PublicnEUro.eu

A European repository to share neuroimaging datasets publicly

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JUNE 23~27, SEOUL, KOREA

novo
nordisk
fonden
Benefiting people and society

I have no disclosures.

Brain imaging data as personal data

- EU GDPR Art. 4 (1). Personal data are any information which are related to an **identified or identifiable** (directly or indirectly) natural person.

Re-identification from structural MRI

Refacing: Reconstructing Anonymized Facial Features Using GANS

Publisher: IEEE   Cite This

David Abramian ; Anders Eklund

Refacing Defaced MRI with PixelCNN
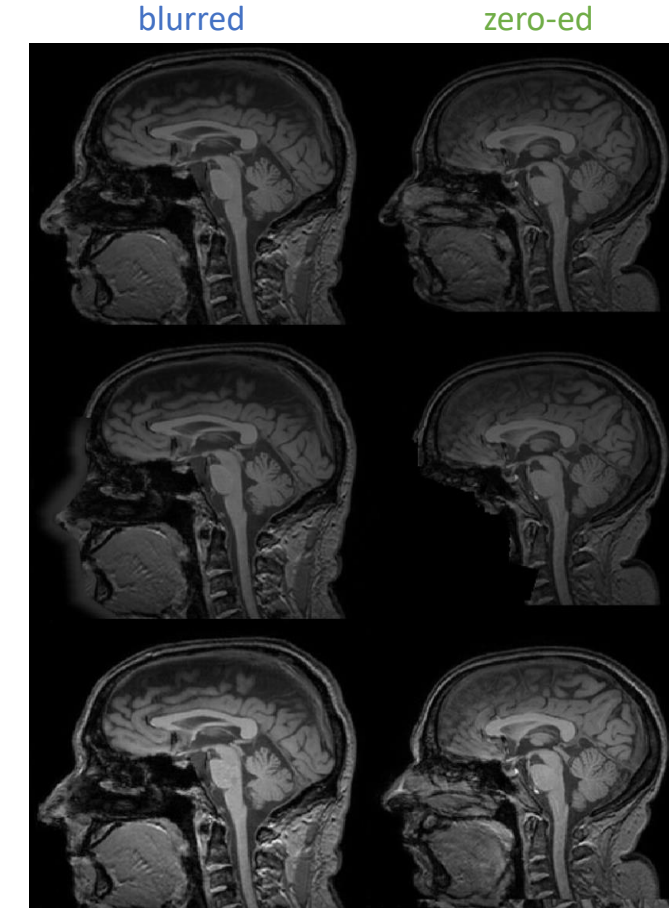
Publisher: IEEE   Cite This   PDF

Yaorong Xiao ; William Ashbee ; Vince D. Calhoun ; Sergey Plis

blurred   zero-ed

Loss of potential information!! defacing is likely not a solution
- Removing facial features degrades perf of image analysis method
- Prevents biophysical modelling for MEEG
- Defacing biases manual and automated quality assessments
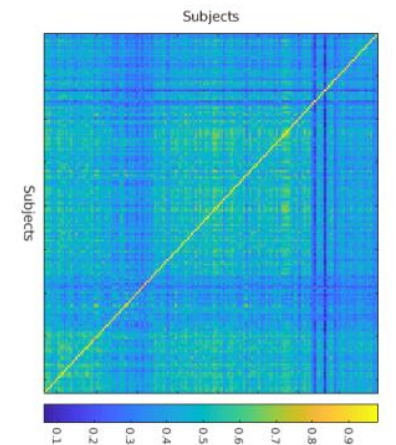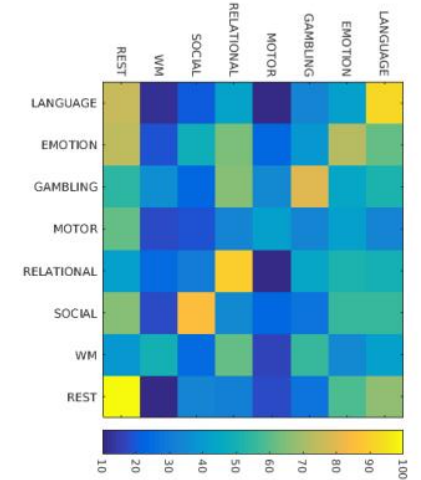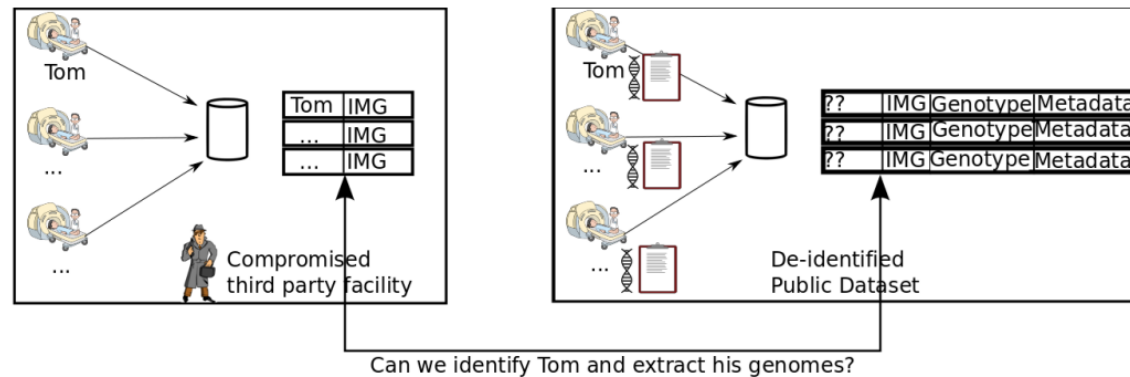
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Re-identification from functional MRI

Re-identification from PET

Face recognition from research brain PET: An unexpected PET problem

Christopher G. Schwarz [a,*], Walter K. Kremers [b], Val J. Lowe [a], Marios Savvides [c], Jeffrey L. Gunter [a], Matthew L. Senjem [a,d], Prashanthi Vemuri [a], Kejal Kantarci [a], David S. Knopman [e], Ronald C. Petersen [e], Clifford R. Jack Jr. [a,#], the Alzheimer's Disease Neuroimaging Initiative [#]

[a] Department of Radiology, Mayo Clinic, Rochester, MN, USA
[b] Department of Health Sciences Research, Division of Biomedical Statistics and Informatics, Mayo Clinic, Rochester, MN, USA
[c] CyLab Biometrics Center and Department of Electrical and Computer Engineering, Carnegie Mellon University, Pittsburgh, PA, USA
[d] Department of Information Technology, Mayo Clinic, Rochester, MN, USA
[e] Department of Neurology, Mayo Clinic, Rochester, MN, USA

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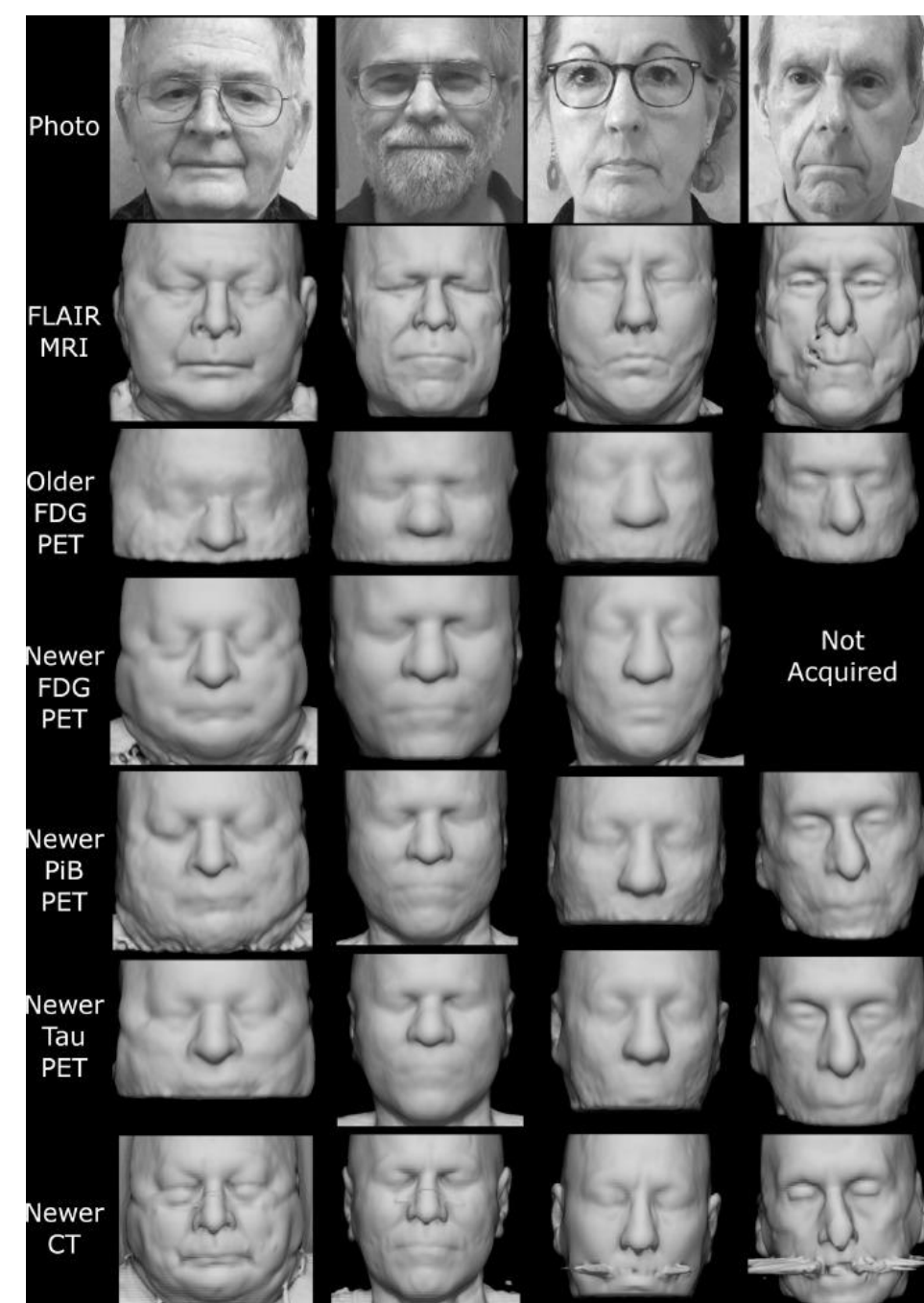
Re-identification from EEG and MEG

Reliability of ERP and single-trial analyses ☆

Carl M. Gaspar [a] ✉, Guillaume A. Rousselet [a], Cyril R. Pernet [b]

Brief segments of neurophysiological activity enable individual differentiation

Jason da Silva Castanheira, Hector Domingo Orozco Perez, Bratislav Misic ✉ & Sylvain Baillet ✉

Permanence of the CEREBRE brain biometric protocol

Maria V. Ruiz-Blondet ✉, Zhanpeng Jin, Sarah Laszlo

HUMAN BRAIN MAPPING

RESEARCH ARTICLE   🔓 Open Access   (cc) (i)

Discovering heritable modes of MEG spectral power

Eemeli Leppäaho, Hanna Renvall, Elina Salmela, Juha Kere, Riitta Salmelin, Samuel Kaski ✉
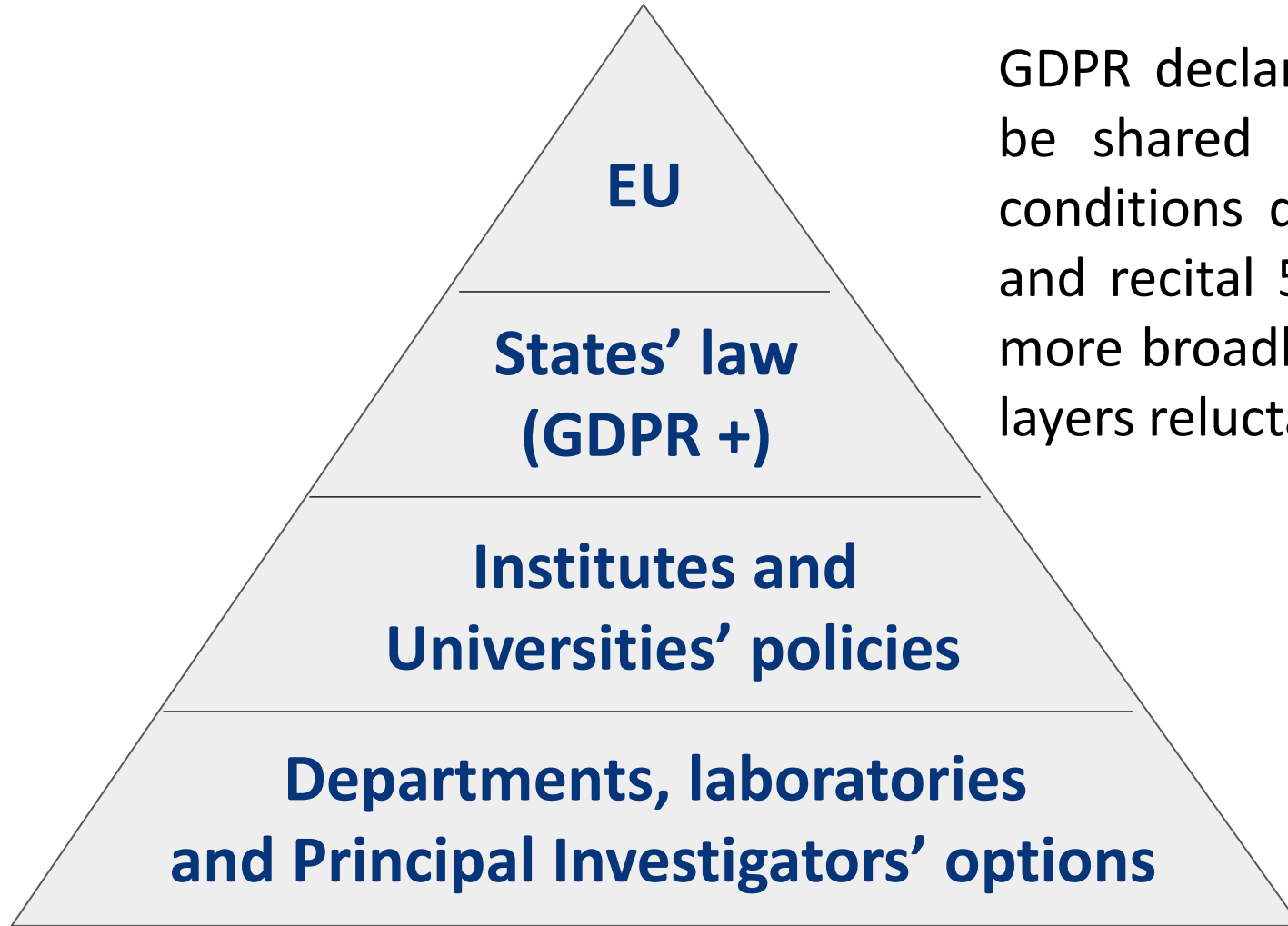
good discriminability, stability over time, and tightly correlated with molecular expression/genes

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Brain imaging data as personal data

- EU GDPR Art. 4 (1). Personal data are any information which are related to an **identified or identifiable** natural person.

- There are only 2 types of data: personal or anonymous.

- For biomedical imaging data, features in the data (e.g. face, ears but also neural fingerprints), and metadata (age, sex, clinical profile) are identifiable. At least we know we can single out individuals, which can be seen as sufficient for being personal data.

- Note: Pseudonymization (the process of removing personal information) does not change the status of the data.

GDPR, states, institutions and labs

EU

States' law (GDPR +)

Institutes and Universities' policies

Departments, laboratories and Principal Investigators' options

GDPR declares that within EU personal data can be shared (Art 1), it also states that general conditions do not apply to research data (Art 5 and recital 50), i.e. scientific data can be shared more broadly without purpose limitation (despite layers reluctance).

Each state has a specific implementation adding different restrictions. Each institution has specific policies and Data Protection Officers interpret the law and those policies differently.

Our Solution
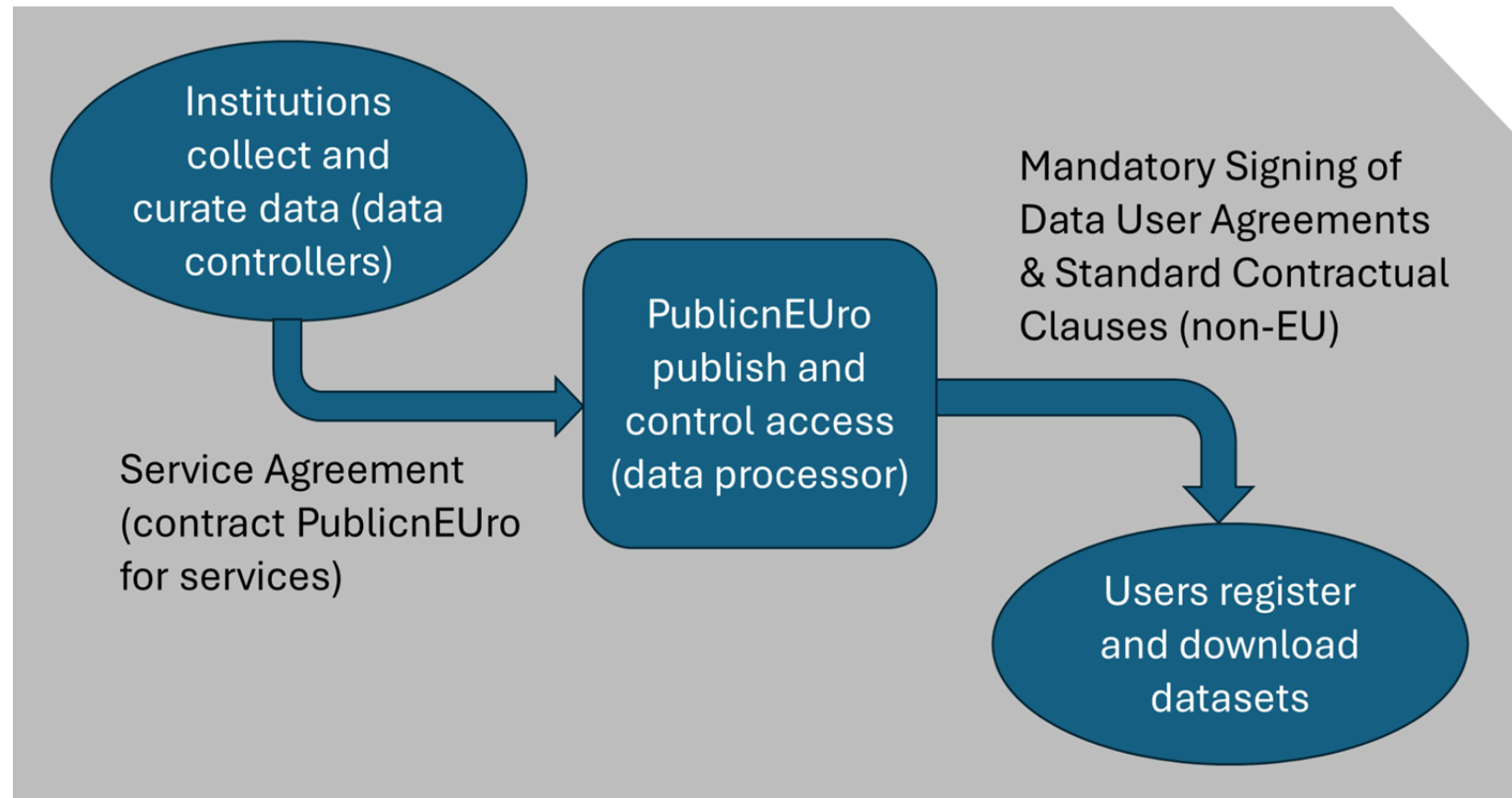
Allows diversity by design – share the data your way!

Institutions collect and curate data (data controllers)

Service Agreement (contract PublicnEUro for services)

PublicnEUro publish and control access (data processor)

Mandatory Signing of Data User Agreements & Standard Contractual Clauses (non-EU)

Users register and download datasets

Figure 1: overview of the data workflow (boxes and arrows) and legal tools around it

Each data set has data user agreements that must be signed before getting access. PubicnEUro allows all combinations of sharing by identifying each user.

Benefits of using PublicnEUro

- Data hosting (Accessible)
- Metadata enhancement and searchability (Findable)
- Unload the administrative burden

➢ data access is managed for you

➢ non-EU paperwork can just as easily be subcontracted

➢ as 'paper' heavy or lightweight as needed (subcontract signing of DUA and SCC or have oversight)

PublicnEUro hosting and security (ready)

- **Public not open**: there is a public register of the data and access is controlled (that public register is the open metadata catalogue)
- Tight control from regulation (GDPR) perspective, 'entrusted' admin access
- Fully identified users are given time-limited access tokens to datasets. All transactions are recorded and available for audits.
- State-of-the-art secured data centre for hosting (computerome DK - ISO27001)

computerome

ENTRUST

PublicnEUro Findability and Accessibility (WIP)

- Data are secured behind firewall - the filesystem maps data using URL/Datalad hashes

- Metadata are open https://github.com/Public-nEUro/DataCatalogue + DOI

- DataLad serves data and DataCat serves metadata - future work will allow data to be also findable on OpenNeuro and metadata browsable jand searchable with Neurobagel just as regular open datasets.

Thank you for your attention

Come and find me at poster 2216 to discuss how we can help you share your data

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