Lesson 2: Data Sharing

Address data sharing throughout the data lifecycle

**Describe** data content, character, and process.
**Deposit** in a location from which it can be accessed.
**Preserve** in formats & on media good for long term.
**Publish** information about the data so that others can discover it easily.

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**Concerns about data sharing**

<table>
<thead>
<tr>
<th>Concern</th>
<th>Solution</th>
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<tbody>
<tr>
<td>Inappropriate use due to misunderstanding of research purpose or parameters</td>
<td>• Provide rich <em>Abstract, Purpose, Constraints of Use, &amp; Supplemental Information</em> as needed</td>
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<tr>
<td>Security and confidentiality of sensitive data</td>
<td>• Provide metadata without actual data</td>
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<td></td>
<td>• <em>Use Constraints</em> can be used to say who may access &amp; how</td>
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<tr>
<td>Lack of credit or acknowledgement</td>
<td>• Specify required data citation in <em>Use Constraints</em></td>
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<td>Loss of advantage when competing for research dollars</td>
<td>• Create a second, public version w/generalized <em>Data Processing Desc.</em></td>
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**The value of data sharing**

**To the scientist**
- Receive research sponsor recognition as an authoritative source
- Improved data quality
- Greater opportunity for data exchange
- Improved scientific network connections & potential collaborations

**To the research sponsor/funder**
- Enhanced value of investments by maximizing the return on research dollars spent.

**To the research community**
- Better ability to build upon rather than repeating the work of others
- Ability to perform meta analyses
- Increased transparency, reproducibility, and comparability of results
- Ability to expand methodology assessment, recommendations, & improvements
- Better education for new researchers on the most current and significant findings

**To the public**
- Better access to information leads to better understanding and contributions toward effective public & personal decision making

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**Methods for making data sharable**

Create discoverable, robust metadata.
Include unique IDs & citation information.
Have contributors review metadata for accuracy.
Publish metadata via a portal or clearinghouse.

**Data sharing to understand Alzheimer’s Disease**

“It’s not science the way most of us have practiced in our careers. But we all realized that we would never get biomarkers unless all of us parked our egos and intellectual-property noses outside the door and agreed that all of our data would be made public immediately.” -- John Trojanowski, U. Penn

More at the NY Times: http://nyti.ms/1pVKe44

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*Local contact information*