RDA P12 Session:

Sharable Data - Metadata, Issues of Privacy and Legal Interoperability

Metadata and Toward FAIRSharing*

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College of Computing and Informatics
Drexel University

*SEE: https://fairsharing.org/

IIS/BD Spokes/Award #1636788

Overview

1. Context
2. NEBDIH Spoke Initiative “A Licensing Model and Ecosystem for Data Sharing”
3. Questions/discussion

Team members

- Sam Madden, Lead PI, Massachusetts Institute of Technology
- Carsten Binnig, PI, Brown University (now Germany)
- Sam Grabus, grad. RA, Drexel University
- Jane Greenberg, PI, Drexel University
- Hongwei Lu, grad. RA, Drexel University
- Famien Koko, grad. RA, MIT
- Tim Kraska, PI, MIT
- Danny Weitzner, PI, MIT

Share BIG DATA

DREXEL UNIVERSITY
Metadata
Research Center
College of Computing & Informatics

MIT CSAIL

NORTHEAST
BIG DATA
INNOVATION HUB

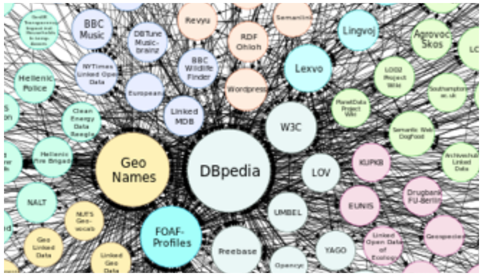
NSF

IIS/BD Spokes/Award
#1636788

Open data

Yeah!

DRYAD



DataONE

DFC DataNet FEDERATION CONSORTIUM

Closed data

Intel-Collaborative Cancer Cloud (CCC) (Dana-Farber, OHSU, Ontario Institute for Cancer Research (OICR))

Collaborative Genomics Cloud (CGC)colocalizing massive genomics datasets)

FICO®

FICO score (Fair Isaac Corporation)

Data sharing barriers

Policy

- Complex regulations governing use of data in different domains
- Data lifecycle – data…living thing

  ~ Do not want to loose control over data downstream

  ~ What if data is redacted?

Licensing, agreements

"Creative commons" (CC, CC0, etc.) does not address need

Security

Technical and systematic aspects

Rights, privacy

Concerns over sensitive information (e.g., PII)

Incentives

Why would someone go to all the effort to share their valuable data?

Still, merit in sharing

No sharing without a legal agreement

Involves lawyers to create individual agreement!

A Licensing Model and Ecosystem for Data Sharing

1. Licensing Framework / Generator

2. Data-Sharing Platform (Enforce Licenses)

   - DataHub

3. Metadata (Search Licenses and Data)

- Principle: Solve the 80% case!

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BIG DATA
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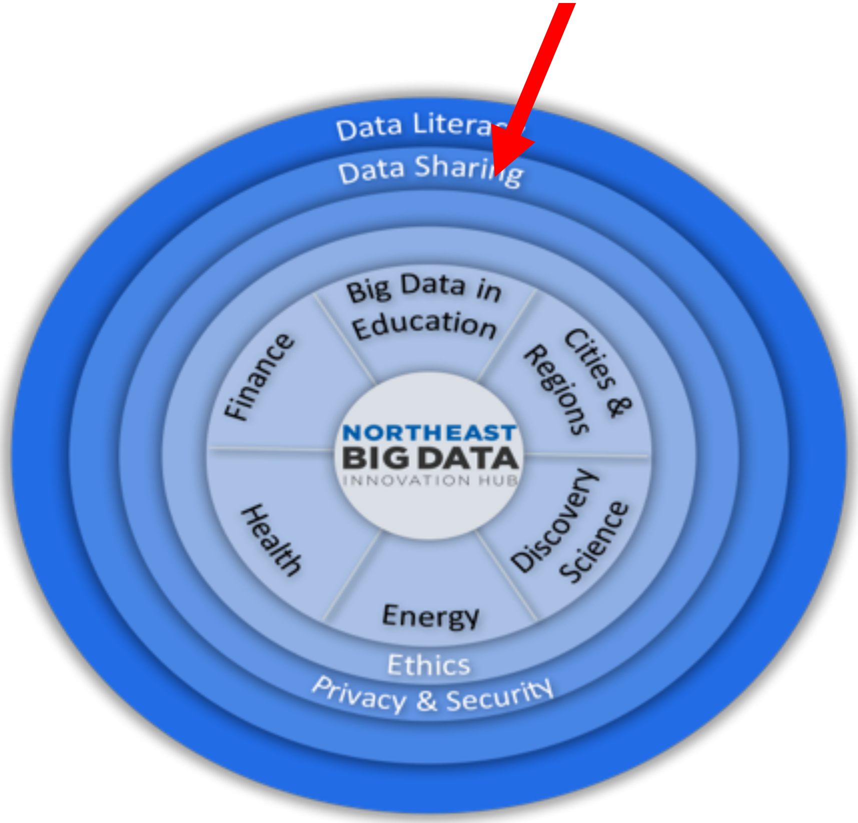
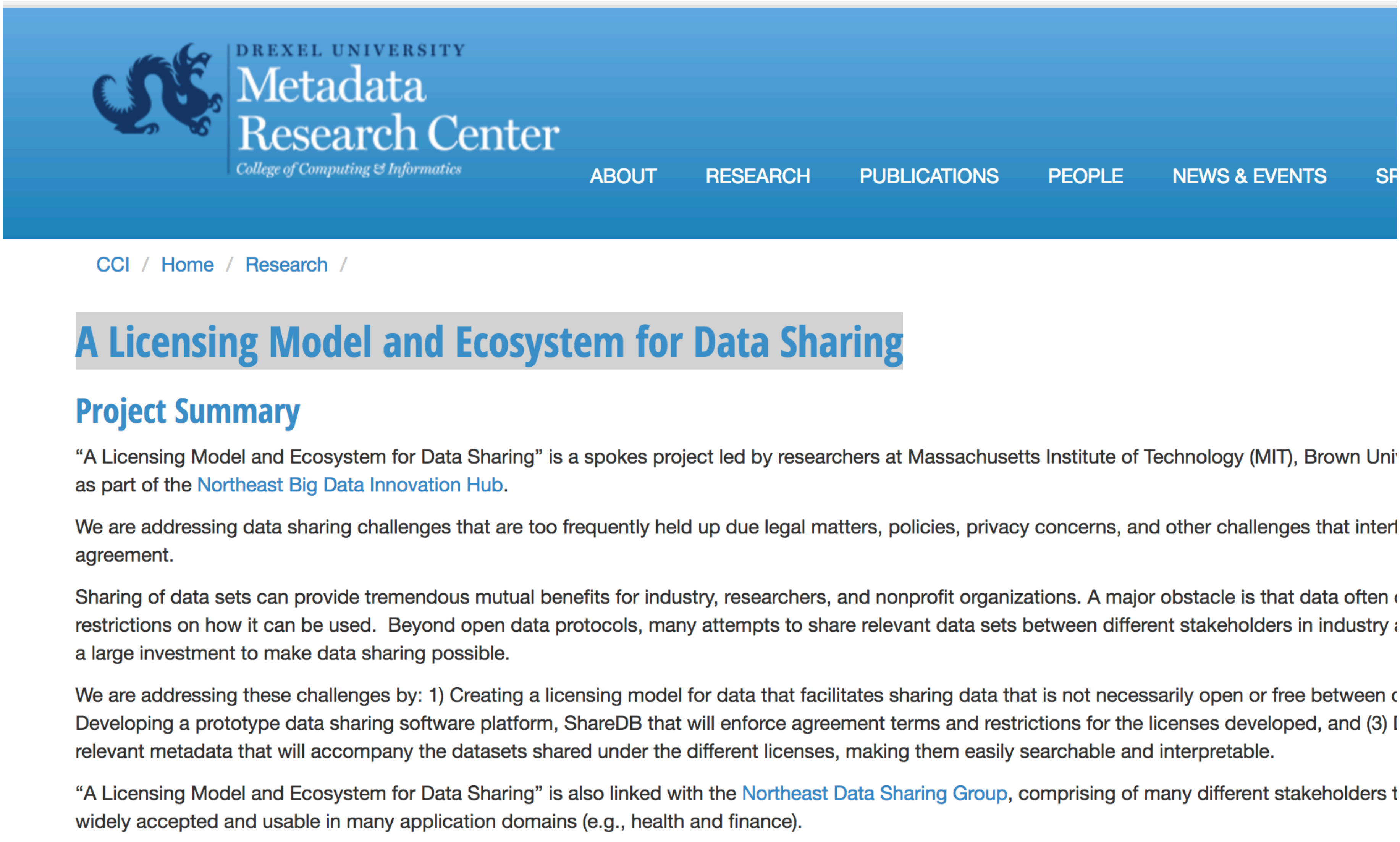
N
E
EDUCATION
DATA SHARING
ETHICS & POLICY
PRIVACY & SECURITY
Health
Energy
Cities & Regions
Finance
Big Data
Applications in Education
Discovery
Science & Engineering



http://cci.drexel.edu/mrc/research/a-licensing-model-and-ecosystem-for-data-sharing



A Licensing Model and Ecosystem for Data Sharing

Project Summary

"A Licensing Model and Ecosystem for Data Sharing" is a spokes project led by researchers at Massachusetts Institute of Technology (MIT), Brown Uni
as part of the Northeast Big Data Innovation Hub.

We are addressing data sharing challenges that are too frequently held up due legal matters, policies, privacy concerns, and other challenges that inter
agreement.

Sharing of data sets can provide tremendous mutual benefits for industry, researchers, and nonprofit organizations. A major obstacle is that data often
restrictions on how it can be used. Beyond open data protocols, many attempts to share relevant data sets between different stakeholders in industry
a large investment to make data sharing possible.

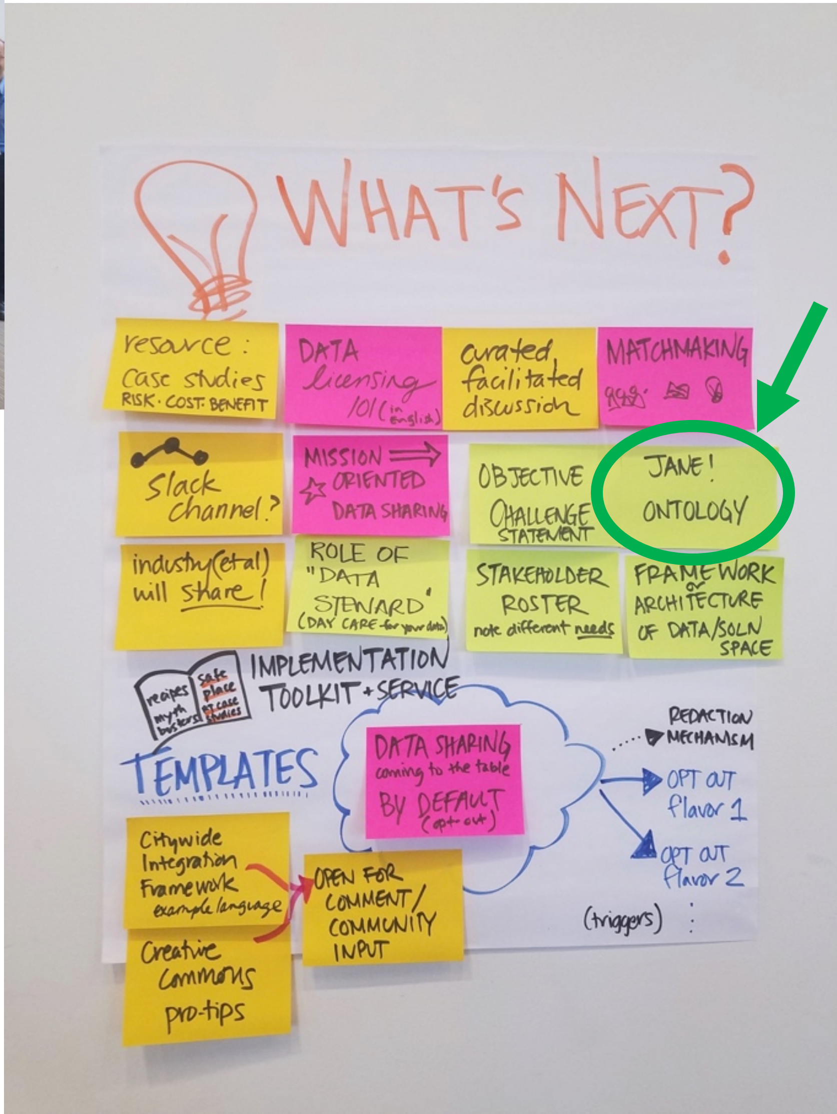
We are addressing these challenges by: 1) Creating a licensing model for data that facilitates sharing data that is not necessarily open or free between
Developing a prototype data sharing software platform, ShareDB that will enforce agreement terms and restrictions for the licenses developed, and (3)
relevant metadata that will accompany the datasets shared under the different licenses, making them easily searchable and interpretable.

"A Licensing Model and Ecosystem for Data Sharing" is also linked with the Northeast Data Sharing Group, comprising of many different stakeholders
widely accepted and usable in many application domains (e.g., health and finance).

Enabling Seamless Data Sharing in Industry and Academia (Fall 2017)

Heard from the trenches…

- Collect agreements
- Build a trusted platform
- Good metadata!

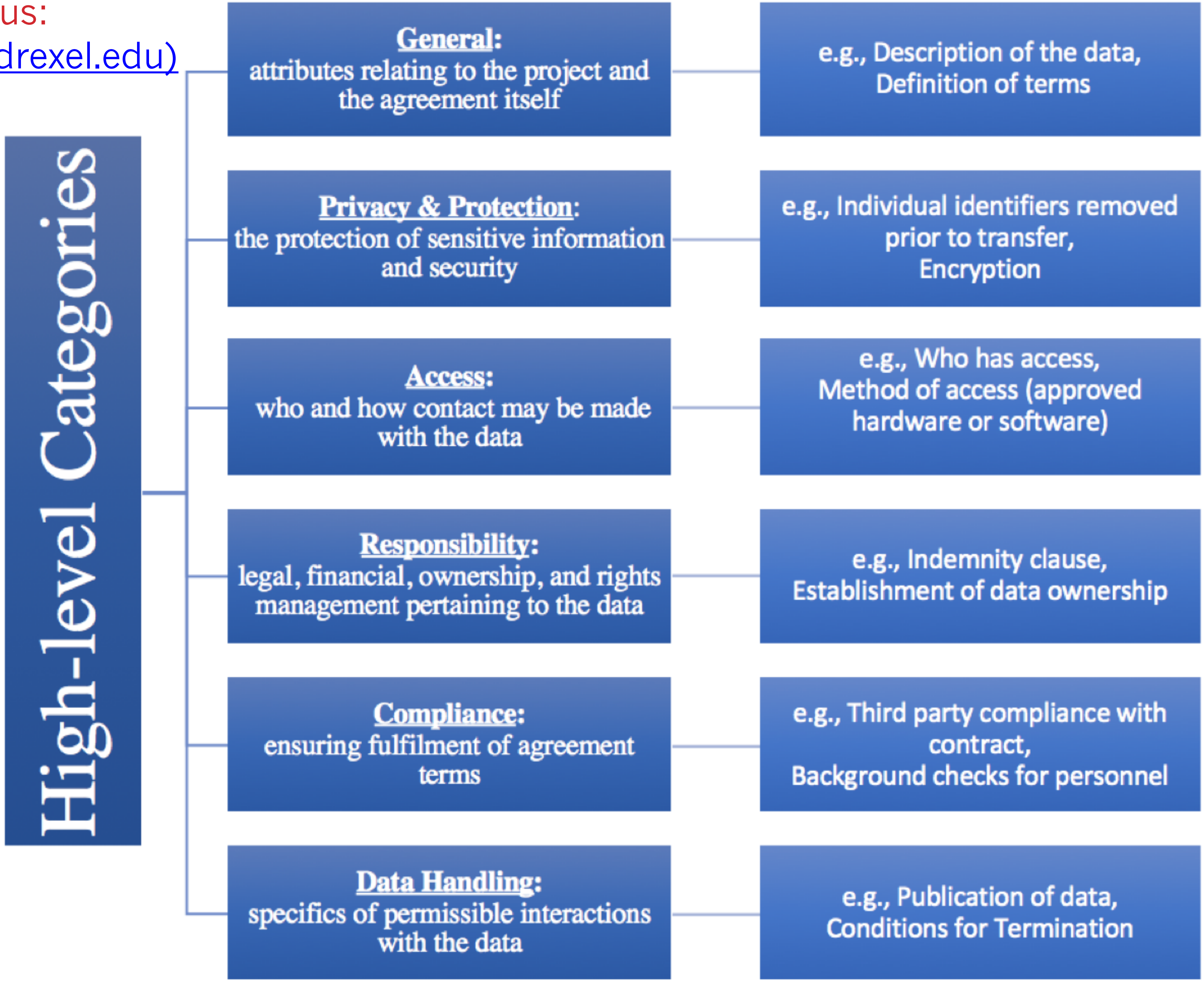

WHAT'S NEXT?
resource : case studies RISK · COST · BENEFIT
DATA licensing 101 (in English)
curated, facilitated discussion
MATCHMAKING
Slack channel?
MISSION ⟹ ORIENTED DATA SHARING
OBJECTIVE CHALLENGE STATEMENT
JANE! ONTOLOGY
industry (et al) will share!
ROLE OF "DATA STEWARD" (DAY CARE for your data)
STAKEHOLDER ROSTER note different needs
FRAMEWORK or ARCHITECTURE OF DATA/SOLN SPACE
recipes myth busters
safe place
case studies
IMPLEMENTATION TOOLKIT + SERVICE
TEMPLATES
DATA SHARING coming to the table BY DEFAULT (opt-out)
REDACTION MECHANISM
OPT OUT flavor 1
OPT OUT flavor 2
(triggers)
Citywide Integration Framework example language
Creative Commons pro-tips
OPEN FOR COMMENT/ COMMUNITY INPUT

A Licensing Model and Ecosystem for Data Sharing" (NSF Spoke)

- First-phase KOS for sharing of restricted data
- Prototyping

Licenses: First Results

(Sam Grabus: smg383@drexel.edu)



High-level Categories

General: attributes relating to the project and the agreement itself

e.g., Description of the data, Definition of terms

Privacy & Protection: the protection of sensitive information and security

e.g., Individual identifiers removed prior to transfer, Encryption

Access: who and how contact may be made with the data

e.g., Who has access, Method of access (approved hardware or software)

Responsibility: legal, financial, ownership, and rights management pertaining to the data

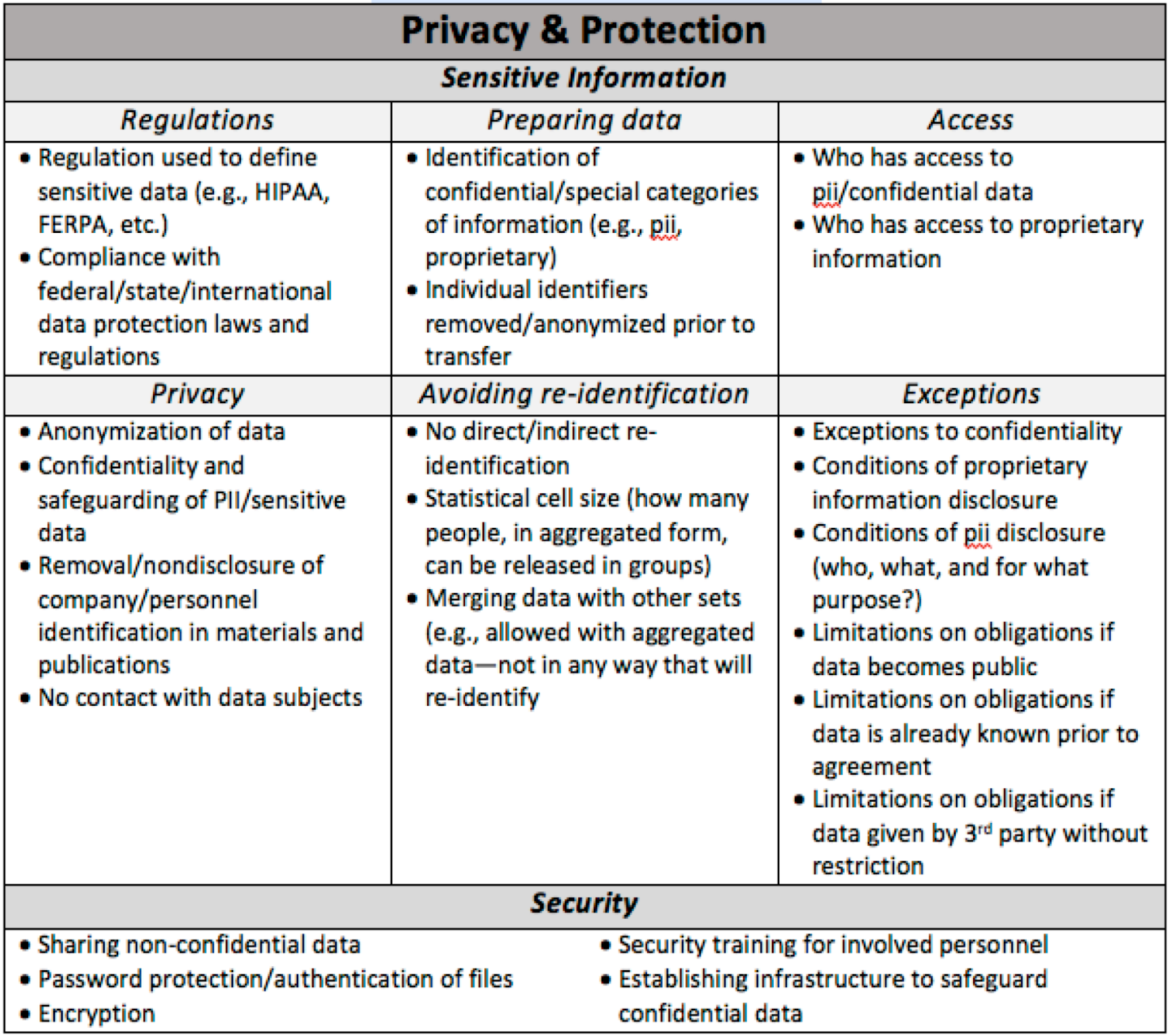
e.g., Indemnity clause, Establishment of data ownership

Compliance: ensuring fulfilment of agreement terms

e.g., Third party compliance with contract, Background checks for personnel

Data Handling: specifics of permissible interactions with the data

e.g., Publication of data, Conditions for Termination



Privacy & Protection

Sensitive Information

Regulations	*Preparing data*	*Access*
• Regulation used to define sensitive data (e.g., HIPAA, FERPA, etc.) • Compliance with federal/state/international data protection laws and regulations	• Identification of confidential/special categories of information (e.g., pii, proprietary) • Individual identifiers removed/anonymized prior to transfer	• Who has access to pii/confidential data • Who has access to proprietary information
Privacy	***Avoiding re-identification***	***Exceptions***
• Anonymization of data • Confidentiality and safeguarding of PII/sensitive data • Removal/nondisclosure of company/personnel identification in materials and publications • No contact with data subjects	• No direct/indirect re-identification • Statistical cell size (how many people, in aggregated form, can be released in groups) • Merging data with other sets (e.g., allowed with aggregated data—not in any way that will re-identify	• Exceptions to confidentiality • Conditions of proprietary information disclosure • Conditions of pii disclosure (who, what, and for what purpose?) • Limitations on obligations if data becomes public • Limitations on obligations if data is already known prior to agreement • Limitations on obligations if data given by 3rd party without restriction

Security

- Sharing non-confidential data
- Password protection/authentication of files
- Encryption
- Security training for involved personnel
- Establishing infrastructure to safeguard confidential data

NLTK – parsing terms

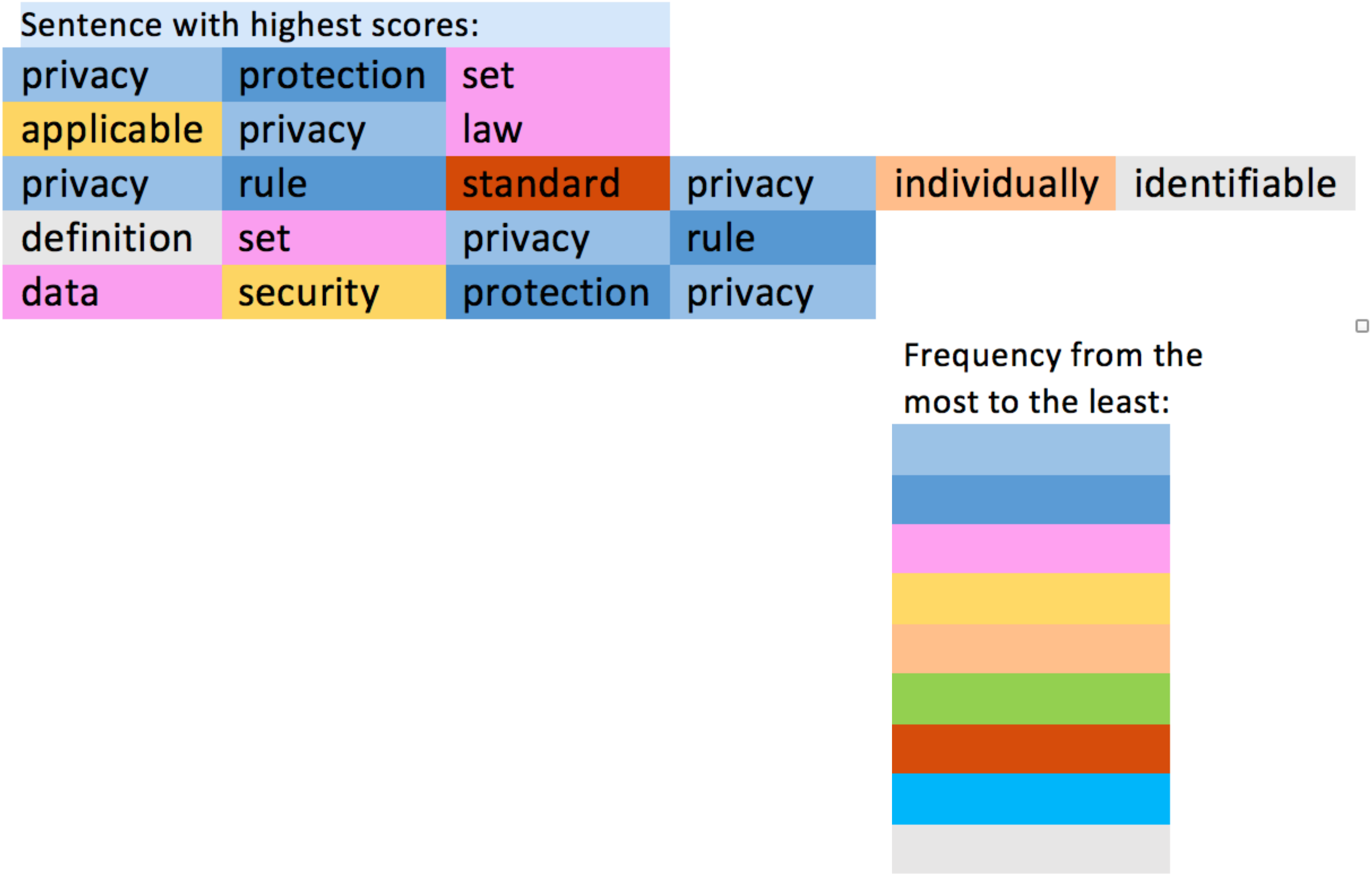
- Set maximum keywords length: 5
  List top 1/5 of all the keywords

  Result:

```
Keyword:  research studies involving human subjects ,
score:  20.4583333333
Keyword:  district assigned student identification numbers ,
score:  18.8387650086
Keyword:  includes personally identifiable student  information ,
score:  17.6168132942
Keyword:  district initiated data research projects , score:  14.8577044025
Keyword:  support effective  instructional practices , score:  13.0
Keyword:  personally identifiable information shared ,
score:  11.3440860215
Keyword:  disclose personally identifiable information ,
score:  11.1440860215
Keyword:  policy initiatives  focused , score:  9.0
Keyword:  informing  education policies , score:  9.0
```

Sample 32 agreements

-5	-4	-3	-2	-1	0	1	2	3	4	5
			educational	right	privacy	act	health	insurance	portability	accountability
applicable	federal	law	regulation	protecting	privacy	citizen	including	family		
	license	agreement	authorized	protect	privacy	individual	subject	nd	study	
				applicable	privacy	law				
consistent	federal	family	educational	right	privacy	act	department	designates	education	alliance
subject	federal	family	educational	right	privacy	act	authorized			
education	record	covered	family	educational	privacy	act	amended			
recipient	agent	subcontractor	violation	agreement	privacy	rule	security	rule	implementing	regulation
comply	applicable	state	local	security	privacy	law	extent	protective	individual	privacy
		data	security	protection	privacy					
information	identified	family	educational	right	privacy	act				
		de	identified	applicable	privacy	law				
				applicable	privacy	law	permit	data	provider	provide
				federal	privacy	act	requirement	apply	agreement	entered
shared	state	subjected	applicable	requirement	privacy	confidentiality				
resolved	permit	covered	entity	comply	privacy	rule				
time	covered	entity	comply	requirement	privacy	rule	hipaa			
		reference	agreement	section	privacy	rule	mean	section	amended	renumbered
					privacy	rule	extent	information	created	received
					privacy	rule	standard	privacy	individually	identifiable
					privacy	rule	include	person	qualifies	personal
tern	defined	agreement	meaning	term	privacy	rule				
set	accordance	term	agreement	hipaa	privacy	security	rule			
hipaa	regulation	promulgated	thereunder	governing	privacy	security	health	information		



Sentence with highest scores:

privacy	protection	set			
applicable	privacy	law			
privacy	rule	standard	privacy	individually	identifiable
definition	set	privacy	rule		
data	security	protection	privacy		

Frequency from the most to the least:

🟦
🟦
🟪
🟨
🟧
🟩
🟥
🟦
⬜

Goal: Licensing Framework

Standard terms that researchers, lawyers, and compliance teams conform with

- ☑ Controlled access
- □ Tracking of access
- ☑ Usage rights (e.g., publication, copying)
- □ Duration of use
- ☑ Warrantees of correctness/completeness/availability
- □ Other requirements

Is this possible: Technology $\bowtie$ Sharing Agreements

Technical

Access control & rights management

Expiration

Logging & auditing

Provenance/Finger printing

De-identification

“Noising”

Aggregation

Agreement Clauses

Controlled access (who & where)

Tracking of access

Usage rights (e.g., publication, copying)

Duration of use

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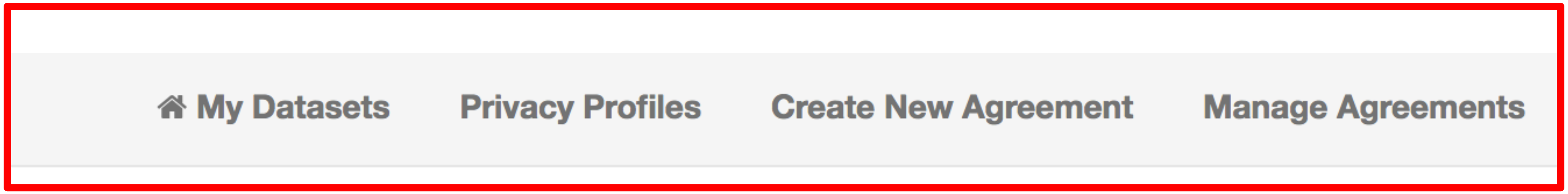
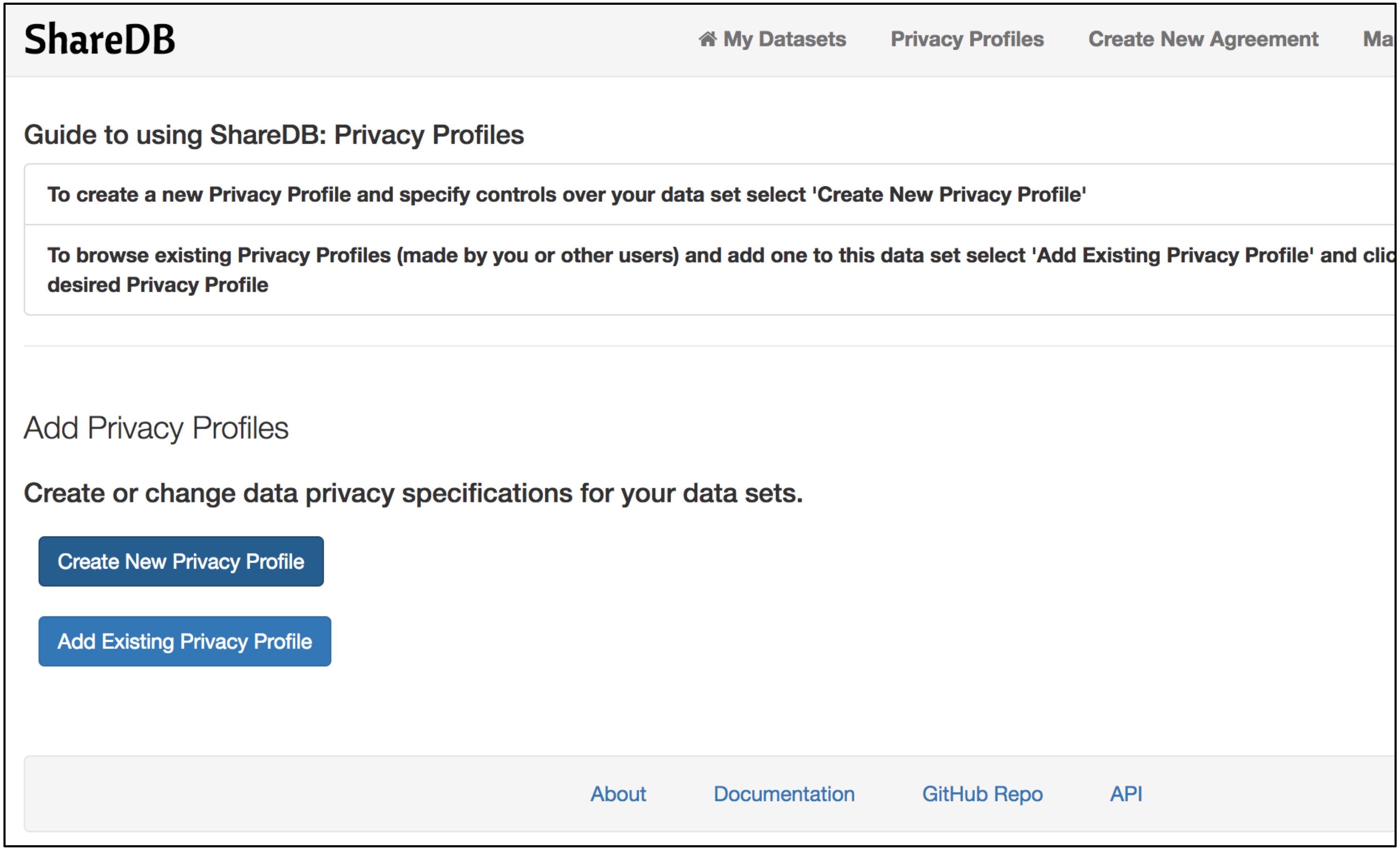




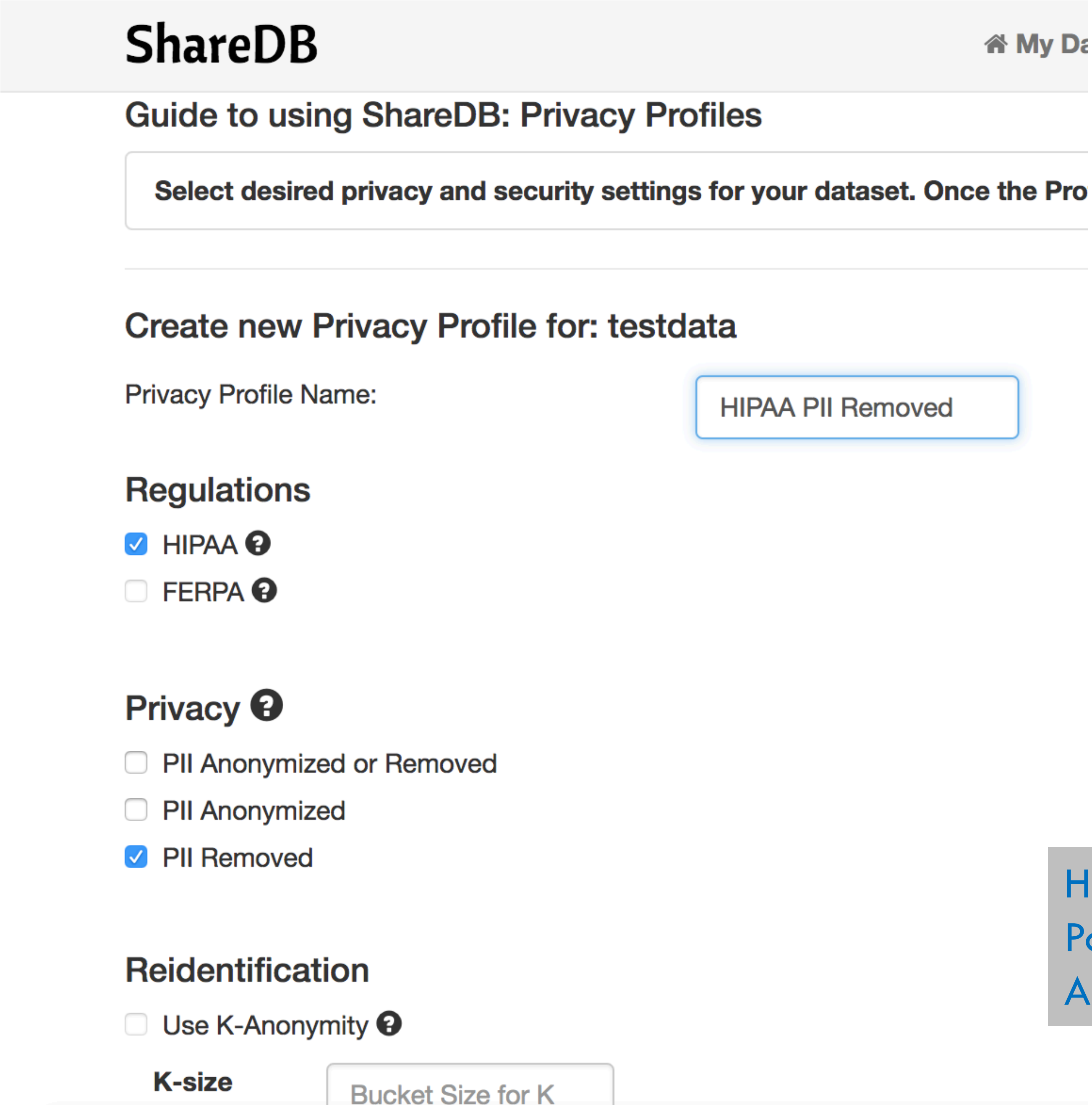
Guide to using ShareDB: Privacy Profiles

To create a new Privacy Profile and specify controls over your data set select 'Create New Privacy Profile'

To browse existing Privacy Profiles (made by you or other users) and add one to this data set select 'Add Existing Privacy Profile' and clic desired Privacy Profile

Add Privacy Profiles

Create or change data privacy specifications for your data sets.



ShareDB

My Da

Guide to using ShareDB: Privacy Profiles

Select desired privacy and security settings for your dataset. Once the Pro

Create new Privacy Profile for: testdata

Privacy Profile Name: HIPAA PII Removed

Regulations

☑ HIPAA ?

□ FERPA ?

Privacy ?

□ PII Anonymized or Removed

□ PII Anonymized

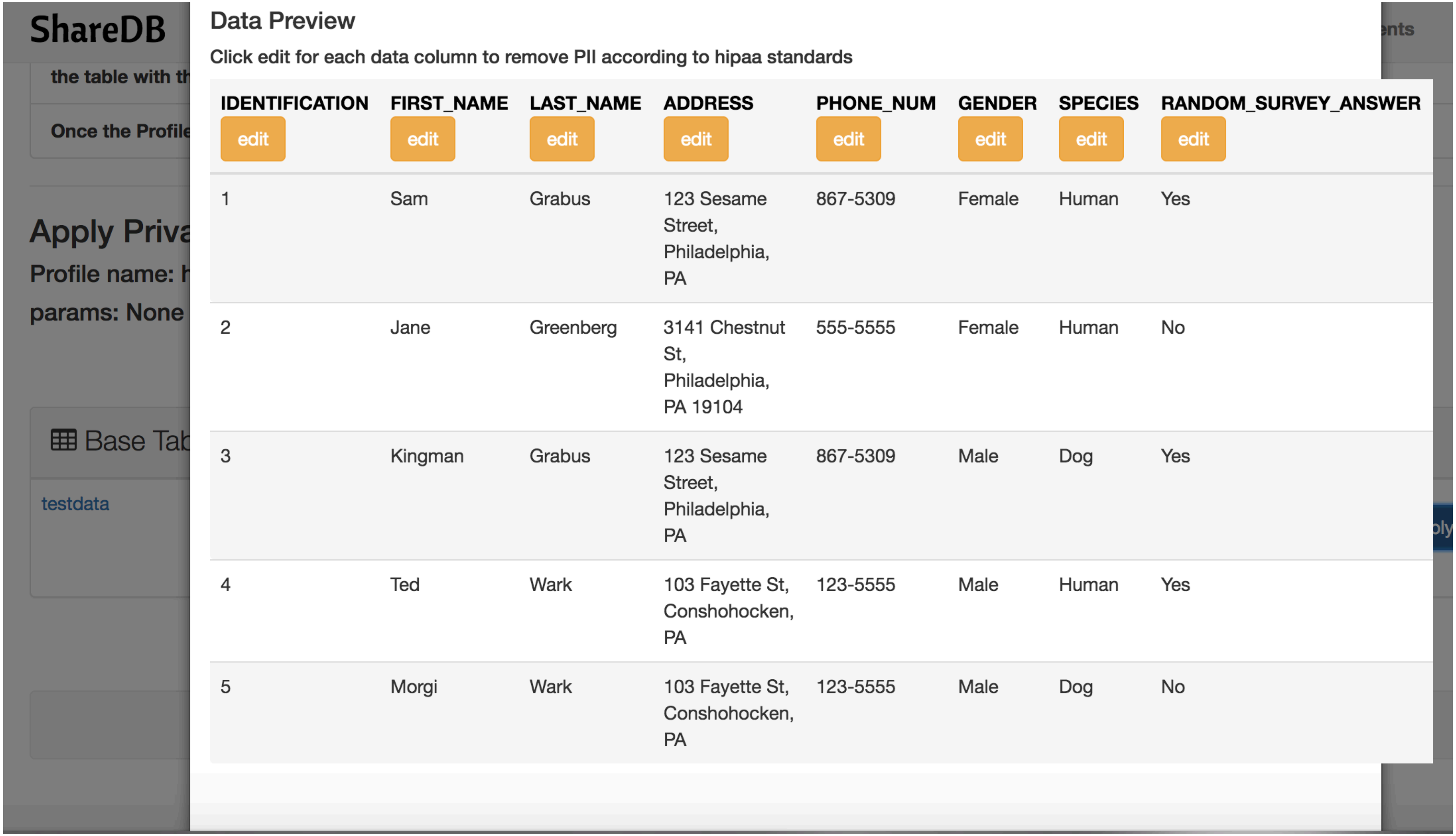
☑ PII Removed

Reidentification

□ Use K-Anonymity ?

K-size Bucket Size for K

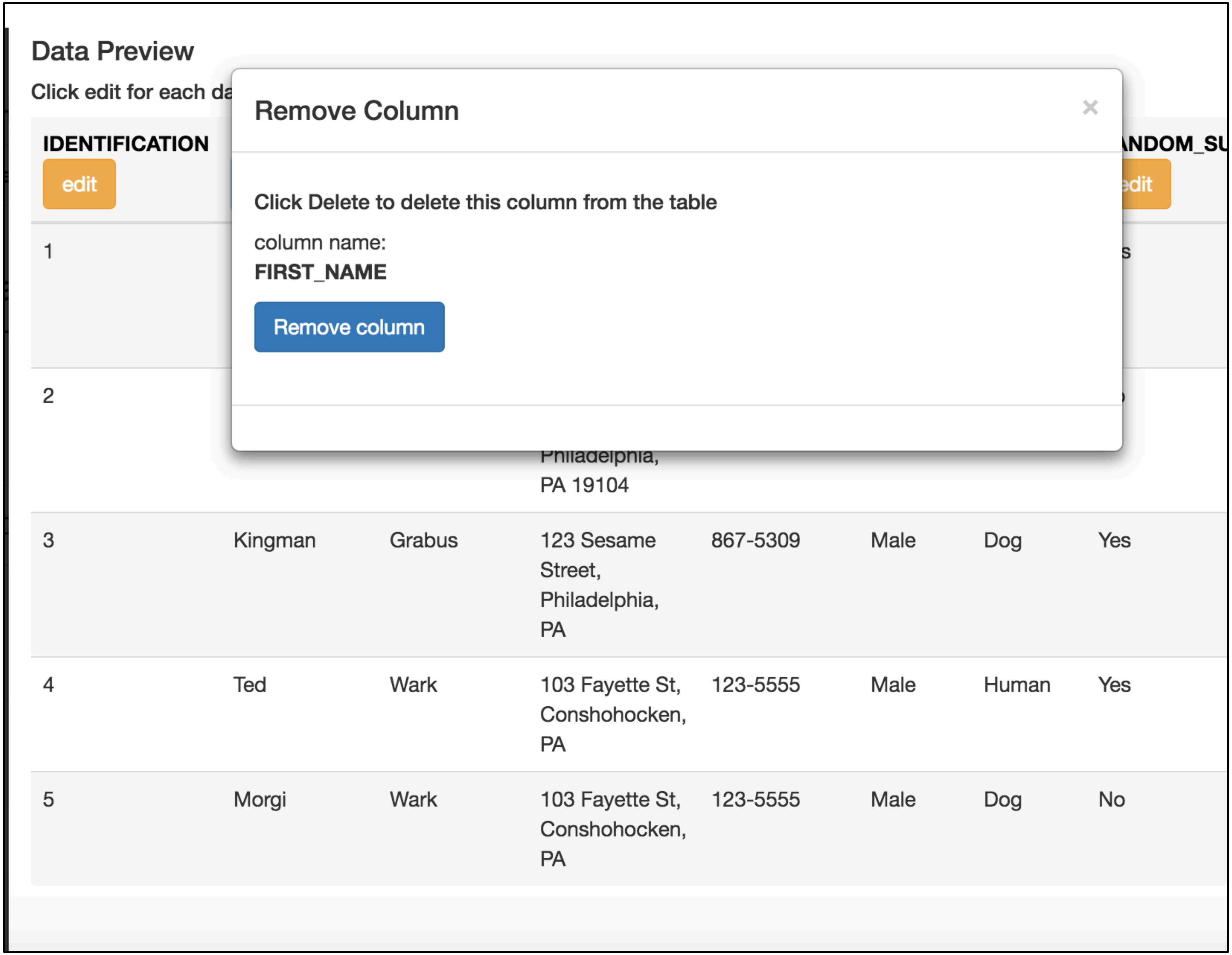
Health Insurance Portability and Accountability Act



Data Preview

Click edit for each data column to remove PII according to hipaa standards

IDENTIFICATION edit	FIRST_NAME edit	LAST_NAME edit	ADDRESS edit	PHONE_NUM edit	GENDER edit	SPECIES edit	RANDOM_SURVEY_ANSWER edit
1	Sam	Grabus	123 Sesame Street, Philadelphia, PA	867-5309	Female	Human	Yes
2	Jane	Greenberg	3141 Chestnut St, Philadelphia, PA 19104	555-5555	Female	Human	No
3	Kingman	Grabus	123 Sesame Street, Philadelphia, PA	867-5309	Male	Dog	Yes
4	Ted	Wark	103 Fayette St, Conshohocken, PA	123-5555	Male	Human	Yes
5	Morgi	Wark	103 Fayette St, Conshohocken, PA	123-5555	Male	Dog	No



Data Preview

Click edit for each da

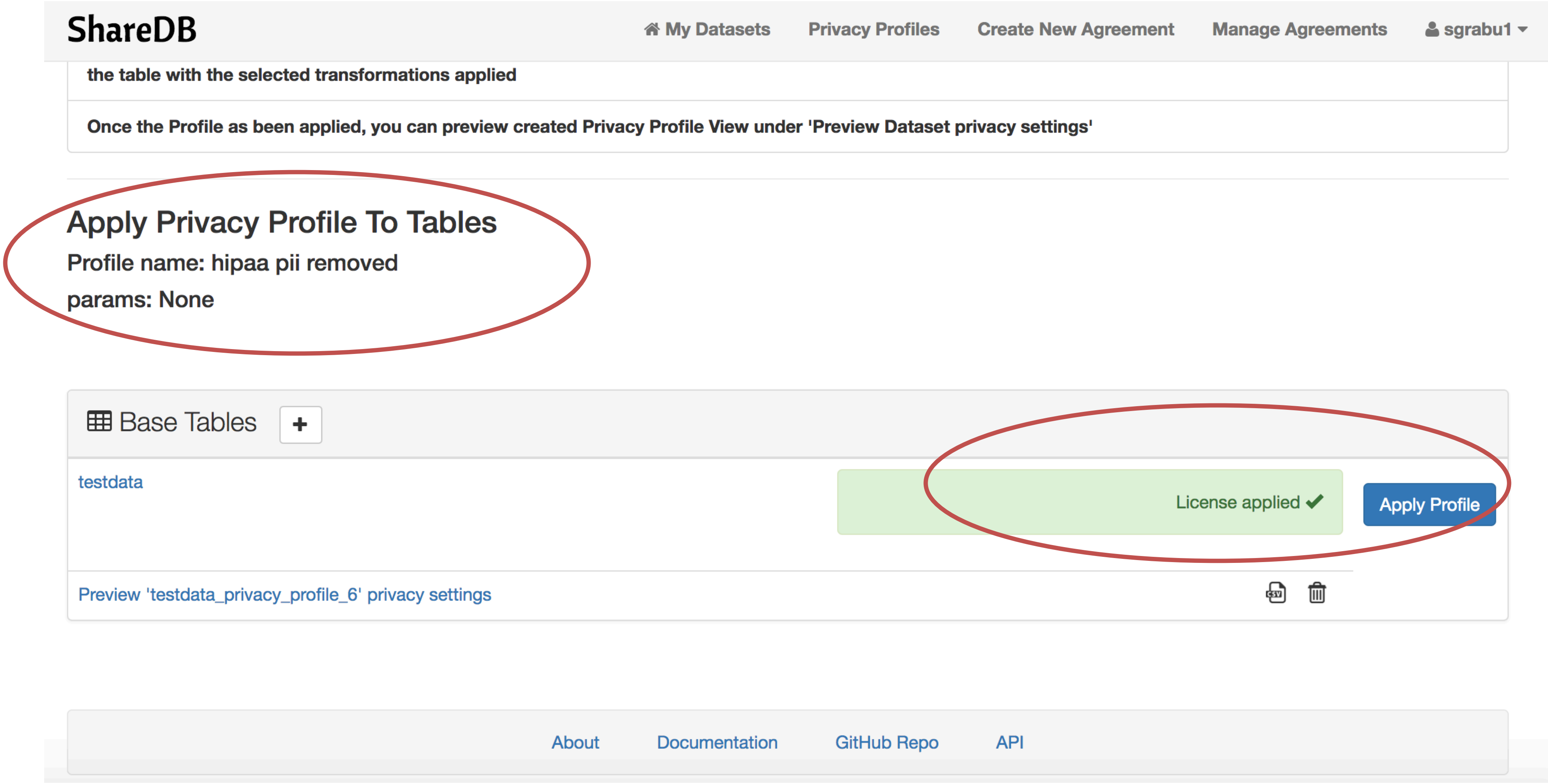
Remove Column

Click Delete to delete this column from the table

column name:

FIRST_NAME

IDENTIFICATION edit							ANDOM_SU edit
1							s
2			Philadelphia, PA 19104				
3	Kingman	Grabus	123 Sesame Street, Philadelphia, PA	867-5309	Male	Dog	Yes
4	Ted	Wark	103 Fayette St, Conshohocken, PA	123-5555	Male	Human	Yes
5	Morgi	Wark	103 Fayette St, Conshohocken, PA	123-5555	Male	Dog	No



the table with the selected transformations applied

Once the Profile as been applied, you can preview created Privacy Profile View under 'Preview Dataset privacy settings'

Apply Privacy Profile To Tables

Profile name: hipaa pii removed

params: None

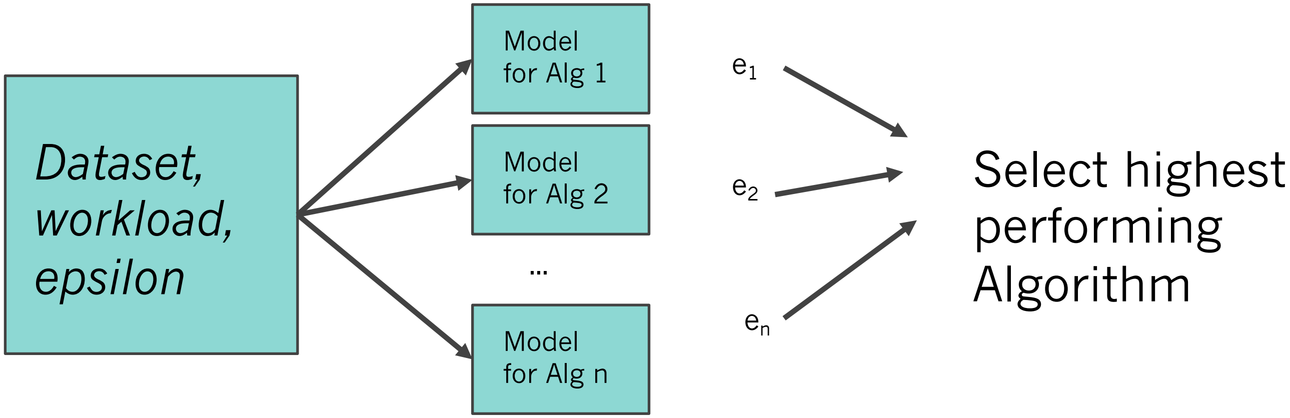
License applied ✓

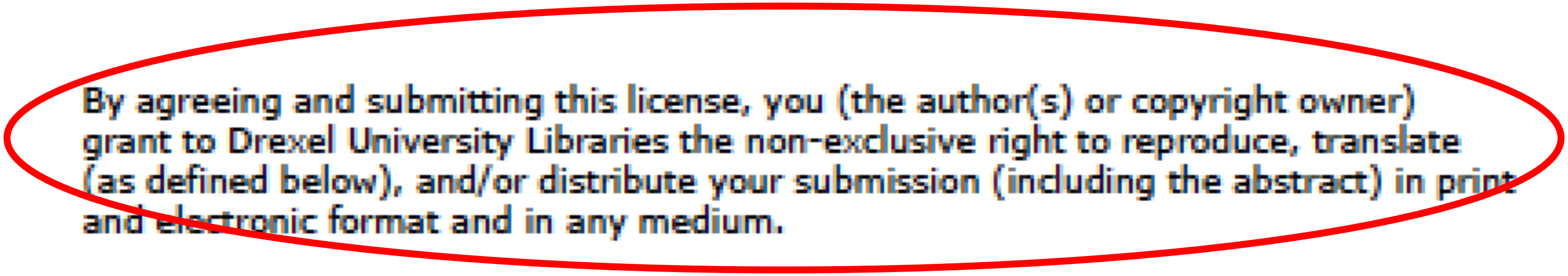
Preview 'testdata_privacy_profile_6' privacy settings

Differentially Private Querying – Improving queries over data that don’t expose private information.

Our approach automatically chooses an algorithm that will achieve a desired error while maximizing privacy.

For each algorithm in, A, create a model which can predict the epsilon to produce desired error rate, given dataset and workload -> select algorithm with highest predicted epsilon


Dataset, workload, epsilon
Model for Alg 1
Model for Alg 2
...
Model for Alg n
e_1
e_2
e_n
Select highest performing Algorithm



Jane Greenberg

Digitally signed by com.apple.idms.appleid.prd.55546a
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Conclusions and next steps

- Work underway, a lot of heavy lifting…
  - Mining licenses shows great diversity, but similarities
  - Usability testing
- Infrastructure to build on assisted with prototyping
- Continue to collect licenses
- Community building
- Workshop 2019

Questions

- What are the most pressing challenges in this space that can be addressed with metadata?
- What is the low hanging fruit in this area – that RDA communities might gather around?
- Which question are we not asking that we should be asking