Legal Approaches to Information Privacy and Data Sharing
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DATA USE AGREEMENTS

OBJECTIVE
- To draft a whitepaper that provides an overview of current contractual approaches to research data sharing.

APPROACH
- Analyzing existing data use agreements (DUAs), licenses, and policies.

RESULTS
- Common DUA approaches at the data ingestion stage.
  - Deposit limited to eligible depositors
  - Data licensed to repository for limited uses
  - Disclosure of data contents to repository
  - Privacy rights and responsibilities
  - Acceptable secondary uses and transfers of data
  - Liability provisions
  - Data retention and disposal requirements
  - Attribution requirements

PRELIMINARY CONCLUSIONS
- Early analysis of trends and themes in 17 DUAs already reviewed:
  - Most data repositories provide publicly-available, broadly-applicable DUAs, terms of use, or policies.
  - Non-repository institutions, government agencies, and businesses often make data available only upon application and create separate agreements for each data transfer.
  - DUAs generally stipulate that the data provider retains ownership of the data after transferring it to a third party.
  - Agreements often limit the use of the data to the purposes listed in the data application and prohibit sharing of the data without prior authorization.
  - It is common for DUAs to establish specific confidentiality, disclosure limitations, and security requirements.

DATA TAGS PROJECT

OBJECTIVE
- To develop an automated system to obtain information about a dataset and generate a tag and a customized license to govern subsequent sharing and use of the data consistent with the relevant privacy interests and statutory restrictions.

APPROACH
- Generating an interview wizard, or a series of questions for a data depositor, to uncover the contents of and legal agreements for a given dataset and drafting modular data use terms that can be used to create a customized license agreement between a repository and a data user.

DATA PRIVACY TOOLS WORKFLOW

OBJECTIVE
- To compile a publicly-available, annotated resource of the hundreds of federal and state laws and regulations with provisions that affect the collection, storage, and transfer of sensitive data.

APPROACH
- Conducting legal research to compile a series of spreadsheets cataloging the privacy-related treaties, articles, and federal and state laws that are relevant to researchers in this area.

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TRACKING POLICY CHANGES

OBJECTIVE
- To monitor legislative and regulatory developments that may have implications for the collection, use, and sharing of data for research purposes.

SAMPLING OF RECENT DEVELOPMENTS

2011
- One-year ban for common law action

2012
- New privacy rules for health records

2013
- Enactment of new data breach legislation

APPROACH
- Reviewing recent and proposed legislative and regulatory changes and analyzing the potential effects of such changes on researchers and data repositories.

REFERENCES
- Berkman Center for Internet & Society Fellows
- Privacy Tools for Sharing Research Data
- A National Science Foundation Secure and Trustworthy Cyberspace Project

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