

SHARING DATA TO ADVANCE SCIENCE



Restricting Data's Use: A Spectrum of Concerns in Need of Flexible Approaches

Dharma Akmon and Susan Jekielek IASSIST 2018 June 1, 2018



MYDATA LOGIN ABOUT US CONNECT WITH US SEARCH Q

Child Care & Early Education RESEARCH CONNECTIONS

Promoting high-quality research and informing policy through free access to thousands of publications and datasets

RESEARCH & POLICY LIBRARY +

DATA -

RESEARCH TOOLS + FEDERAL EFFORTS +

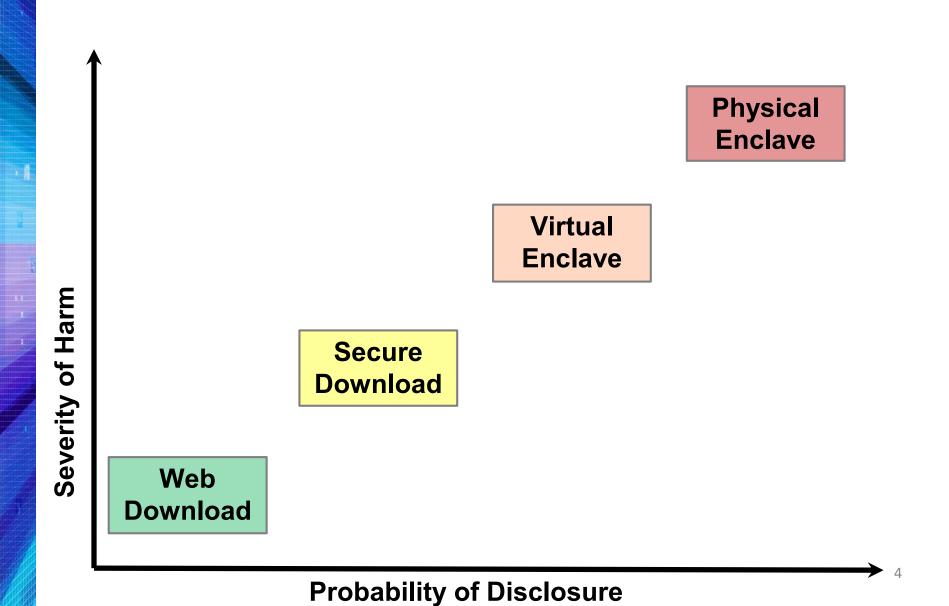


Presentation Outline

- ICPSR's options for restricting access to data
- Three case examples demonstrating nuance in restriction needs

System design implications

ICPSR's Restricted Access Options



Three Case Examples



Head Start Family & Child Experiences Survey (FACES)



Head Start Impact Study



American Indian and Alaska Native

American Indian/Alaska Native Head Start Family & Child Experiences Survey (AI/AN FACES)

Head Start Family & Child Experiences Survey



- Nationally representative sample of HS programs and 2000+ children/families
- Probability of disclosure = tiny
- •Severity of harm = moderate
- •Sponsor wants ICPSR to track who is using the data, have documented purpose of research, have recourse for dealing with misuse

Physical Enclave

Virtual



Moderate, Tiny

Severity of Harm

- Collect user information outside any of our systems
- Deliver data to researcher with same terms of use as public use data

Download

Web Download

Head Start Impact Study



Head Start Impact Study

Nationally representative sample of HS programs and 4500+children

- Probability of disclosure = Moderate (direct IDs removed)
- •Severity of harm = Moderate
- •The Center Analysis File (1 file in the study) has a different risk profile than the others (disclosure of centers more likely)

HSIS Mapped to Harm-Risk Profile

Severity of Harm



Head Start Impact Study

Center Analysis
File removed

Moderate, Moderate

Secure Download



Head Start Impact Study

With Center Analysis File

Moderate, Higher

Virtual Enclave

Al/AN Head Start Family & od S Child Experiences Survey

American Indian and Alaska Native

- •First national study of AI/AN HS children/families n=1000+
- Probability of disclosure = Moderate (direct IDs removed)
- •Severity of harm = moderate
- •Need to protect against reidentification inside Al/AN community; fulfill sharing requirement to include external review panel w/ Al/AN reps

Severity of Harm



Moderate, Moderate

Secure Download

+ package submitted to 3rd party panel Signed PDF approval from panel for ICPSR to approve

Summary of Restriction Needs Revealed

- Options to collect, share/report out on user data (e.g. institution, research question, contact info)
- Setting restrictions at the file level
- Third party sign-off, application review

Technology Implications

- Good news: ICPSR is designing a new restricted use application system to:
 - Streamline the application and access processes;
 - Send data applicants to one system
- Apply restrictions and associated requirements at the file level
- Integrate terms that inform researchers if their information might be shared as part of their use of data
- Rely on a researcher credentialing system