

Legal Approaches to Information Privacy and Data Sharing

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Privacy Tools for Sharing Research Data

A National Science Foundation
Secure and Trustworthy Cyberspace Project



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 from data repositories, academic institutions, government agencies, and businesses and mapping the common contractual terms to general categories.

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
- Repository rights and responsibilities
- Acceptable secondary uses and transfers of data
- Liability provisions
- Data retention and disposal requirements
- Attribution requirements

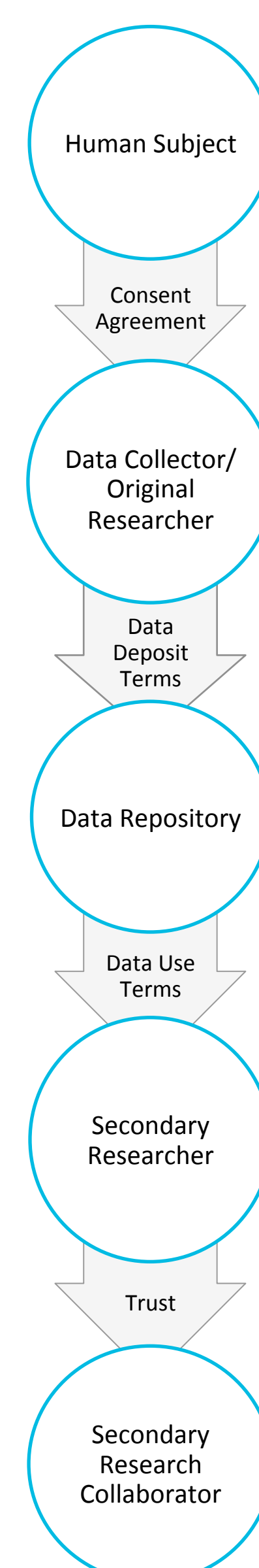
Common DUA approaches at the data use and sharing stages

- Data ownership provisions
- Access restrictions and procedures
- Limitations on data uses
- Restrictions on internal and external sharing
- Confidentiality and security procedures
- Data retention requirements
- Enforcement provisions
- Liability waivers
- 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, while non-repository academic 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 limitation, and security requirements.
- Data repositories typically adopt licenses that shift liability to other parties.

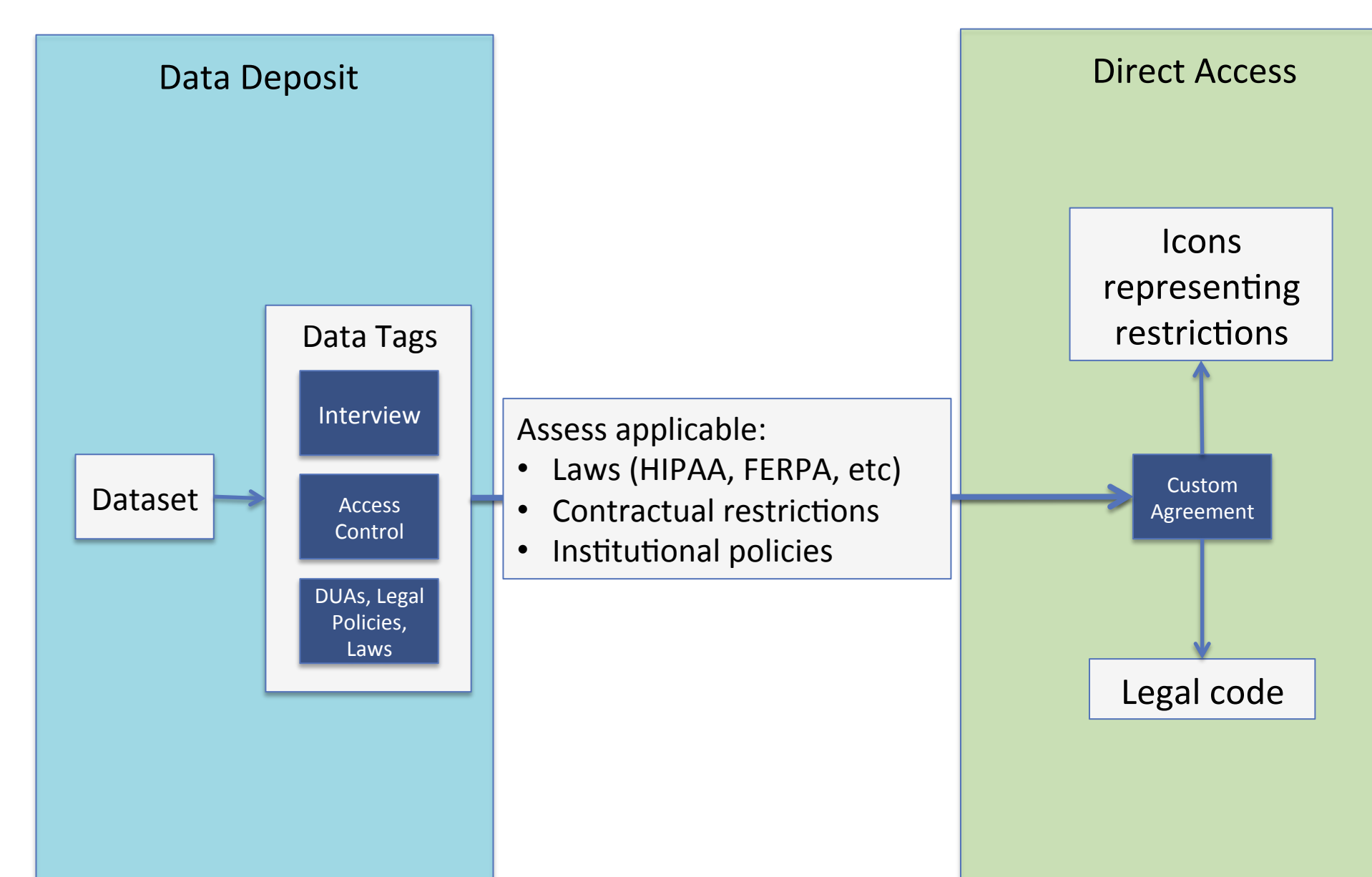


DATA TAGS PROJECT

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.

DATA PRIVACY TOOLS WORKFLOW



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.

Laws examined to date

- The Privacy Act of 1976
- Children's Online Privacy Protection Act (COPPA)
- Family Educational Rights and Privacy Act (FERPA)
- Fair Credit Reporting Act
- Gramm-Leach-Bliley Act
- Health Insurance Portability and Accountability Act (HIPAA)

Outline of example interview wizard questions

- How did you obtain the dataset?
- Does the dataset contain information about individuals?
- Have the individuals consented to the disclosure of their information?
- Does the dataset contain any of the following types of sensitive information?
- Questions related to any legal agreements that apply to the dataset.
- Questions based on statutory and regulatory requirements that potentially apply to the dataset.

Modular license agreement terms

- Terms restricting data access, use, and sharing with other researchers based on the requirements of the legal agreements and statutes that apply to a dataset.
- Terms establishing the confidentiality, security, and retention requirements that apply to a dataset.

PRIVACY LAW RESOURCES

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 treatises, articles, and federal and state laws that are relevant to researchers in this area.

Privacy Law Treatises

- Spreadsheet provides links to, citations for, main topic areas of, and the tables of contents of 43 of the most prominent legal treatises with a privacy focus.
- Includes comprehensive privacy law treatises and topical treatises (medical privacy, financial privacy, government records, communications privacy, national security, children's and students' privacy, data security, privacy torts, and others).
- Treatises cover state, federal, and foreign laws.

Privacy Law Articles

- Spreadsheet and collection of article synopses catalog over 50 articles on privacy-related topics from law, ethics, and social science journals.
- Annotations provide citations, links, abstracts, a list of topics covered, analytical approaches used, and a list of laws examined for each article.

Federal Privacy Laws

- Spreadsheet lists over 40 of the federal privacy laws that are most significant to the collection, use, and sharing of research data.
- Includes citations, topics covered, brief descriptions, statutory requirements, to whom and when the laws apply, enforcement provisions, harm sought to prevent, stages in the research information lifecycle affected, relevant definitions, and judicial interpretations for each of the laws.

State Privacy Laws

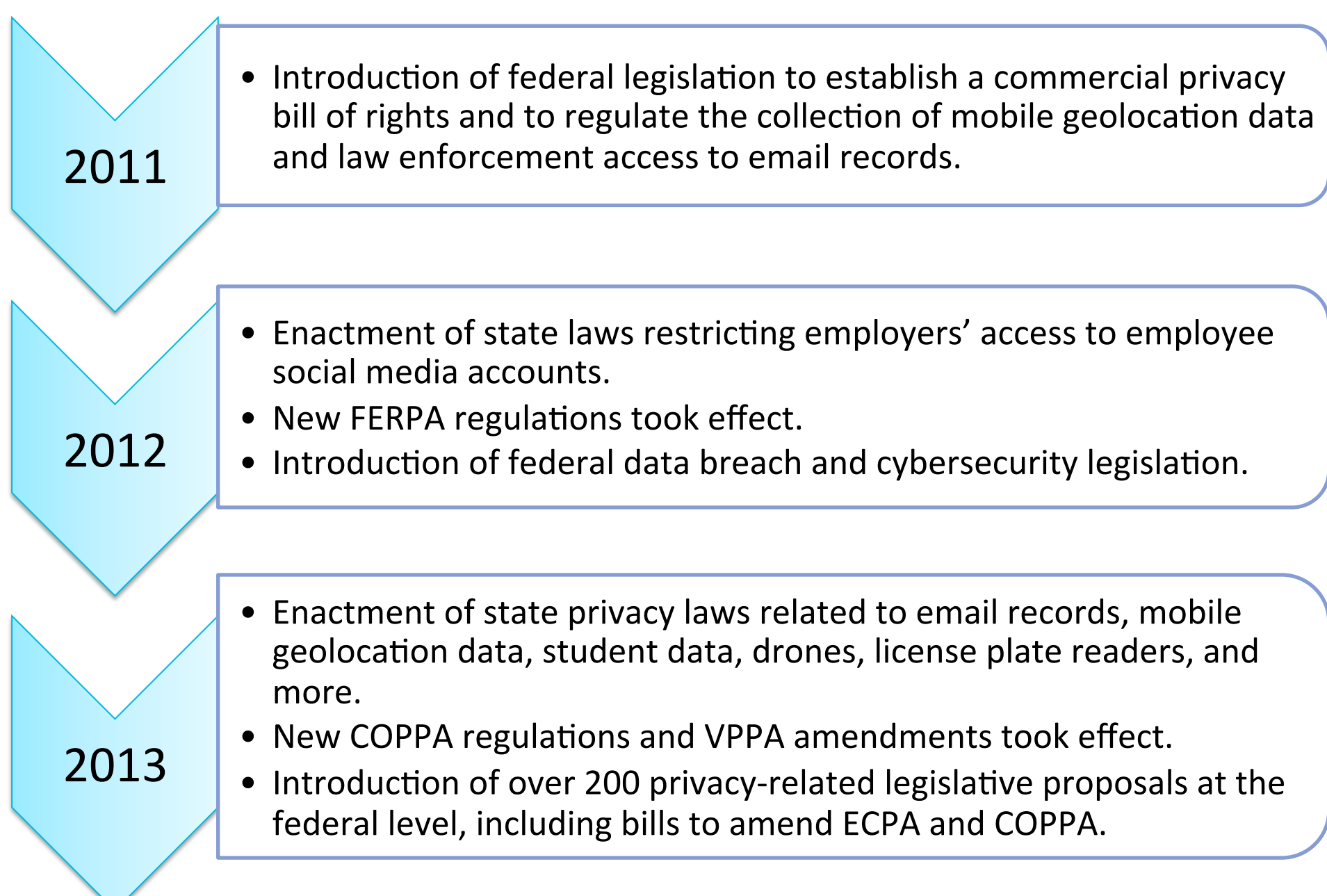
- Spreadsheet contains over 150 state laws related to data breaches, identity theft, government data collection and security practices, web site privacy policies, public records, and wiretapping laws.
- Outlines topics covered, key requirements, definitions, enforcement provisions, and judicial interpretations for each law.

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



APPROACH

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

Family Educational Rights and Privacy Act (FERPA)

- Summary of the 2012 revisions to the Department of Education's regulations governing the collection and disclosure of student information.
- Compilation of the regulatory history of the revisions and comments from privacy advocates submitted during the rulemaking process.
- Analysis of the effect of the revised regulations on the future use of student information for research purposes.

Children's Online Privacy Protection Act (COPPA)

- Summary of the changes made in 2013 to the definitions, notice and consent, disclosure, and data security and retention provisions of the COPPA regulations.
- Analysis of the potential impact of these changes on social science researchers and data repositories.
- Discussion of the proposed COPPA amendments in the Do Not Track Kids Act of 2013.

Data Security Breach Laws

- Summary of state-by-state approaches in the following areas: (1) data security requirements, (2) triggers for breach notification, (3) exceptions to the notice requirement, (4) parties to be notified in the event of a breach.
- Analysis of the data breach and security requirements from the perspectives of researchers and data repositories.
- Review of federal data breach legislation and how it compares to the existing state-level requirements.