			Remove
Video file displaying person(s)	x			Remove
Photograph of person(s)	x			Remove

Example from brain research

Ethical approval

Recruiting volunteers

Communication with volunteer

Consent to take part to the exp

- Email
- Phone
- Name and Surname
- Arranging scanning date
- Questions on MRI safety
- Specific questions related to the study (e.g. mother tongue, sexual orientation)

- Consent form to be signed (this is NOT the consent to process participant's data)
- Info notice on legal bases for data processing and sharing
- Privacy notice

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Data collection

Physiological data (GSR, HR, BR, Eye tracking, ...)

Functional brain data (MEG, EEG, fMRI, ...)

Neuropsychological tests (IQ, AQ, EQ, PANAS, BDI, ...)

Behavioural data

(sex, age, responses, audiovisual rec, ...)

Anatomical brain data (MRI)

- Data collection can happen in more than one day, sometimes on purpose
- Not all data types are collected

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Anatomical brain data (MRI) Data de-identification

8

Data processing

Data de-identification at step zero

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Part of the data that is needed for research

Data are ready to be opened

Data collection

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Data processing



However, consider each specific case

- Data de-identification sometimes is not possible (e.g. developing algorithms for face recognition)
- Some individuals are more difficult to de-identify (e.g. somebody with a rare disease, a celebrity with an unique skill, a psychopath who was in the news)
- It is a trade off between the risks for the individual and the benefit for society

You need to consider these implications before applying for ethical approval and discuss them with the ethical board.

Take home messages

- GDPR will change the workflow of those who daily work with human data. However, it is for the best of the subjects as well as the best for science (think of double blind trials)
- Grant applications will reflect the changes introduced by GDPR. Be ready to justify which personal data you must keep and which can be de-identified in your data management plan.
- GDPR is a big step towards openness in research. These changes will produce data that are ready to be opened from step zero.
- Slides are on twitter @eglerean