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 Debablet
  - BIRN DUP
  - DICOM Browser
  - 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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