

# The Spectrum of Data Sharing Policies in Neuroimaging Data Repositories

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# Ethical and Legal Challenges in Neuroimaging Data Sharing

- Data sharing is a scientific imperative to maximize the contributions of research subjects and the public's investment.
- However, the sharing of human neuroimaging data raises critical ethical and legal issues, such as research subjects' privacy and confidentiality of data.
- Recent advancements in software tools and algorithms to reidentify neuroimaging data sets (e.g., facial reconstruction<sup>a</sup> and fMRI fingerprinting<sup>b</sup>) have raised concerns about data privacy, and the regulatory landscape around data sharing has also been evolving rapidly.
- Understanding current practice of neuroimaging data sharing in the field would shed light on the impact of these novel privacy risks and the adequacy of the current regulatory regime.

<sup>a</sup> Abramian & Eklund, 2019. IEEE 16th International Symposium on Biomedical Imaging (ISBI 2019).

<sup>b</sup> Ravindra & Grama, 2019. arXiv.

# Current Practice of Data Sharing in Existing Neuroimaging Data Repositories

- Our survey on data use agreement and data sharing policy in existing neuroimaging data repositories shows a wide spectrum of data sharing practice (Table 1).

<Table 1: Current practice of data sharing in existing neuroimaging data repositories><sup>\*</sup>

	Fully Open Sharing		Sharing with Data Sharing Policy or Data Use Agreement					
	OpenNeuro	INDI/FCP	OASIS Project	HCP			NDA	ADNI
				WU/Minn HCP		Harvard/MGC-USC HCP		
				Open Access Data	Restricted Data			
De-identification of data for sharing	✓	✓	✓	✓	✓	✓	✓	✓
Prohibition on re-identifying subjects			✓	✓	✓	✓	✓	✓
Limitations on further disclosure or use of data					✓	✓	✓	✓
Security measures in place					✓	✓	✓	✓
Acknowledgement of data repository as data source		✓	✓	✓	✓	✓	✓	✓ <sup>†</sup>
Report research use of data upon request			✓			✓	✓	✓
Report of violation						✓	✓	✓

<sup>\*</sup> This table is based on requirements or restrictions *explicitly* stated in the data sharing policy or data use agreement.

<sup>†</sup> Additional requirement of review of manuscripts by the ADNI Data and Publication Committee prior to journal submission.

# Current Practice of Data Sharing in Existing Neuroimaging Data Repositories

- The level of restrictions in these repositories varies depending on
  - the sensitivity of data and
  - other relevant factors,
    - ✓ whether original contributors still retain some control over shared data (e.g., by employing strict acknowledgment requirement) or
    - ✓ whether a federal agency (e.g., NIH or FDA) is involved as a governing body of a repository.

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# Towards a Better Protection against Re-identification Risks in Neuroimaging Data Sharing

- The software tools and algorithms to reidentify neuroimaging data are still at an exploratory stage and have only been used for demonstration purposes.
- A more cautious approach needs to be developed to promote responsible sharing of neuroimaging data, such as tiered control of data carefully calibrated to a realistic assessment of privacy risks.<sup>3</sup>
- In fact, our survey showed that existing neuroimaging databases have already developed varying levels of access control and limitations on the use of data depending on the sensitivity of the data.
- However, even with the best available privacy and security measures, it would be impossible to completely eliminate the risks of re-identification.
- The remaining risks could be addressed by introducing a regulatory safeguard against the misuse of information collected or disclosed as part of a research study, similar to the safeguard in the Genetic Information Non-Discrimination Act in the U.S.

<sup>3</sup> Ross et al., 2018. Am Psychol.

**Thank you!**

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