



## Role of the Data Archive in Ensuring Ethical Practices in Data Sharing

Amy Pienta  
ICPSR, Institute of Social Research  
University of Michigan

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# NIH-Funded Repositories at ICPSR

**NACDA** National Archive of  
Computerized Data on Aging

 **DSDR** Data Sharing for  
Demographic Research

 **NAHDAP**  
National Addiction & HIV Data Archive Program

Also... National Human Genome  
Research Institute (NHGRI),  
National Center for Medical  
Rehabilitation Research (NCMRR)

# Patients' Views on Data Sharing

NEJM Paper: Mello, Van Lieou, Goodman, 2018

<8% of clinical trial patients felt the potential negative consequences of data sharing outweighed the benefits.

93% were very or somewhat likely to allow their own data to be shared with university scientists

\*\*\* Concerns center on use in litigation, use for profit, worries about discouraging study participation

# Early Planning Activities for Researchers

- Repositories (including scientists and research staff) offer expertise and guidance in data management
- Planning for costs
- Selecting a “trusted” repository that can fully support dissemination and preservation.
  - Understand any repository requirements
- Creating research protocols with data sharing in mind (informed consent)

# Data Sharing in Informed Consent

- Ethical requirement in research that is relevant at all stages of the research lifecycle from planning to collection to publication to data sharing.
- Understand how their data will be used, by whom, and any associated risks to privacy
  - How confidentiality will be maintained when data are shared

# Informed Consent Language

- Avoid limiting statements prohibiting data from being shared
- Inform participants that their information may be used beyond the purposes that they were originally collected for
- Whether direct identifiers will be kept, how they will be kept, and if they will be part of information that shared with others

# Data Depositor Agreement

Formal institutional agreement between the organization(s) collecting data and the Repository

Communicate institutional responsibilities, obligations, and conditions for access, management and so on

This agreement should match the commitments made through the language of the informed consent

# Management of Disclosure Risk at the Repository

- Repository practice is to review all data for disclosure risk
- Assess both risk of reidentification (both direct and inferential) and risk of harm (and mitigation)
  - Review and remove direct identifiers (usually)
  - Combinations of other attributes can become identifiers



# Managing Access to Confidential Data

Secure Download - ICPSR manages data access by authorized users (RDUA & Data Security Plan) (output is self-vetted)

Virtual Data Enclave - ICPSR manages data access by authorized through a secure, Windows environment & all microdata remain securely at ICPSR (staff authorize output)

Physical Data Enclave - onsite, monitored (staff authorize output)

# Examples of Data Ethically Shared via ICPSR

- Large-scale, national survey data
- Qualitative data, including video data
- Clinical, experimental, interventions
- Administrative records data (e.g.)
- Brain images, sensor data, and more...
- Sensitive Information: IPV, Criminal Behavior, HIV status, Drug Use

# NCI-Funded Focus Group Data



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## Colorectal Cancer (CRC) Screening and Somali Men, Minnesota, 2016-2017 (ICPSR 38312)

Version Date: Feb 15, 2022 [Cite this study](#) | [Share this page](#)

### Principal Investigator(s):

[Charles R. Rogers](#), University of Utah, School of Medicine

### Series:

- [Qualitative Data Sharing \(QDS\) Project Series](#)

<https://doi.org/10.3886/ICPSR38312.v1>

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\* past three years

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### Notes

- The public-use data files in this collection are available for access by the general public. Access does not require affiliation with an ICPSR member institution.
- One or more files in this data collection have special restrictions.** Restricted data files are not available for direct download from the website; click on the Restricted Data button to learn more.

# Demonstrating Impact of Data that are Archived

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## National Survey of Black Americans, 1979-1980 (ICPSR 8512)

Version Date: Nov 4, 2005 [Cite this Study](#) | [Share this study](#)

### Principal Investigator(s):

[James S. \(James Sidney\) Jackson](#), University of Michigan. Institute for Social Research. Survey Research Center; [Gerald Gurin](#), University of Michigan. Institute for Social Research. Survey Research Center

### Series:

- [National Survey of Black Americans Series](#)

<https://doi.org/10.3886/ICPSR08512.v1>

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### Project Description

#### Summary

The purpose of this data collection is to provide an appropriate theoretical and empirical approach to concepts, measures, and methods in the study of Black Americans. The questionnaire was developed over two years, with input from social scientists, students, and a national advisory panel of Black scholars. The final instrument encompasses several broad areas related to Black American life. The study explores neighborhood-community integration, services, crime and community contact, the role of religion and the church, physical and mental health, and self-esteem. It also examines employment, the effects of chronic unemployment, the effects of race on the job, and interaction with family and friends. In addition, the survey provides information on racial attitudes, race identity, group stereotypes, and race ideology. Demographic variables include education, income, occupation, and political behavior and affiliation.

#### Citation

Jackson, James S. (James Sidney), and Gurin, Gerald. National Survey of Black Americans, 1979-1980. Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor], 2005-11-04. <https://doi.org/10.3886/ICPSR08512.v1>



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**190**  
[related](#)  
publications

### Notes

- Data in this collection are available only to users at ICPSR member institutions.
- The citation of this study may have changed due to the new version control system that has been implemented.

## NACDA

Program on Aging

This study is maintained and distributed by the [National Archive of Computerized Data on Aging](#) (NACDA), the aging program within ICPSR. NACDA is sponsored by the National Institute on Aging (NIA) at the National Institutes of Health (NIH).

# Methodological Comparisons

Long, Laura J., Lu, Qian, Walker, Rheeda L., Gallagher, Matthew W.  
(2022)

Examining the measurement invariance of the LOT-R measure of optimism in the United States and Japan

*Journal of Well-Being Assessment*

## Studies related to this publication:

- [Midlife in the United States \(MIDUS 2\), 2004-2006 \(ICPSR 4652\)](#)
- [Survey of Midlife in Japan \(MIDJA\), April-September 2008 \(ICPSR 30822\)](#)

# Drawing on Multiple Samples

Stephan, Yannick et al., (2022)

Personality and subjective age: Evidence from six samples.

*Psychology and Aging*

## Studies related to this publication:

- [Midlife in the United States \(MIDUS 1\), 1995-1996](#) (ICPSR 2760)
- [Midlife in the United States \(MIDUS 2\), 2004-2006](#) (ICPSR 4652)
- [Midlife in the United States \(MIDUS 3\), 2013-2014](#) (ICPSR 36346)
- [National Health and Aging Trends Study \(NHATS\), \[United States\], 2011-2017](#) (ICPSR 37107)
- [Health and Retirement Study \(HRS\)](#) (ICPSR 6854)

# Review Articles

Addington, Lynn A., Lauritsen, Janet L. (2021)

Using national data to inform our understanding of family and intimate partner violence victimization: A review of a decade of innovation.

*Feminist Criminology*

## Series related to this publication:

- [National Crime Victimization Survey \(NCVS\) Series](#)
- [National Incident-Based Reporting System \(NIBRS\) Series](#)
- [National Intimate Partner and Sexual Violence Survey \(NISVS\) Series](#)

# Integrated Data Analysis

Graham, et al., (2020)

Is healthy neuroticism associated with health behaviors? A coordinated integrative data analysis.

*Collabra: Psychology*. 6, (1), 32.

## Studies related to this publication:

- [Midlife in the United States \(MIDUS 1\), 1995-1996](#) (ICPSR 2760)
- [Midlife in the United States \(MIDUS 2\), 2004-2006](#) (ICPSR 4652)
- [Midlife in the United States \(MIDUS 3\), 2013-2014](#) (ICPSR 36346)
- [Long Beach Longitudinal Study](#) (ICPSR 26561)



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