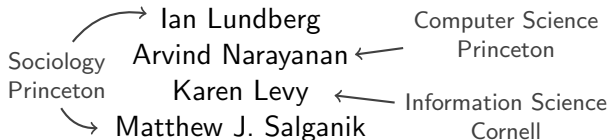


# Privacy, ethics and data access

## A case study of the Fragile Families Challenge

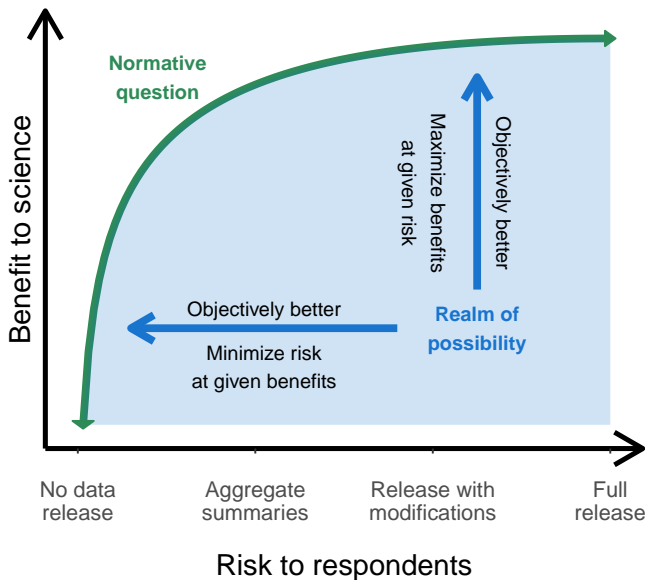
This research is supported by the Russell Sage Foundation. We are grateful to the members of the Board of Advisors of the Fragile Families Challenge. Source for these slides:

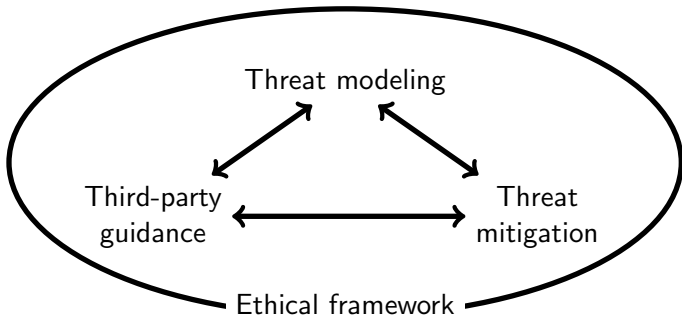
[www.github.com/fragilefamilieschallenge](https://www.github.com/fragilefamilieschallenge).



13 August 2018

Annual Meeting of the  
American Sociological Association







# Fragile Families

& Child Wellbeing Study  
PRINCETON | COLUMBIA



- ▶ Birth cohort panel study
- ▶  $\approx 5,000$  children born in 20 U.S. cities
- ▶ Followed from birth through age 15



Features relevant to privacy:

1. Informed consent



Features relevant to privacy:

1. Informed consent
2. Already available to researchers



Features relevant to privacy:

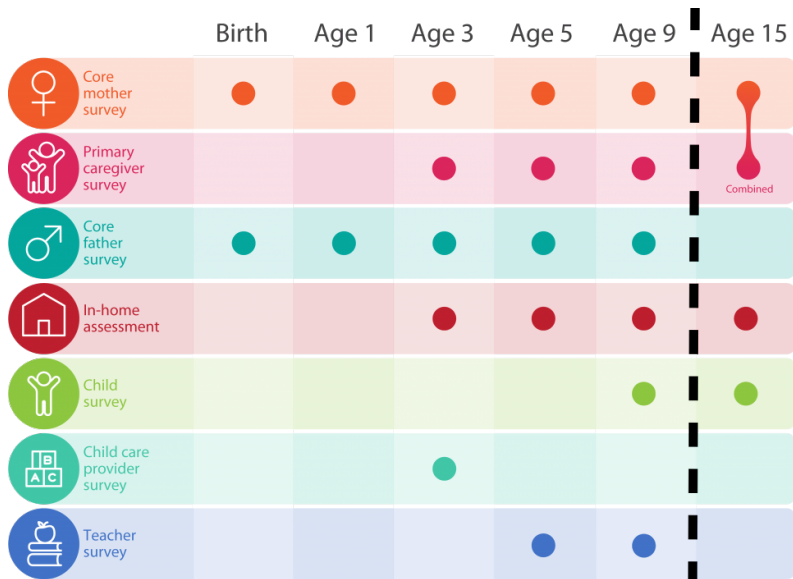
1. Informed consent
2. Already available to researchers
3. Already used in scientific and policy debates



Features relevant to privacy:

1. Informed consent
2. Already available to researchers
3. Already used in scientific and policy debates
4. Contain information from many respondents





4,242 families

Birth to age 9  
12,942 features



Age 15  
6 outcomes

Training

Leaderboard

Holdout

The Princeton IRB approved the project.

The Princeton IRB approved the project.  
The data met standards for de-identification.

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The data met standards for de-identification.

**Why worry?**



Art by David Finch  
Source: Wikipedia

## A. Sweeney (1997) re-identified Massachusetts medical records

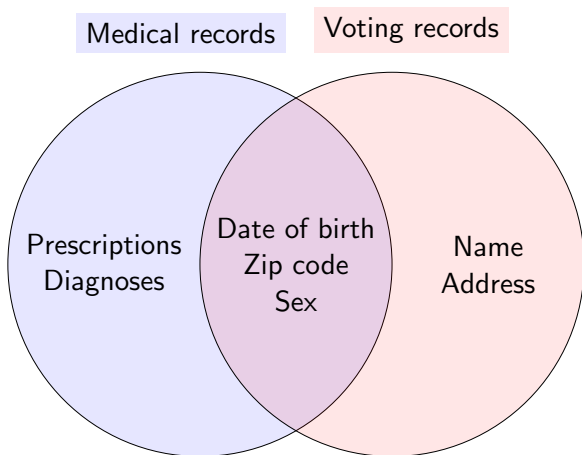
Medical records

Prescriptions  
Diagnoses

Voting records

Name  
Address

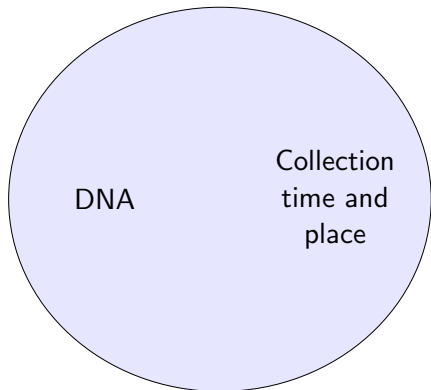
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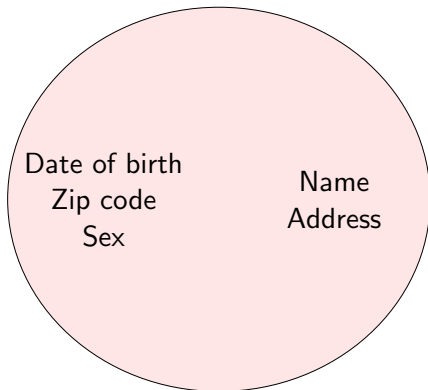


## B. Malin and Sweeney (2004) re-identified genomics data

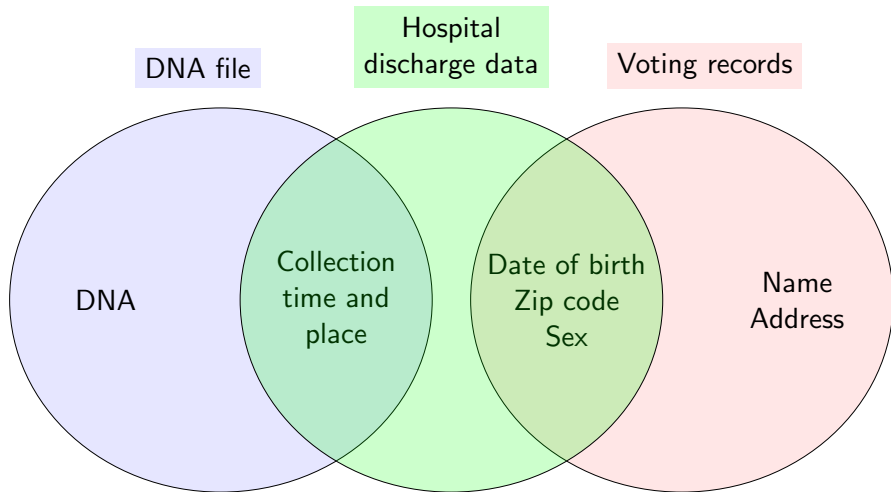
DNA file



Voting records



## B. Malin and Sweeney (2004) re-identified genomics data



C. We don't know the auxiliary data that may exist.

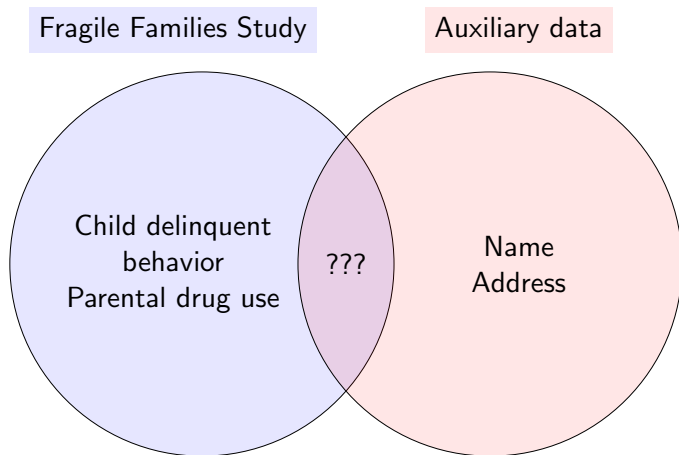
### Fragile Families Study

Child delinquent  
behavior  
Parental drug use

### Auxiliary data

Name  
Address

C. We don't know the auxiliary data that may exist.



# Provable privacy protections

Promising areas of active research:

- ▶ Differential privacy
- ▶ Cryptography

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At their present development,  
neither applied in our setting.

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Promising areas of active research:

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At their present development,  
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Turned to approaches  
without  
provable guarantees.

# Threat modeling

**Criteria** that represent a threat of a re-identification attack:

- ▶ skills
- ▶ auxiliary data
- ▶ incentives



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2. Nosy neighbor
3. Troll
4. Journalist
5. Cheater

← Mitigations →

Threats ↑		Low profile	Careful language	Challenge structure	Application process	Ethical appeal	Modifications to data
	Privacy researcher	✓	✓	✓	✓	✓	✓
	Nosy neighbor	✓			✓		
	Troll	✓		✓	✓		✓
	Journalist	✓	✓	✓	✓	✓	✓
	Cheater		✓	✓		✓	✓

# Response plan

We mitigated but did not eliminate risks.

We needed a team ready to respond in a crisis

- ▶ Computer scientist who had re-identified datasets previously
- ▶ Lawyer and sociologist who studies privacy and inequality
- ▶ Respected journalist

We were prepared to respond **quickly**.



## Third-party guidance: Avoid groupthink

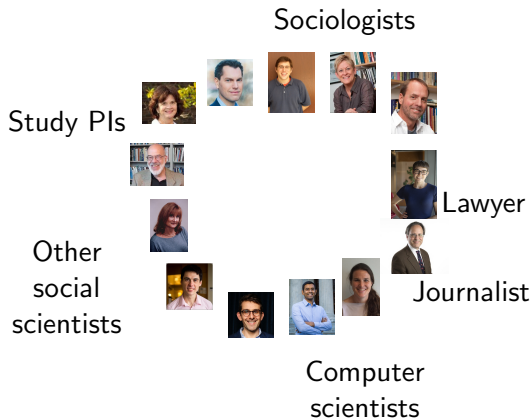
Third-party guidance: Avoid groupthink

**Basic oversight**

Princeton IRB

# Third-party guidance: Avoid groupthink

## Board of Advisers

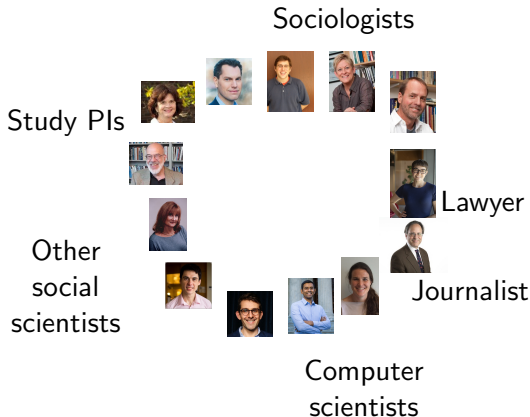


**Basic oversight**

Princeton IRB

# Third-party guidance: Avoid groupthink

## Board of Advisers



**Basic oversight**

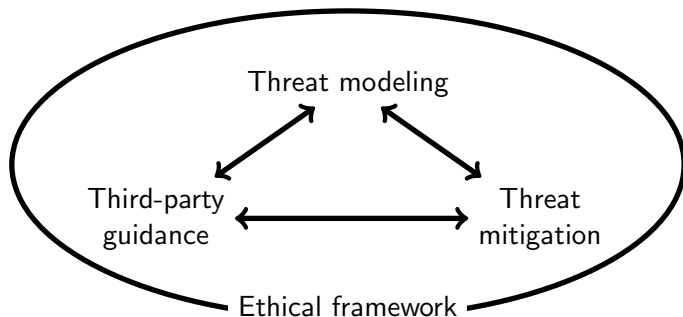
Princeton IRB

**Outside advice**

Philosophy professor  
Health lawyer  
Public interest lawyer  
Member of military

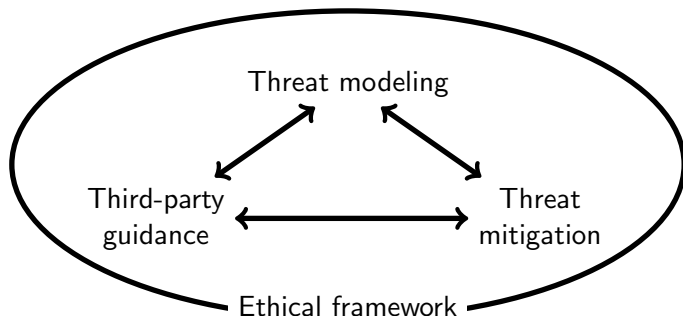
# Ethics grounded in the Belmont Report

- ▶ Respect for persons
- ▶ Beneficence
- ▶ Justice



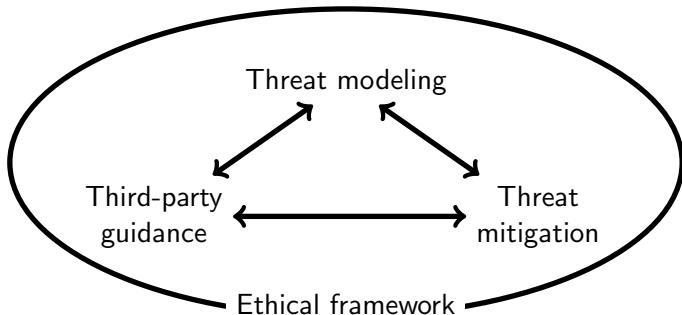
# Ethics grounded in the Belmont Report

- ▶ Respect for persons → honor participants' agreement
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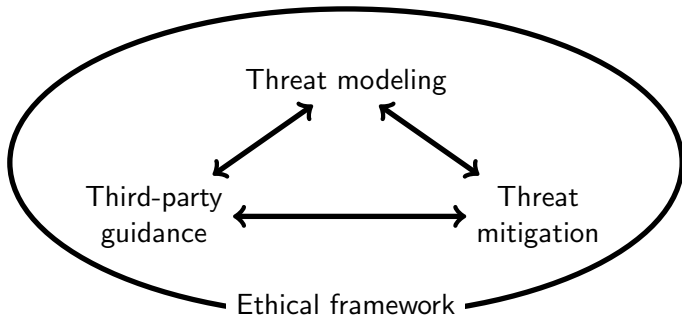
# Ethics grounded in the Belmont Report

- ▶ **Respect for persons** → honor participants' agreement
- ▶ **Beneficence** → maximize benefits and minimize harms
- ▶ **Justice**



# Ethics grounded in the Belmont Report

- ▶ **Respect for persons** → honor participants' agreement
- ▶ **Beneficence** → maximize benefits and minimize harms
- ▶ **Justice** → population to benefit is similar to study population





# Decision time

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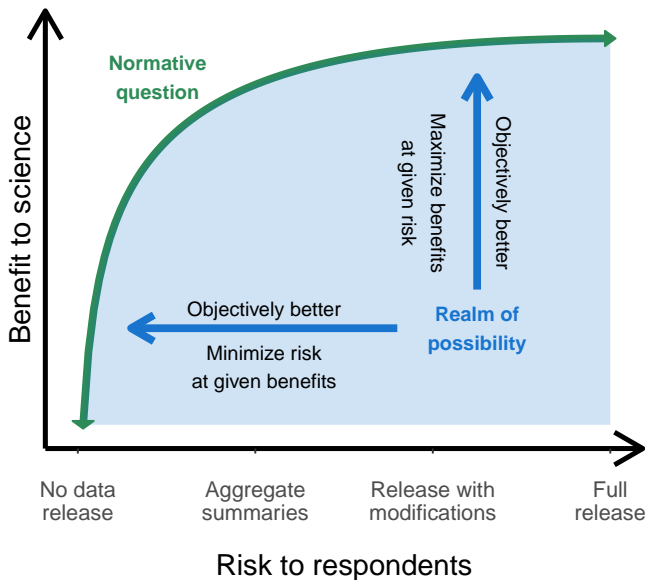
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# Decision time

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5. Pilot test in a machine learning class (early spring 2017)
6. Full-scale launch (mid-spring 2017)
7. Continuous consideration overseen by Board of Advisers





# Privacy, ethics, and data access: Generalizable principles

**Key elements** of our process may help promote the **ethical use of other data sources** by future researchers.

