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\textsuperscript{a} and fMRI fingerprinting\textsuperscript{b}) 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.

\textsuperscript{a}Abramian & Eklund, 2019. IEEE 16th International Symposium on Biomedical Imaging (ISBI 2019).
\textsuperscript{b}Ravindra & Grama, 2019. arXiv.
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).

* This table is based on requirements or restrictions explicitly stated in the data sharing policy or data use agreement.
† 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.

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

<table>
<thead>
<tr>
<th></th>
<th>Fully Open Sharing</th>
<th>Sharing with Data Sharing Policy or Data Use Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OpenNeuro</td>
<td>INDI/FCP</td>
</tr>
<tr>
<td>De-identification of data for sharing</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Prohibition on re-identifying subjects</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Limitations on further disclosure or use of data</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Security measures in place</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Acknowledgement of data repository as data source</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Report research use of data upon request</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Report of violation</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

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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.  
- 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.

3 Ross et al., 2018. Am Psychol.
Thank you!

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