



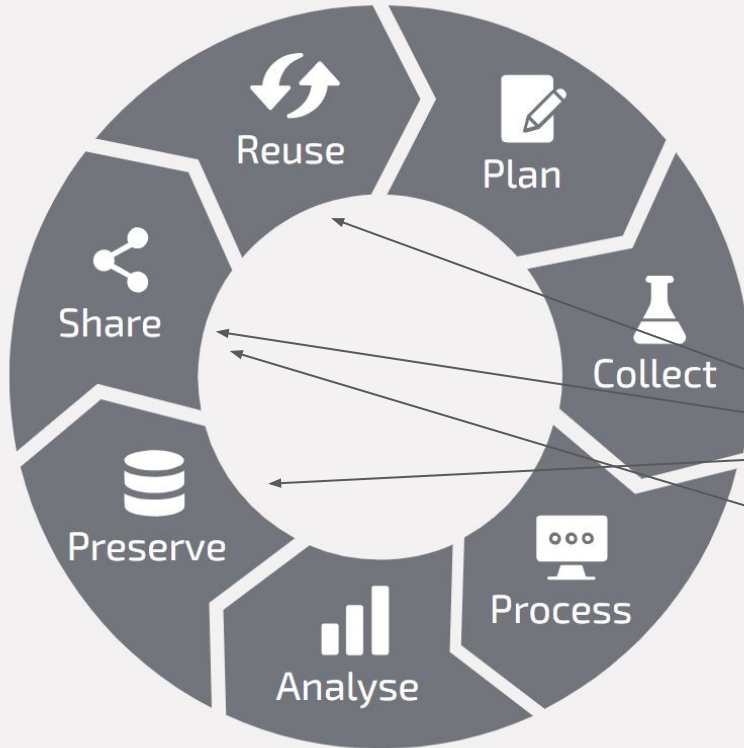
Data Privacy, Ethics and GDPR

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Intended Learning Outcomes

- Know what is GDPR and be able to explain in which cases this applies
- Arguments for and against data privacy vs openness

(Traditional) Modern Research Data Cycle



Research Data Privacy:

(1) individuals should have control over their data

(2) protect/minimize risks for participants in exposing their data

What do you know?

Write what you know, or think GDPR does

- Who does it protects?
- Where does it applies
- How does this affects your research?

tiny URL

Teacher notes: use some platform for students to share (preferably allow anonymous input for those not feeling comfortable with that - also nothing is mandatory here)

What do you know?

Write what you know, or think GDPR does

- Who does it protects?
- Where does it applies
- How does this affects your research?

https://padlet.com/wamcyril/GDPR_fun

Foreword: ethics and GDPR

- Data ethics means generate, collect, use, process or share data whilst minimising harm, ensuring morally good outcomes and fairness, and protecting human autonomy.
- The law tends to follow ethics - Many of protections in place in GDPR are teleological - that is they consider the purpose and consequences of having data available and shareable (see consequentialism)

What is it, who for?

The Protection and Information about processing of personal data is a human right.

GDPR grants rights and places obligations on organization that hold Personal Identifiable Information (PII).

It applies to organizations based in the EU (for PII from anywhere) and for organization using EU PII (wherever they are based).

Data collected can only be used for the purpose specified.

<i>Does GDPR apply?</i>	ORG inside EU	ORG outside EU
Person inside EU	✓	✓
Person outside EU	✓	✗

PII (article 4)

Question: What are Personal Identifiable Information (PII)?

‘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, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

pretty much anything

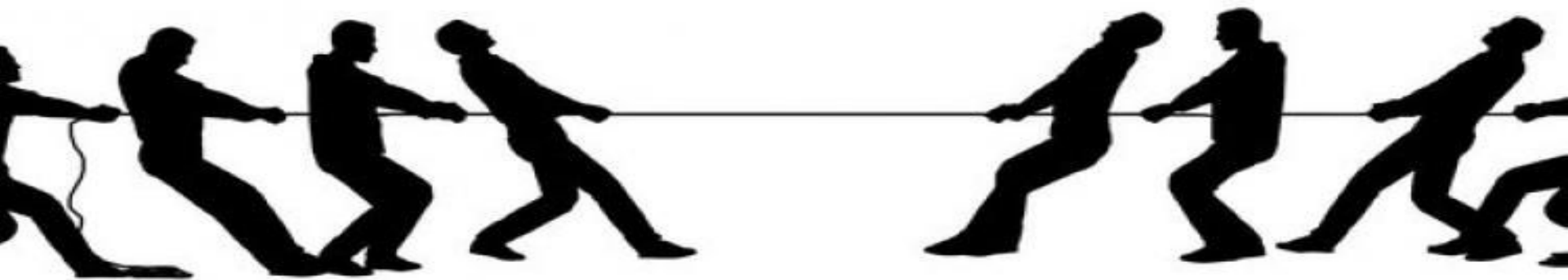
a living human being

Keeping the link pseudoid <--> won't cut it, it remains PII

PII and ethic

I am sharing publicly the information about my patients: young children who died from a rare disease, including age, sex, geographical info, etc ... very valuable information for research but that was not consented -- what does GDPR says?

Openness versus Privacy



Personal data

name

address

date of birth

phone number

license plate

IP address

...



Crime Scene Investigation

<http://www.abc.net.au/news/2017-09-19/csi/8960590>

(Biometric) personal data

fingerprint

facial details

dental record

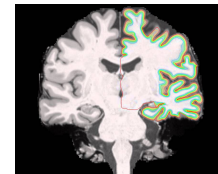
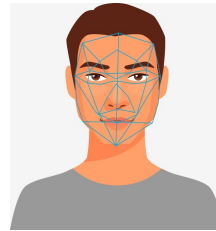
genetics

cortical folding pattern

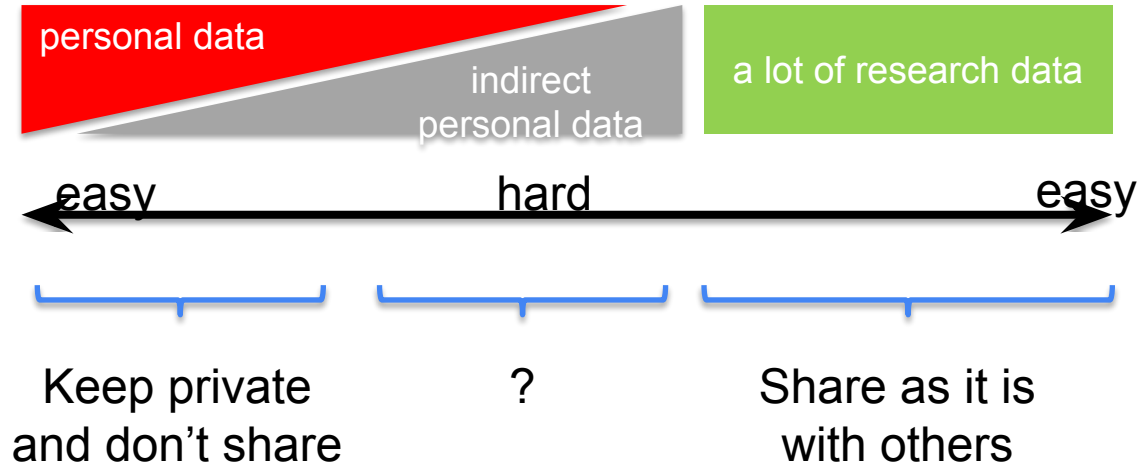
clinical data

gait/movement pattern

responses on questionnaires



Gradient between personal and research data



Limit possible identification

Personal data

- restrict access to personal data

- protect the key that maps between the pseudonym and the identity

Biometric data

- data minimization only acquire, store and share data that is needed

- acquire ***anonymous*** data

- acquire data using a ***pseudonym***

- use ***de-identification*** techniques

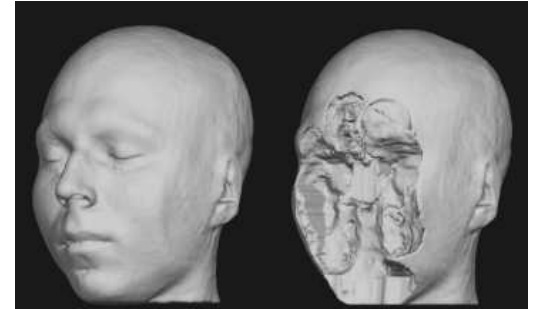
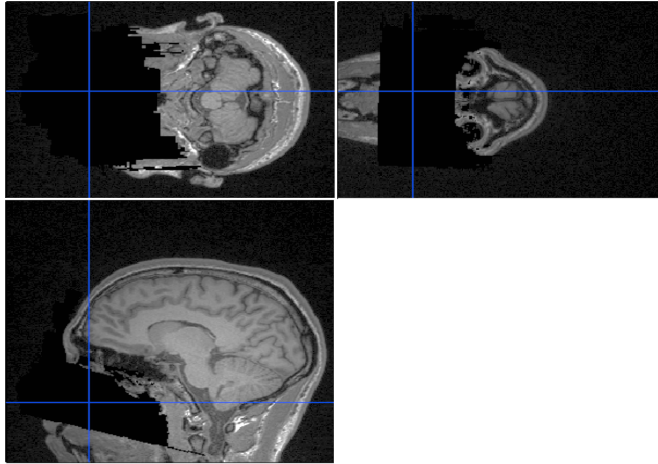


Legal constraints

- collaboration: access only for specific authorized researchers

- sharing: access for everyone but only following data use agreement

Appropriate blurring depends on the situation



Appropriate blurring depends on the situation

... for example blurring the age of the subject



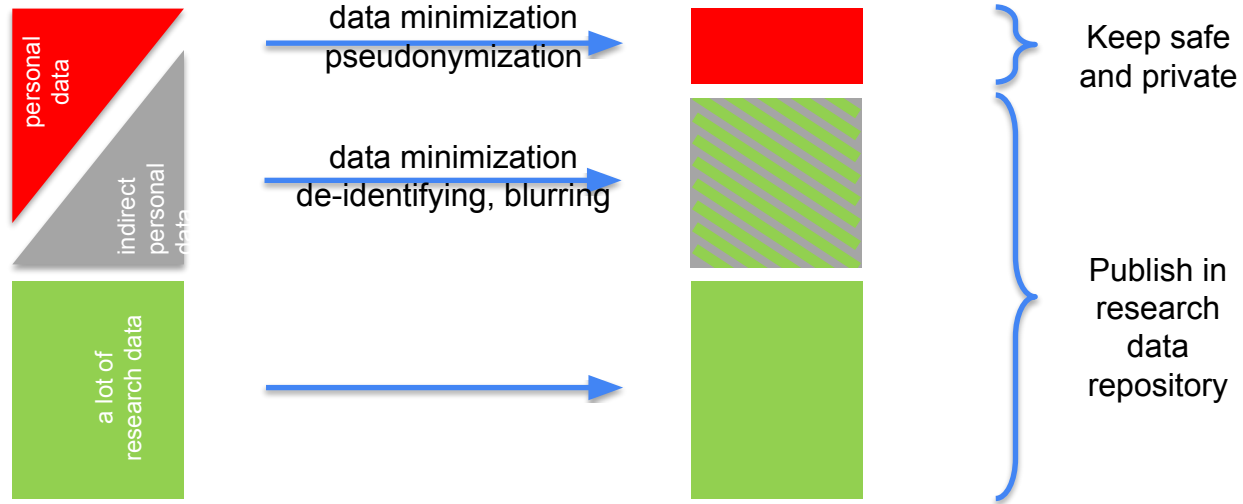
1 month bins



5 or 10 year bins

Personal and research data

GDPR recognizes only 2 types of data: PII or anonymous data (pseudonymization is a process)



~~Openness versus Privacy~~

Transparency & Privacy



Privacy does not impede research transparency

→ privacy is ensuring participants and patients rights are preserved and data are protected, research transparency is about the process

→ balancing FAIRness with privacy is more difficult

Have you thought about

- (1) Informed consent for sharing data - often required (depends on countries)
- (2) How is data provenance tracked/documentated
- (3) How participants can ask to see, modify, remove data (links to (1 and 2))
- (4) Findability, Accessibility Interoperable and Resuable
- (5) Challenge: define which part of the derived data are anonymous

Quiz time

Your colleague has collected (PII) data for his/her own PhD but some information can be usefully repurposed to complement your own analyses -- can you access those PII and do this new analysis?

Article 5: Principles relating to processing of personal data. 1.b. Personal data shall be collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; **further processing for** archiving purposes in the public interest, **scientific** or historical **research purposes** or statistical purposes **shall**, in accordance with Article 89(1), **not be considered to be incompatible with the initial purposes** ('purpose limitation');

Quiz time

A colleague in Germany has research data which are PII, and want to send them to you so you can try your new super machine learning model.

Can you do it as it or you need either a special authorization, or consent?

[Article 1](#)(3): The free movement of personal data within the Union shall be neither restricted nor prohibited for reasons connected with the protection of natural persons with regard to the processing of personal data

Quiz time

You have research data which are PII, and need to send them to colleagues in Japan and in USA for further analysis.

Can you do it as it or you need either a special authorization, or consent?

[Article 46](#) (b): The appropriate safeguards referred to in paragraph 1 may be provided for, **without requiring any specific authorisation from a supervisory authority**, by: (a) legally binding and enforceable instrument between public authorities or bodies; binding corporate rules in accordance with Article 47; **(b) standard data protection clauses adopted by the Commission in accordance with the examination procedure referred to in Article 93(2)**; -> check the countries in the [adequacy decision](#)

Solving the challenges of sharing potentially identifiable data

Pseudonymisation of neuroimages and data protection: *Increasing access to data while retaining scientific utility*

Damian Eke ^{a,*,}, Ida E.J. Aaseba ^{b,}, Simisola Akintoye ^{c,}, William Knight ^{a,}, Alexandros Karakasidis ^{d,e,}, Ezequiel Mikulan ^{f,}, Paschal Ochang ^{g,}, George Ogo ^{h,}, Robert Oostenveld ^{h,b,}, Andrea Pigorini ^{f,}, Bernd Carsten Stahl ^{a,}, Tonya White ^{i,}, Lyuba Zehl ^j

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<https://doi.org/10.1016/j.ynirp.2021.100053>

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[Editorial](#) > [Hum Brain Mapp.](#) 2021 May;42(7):1945–1951. doi: 10.1002/hbm.25351.

Epub 2021 Feb 1.

The Open Brain Consent: Informing research participants and obtaining consent to share brain imaging data

Elise Bannier ^{1, 2,}, Gareth Barker ^{3,}, Valentina Borghesani ^{4,}, Nils Broeckx ^{5,}, Patricia Clement ^{6,}, Kyrre E Emblem ^{7,}, Satrajit Ghosh ^{8, 9,}, Enrico Gleran ^{10, 11,}, Krzysztof J Gorgolewski ^{12,}, Marko Havu ^{13,}, Yaroslav O Halchenko ^{14,}, Peer Herholz ^{15,}, Anne Hespel ^{16,}, Stephan Heunis ^{17,}, Yue Hu ^{18,}, Chuan-Peng Hu ^{19,}, Dorien Huijser ^{20,}, María de la Iglesia Vayá ^{21,}, Radim Jancalek ^{22,}, Vasileios K Katsaros ^{23, 24,}, Marie-Luise Kieseler ^{25,}, Camille Maumet ^{26,}, Clara A Moreau ^{27,}, Henk-Jan Mutsaerts ^{28, 29,}, Robert Oostenveld ^{30,}, Esin Ozturk-Isik ^{31,}, Nicolas Pascual Leone Espinosa ^{32,}, John Pellman ^{33,}, Cyril R Pernet ^{34,}, Francesca Benedetta Pizzini ^{35,}, Amira Šerifović Trbalić ^{36,}, Paule-Joanne Toussaint ^{37,}, Matteo Visconti di Oleggio Castello ^{38,}, Fengjuan Wang ^{39,}, Cheng Wang ^{40,}, Hua Zhu ⁴¹

[Affiliations](#) + [expand](#)

PMID: 33522661 PMCID: [PMC8046140](#) DOI: [10.1002/hbm.25351](#)

[Free PMC article](#)

> [Neuroimage.](#) 2022 Jul 1;254:119165. doi: 10.1016/j.neuroimage.2022.119165. Epub 20

Sharing individualised template MRI data for MEG source reconstruction: A solution for open data while keeping subject confidentiality

Mikkel C Vinding ^{1,}, Robert Oostenveld ²

[Affiliations](#) + [expand](#)

PMID: 35378289 DOI: [10.1016/j.neuroimage.2022.119165](#)

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If you are going to get ethics approval, consider consenting to the study (ethic committee) and SEPARATELY consenting for data sharing (your employer / institution approval - legal issue)

