

SHARING DATA TO ADVANCE SCIENCE



## Best Practices for Protecting and Sharing Data

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# Promoting transparency and confidentiality

- ➤ What is ICPSR?
- Preserving and accessing shared data and data-related content
- ➤ Journal repositories and journalrelated deposits
- ➤ LinkageLibrary
- > Researcher passport

#### **ICPSR**



- ➤ Founded in 1962 by 22 universities, now consortium of over 760 institutions world-wide
- Focus on social and behavioral science data, broadly defined
- Current holdings
  - ➤ 10,000 studies, quarter million files
  - > 1500 are restricted studies, almost always to protect confidentiality
  - ➤ Bibliography of Data-related Literature with 70,000 citations
- ➤ Approximately 60,000 active MyData ("shopping cart") accounts
- ➤ Thematic collections of data about addiction and HIV, aging, arts and culture, child care and early education, criminal justice, demography, health and medical care, and minorities

## Preserving and accessing shared data and data-related content

- ➤ Make data sharing feasible
  - ➤ICPSR's General Archive
    - ➤ Anyone can deposit
    - Curated and preserved
  - ➤ Guidance over data life cycle
    - > Templates for consent, IRB, DMP consistent with transparent and reproducible access
- ➤ Incentivize data sharing
  - > Standard citation
  - ➤ Bibliography
  - Usage statistics

#### Publication-related sharing

- >Journal repositories for article-specific materials
  - ➤ Data extracts (exactly as used in article)
  - Maintaining provenance: code to reproduce data extract & point to original data source
  - ➤ Code for reproducing analytical results
  - ➤ Integrated work flow with publication
- ➤ Data-specific collections
  - > Extracts and re-codes used in publications
- Moving toward capsules
  - > Jupyter notebooks with code, data, and results
  - > Articles are the advertisement
    - > Code and data are the research
    - ➤ Credit: Victoria Stodden, University of Illinois

## ICPSR LinkageLibrary

- Linked data present challenges for both confidentiality and reproducibility
  - ➤ Linkage more accurate with more detailed information
    - ➤ Need standards for safe, ethical ways to enhance data with new linkages
  - Linked data easier to re-identify, even after removing unique identifiers
    - ➤ Need safe places to analyze linked data
  - Linkage strategies introduce differences in datasets that are often not well documented

## ICPSR LinkageLibrary

- ➤ LinkageLibrary
  - ➤ Encourage researchers to share linked (or linkable) data, and linkage strategies
    - > Algorithms, code
  - Compare approaches across projects, datasets, disicplines
    - ➤ Improve linkage practices
    - > Improve transparency
- Coming this fall
  - ➤ Looking for beta testers now!

#### **Protecting Confidential Data**

**Safe data**: Modify data to reduce risk of reidentification

Safe places: Physical isolation and secure

technologies

Safe people: Training and data use agreements

Safe outputs: Results reviewed before being released

Safe data and safe places are complements, not substitutes

The safer the data, the more we need safe places

## Safe places

- > Require technological and social solutions
- Transparency via restricted computing environment protects confidentiality
  - ➤ Intentionally limits access
  - Need to make process data simpler, more efficient, limiting as much as necessary but not more

#### Alternative safe places

- ➤On-line analysis with automatic disclosure control
  - > Researcher cannot see underlying data
    - ➤ Limited use in teaching, as we want students to look at data!
    - ➤ Limited use for non-designed data with minimal metadata
- Secure download to local computing environment
  - ➤ With data use agreements
    - > Requires institutional credibility and enforcement
- Virtual data enclaves
- ➤ Physical enclaves

## Safe people

- ➤The Researcher Passport: Improving Data Access and Confidentiality Protection
  - ➤ ICPSR's Strategy for a Community-normed System of Digital Identities of Access
  - https://deepblue.lib.umich.edu/handle/2027.42/143808
  - ➤ Identifies inconsistent language and policies that impede access
- ➤ Passports for safe people
  - > Verified identities, institutional affiliation
  - > Training
  - > Experience (good and bad)
- Visas to control access
  - > Permission to "enter" (access) specific data specifying
    - Passport holder
      - > Project, Place, Period

## Researcher passport

- >Implementation plan
  - ➤ Issue passports as digital identifiers associated with ICPSR MyData Accounts
    - ➤ Other passport issuers?
    - > Blockchain
  - ➤ Issue visas to access restricted data
    - At ICPSR, visa controls access to secure download or VDE
      - Visa issued after signed DUA
  - > Establishing content of training requirements
    - > Determining which existing training include that content
  - ➤ Governance system to provide due process for allegations of misconduct

#### Questions

- ➤ Can reach ICPSR at <a href="mailto:help@icpsr.umich.edu">help@icpsr.umich.edu</a>
- ➤ Questions or interest in Researcher Credentialing to me at <a href="MaggieL@umich.edu">MaggieL@umich.edu</a>