

# Neuroimage Data Sets: Rethinking Privacy Policies

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# Neuroimages

- Imaging of function or structure of the brain
- Contains metadata and image data

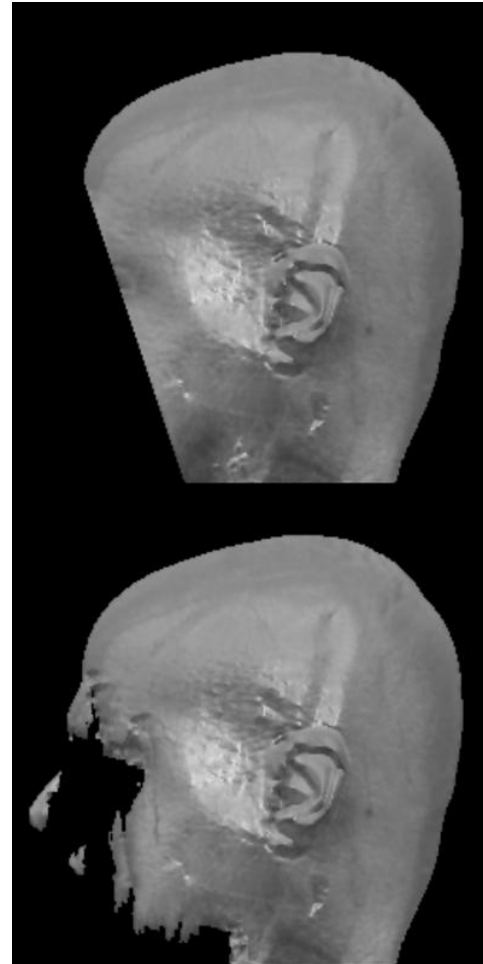


# Neuroimage Data Sharing

- Advantages:
  - Neuroimaging studies tend to have low enrollment and high upfront costs
  - Data sharing increases subject pool, allows for meta-analysis and secondary use
- Challenges:
  - Ownership of data
  - Data usage
  - Privacy
    - Metadata can be deleted/replaced with dummy data
    - Image data is more challenging—potential for reidentification through facial features

# Deidentification Solutions

- Metadata removal
  - LONI Deidentification Debabelt
  - BIRNDUP
  - DICOMBrowser
  - XNAT Redaction Toolkit
  - Many more
- Image Deidentification
  - Skull stripping
  - Quickshear
  - MRI Defacer



# Reidentification Problem

- There is no consensus on image reidentification
- Disjointed, conflicting policies
- Data sets are published as deidentified when they may not be
- Potential for financial and legal penalties
- Exaggerating privacy threat may discourage potential subjects
- Unnecessary image deidentification may degrade image quality

# Example: fMRIDC

- Collected data from 2000-2006, required for articles appearing in Journal of Cognitive Neuroscience
- Requested uploads be deidentified by researchers
- Reserved right to skull strip and remove metadata where necessary

# Example: BIRN

- Bioinformatics Research Network
- License prohibits reidentification
- BIRN Deidentification and Upload Pipeline (BIRNDUP) used MRI Defacer
- Progress on hold until conclusive evidence is available for image data

# Example: ADNI

- Ongoing multisite effort
- Administrative access controls to ensure proper use of images
- User agreement prohibits reidentification
- LONI provides underlying infrastructure



# Determining Reidentifiability

- No consensus on potential for reidentification
- Joint effort to explore possibility of reidentification
  - Work within User Agreements
  - Collaborate with key institutions
- Determine efficacy for image deidentification techniques

# Progress through Policy

- Adopt standard approach to reidentifiability
  - Implement practical privacy measures
  - Improve efficiency and effectiveness of privacy policies
- Establish baseline policy
  - Create guidelines for image privacy
  - Larger organizations can expand to fit their needs
  - Guide smaller collaborations and ad hoc efforts
  - Provide clarity about privacy risks for subjects

# Moving Forward

- Adopt adequate privacy policies
  - Users cannot be relied on to behave properly
  - Conflicting views on the necessity of privacy impedes progress
- Adopt a stance on reidentifiability
  - Assuming images are not PHI may lead to disclosure of subjects' identities
  - Incorrectly assuming images are PHI may discourage potential subjects and unnecessarily complicate data sharing

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