

Protecting Private Data: Research Data, Data Sharing, and Privacy

Data in Libraries: the Big Picture - August 10, 2016

Nettie Lagace, National Information Standards Organization

nlagace@niso.org * [@abugseye](https://twitter.com/abugseye)

Background

- **Increasing pressure to make research data available**
 - Greater availability = good of science
 - Publishing boards show transparency & reproducibility
 - Funding mandates
- **Use of repositories growing**
- **Better tools for data management**

Towards a richer data-sharing ecosystem

- Tools improve ... Policies need to, too
- More focus needed to improve policy frameworks
 - Copyright and intellectual property
 - Provide researcher credit
 - Privacy

Privacy

- Data sets that include human-subject information
- Pitfalls exist as data enters the broader information landscape
- Greatest value of data is potential to be reused and combined with other data sets to advance understanding
 - But ... de-anonymization a major concern

SMILE

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RDA P5 BoF Privacy Topics

- PII may exist in data set; reviewed by IRB or university policy
- Data may not contain PII but could if combined with other data set
- Historical data could include PII – could link data to living subjects
- Back-end usage data
- Security of data replication
- Metadata re provenance, consent, license/reuse, legal jurisdiction

RDA-NISO Data Privacy Interest Group

- Phase 1: Group organization
- Phase 2: Development of framework of concerns and draft recommendations
- Phase 3: Expand on framework with use cases, guidelines for implementation, development of metadata structure to describe privacy-related information
- Phase 4: Adoption and implementation

Benefits

- Explain precautions to take in creating, using, preserving and providing access to research data
- Definition of key vectors; outline of situations where principles can be applied
- Identification of key areas of variance in privacy laws
- Technical metadata to use to describe privacy-related information
- Outreach and communication: **improve understanding; support dialogue; reduce risk**

http://bit.ly/niso-rda-interest-group

RESEARCH DATA SHARING WITHOUT BARRIERS

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RDA/NISO Privacy Implications of Research Data Sets WG Case Statement

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RDA/NISO Privacy Implications of Research Data Sets WG Case Statement

Revised Charter
See document link below.

[Old Case Statement]

Working Group Charter

This Working Group will explore issues related to scientific research data sets that contain human subject information, as well as related datasets that have the potential to be combined in a way that can expose private information. Over a period of 18 months, the group will develop a framework for how researchers and repositories should appropriately manage human-subject datasets, to develop a metadata set to describe the privacy-related aspects of research datasets, compile a bibliography of related resources, and to build awareness of the privacy implications of research-data sharing. While privacy is related to the ethical, legal, and data-publishing issues surrounding data management of

RDA/NISO Privacy Implications of Research Data Sets IG

Status: Under TAB review

Chair(s): Todd Carpenter, Bonnie Tijerina

Group Email:

Secretariat Liaison: Timea Biro

TAB Liaison: Ingrid Dillo

Public - accessible to all site users

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Privacy Implications of Research Data: A NISO Symposium

Sponsored by the NISO-RDA Joint Interest Group

Sunday, September 11, 2016

**9:00 a.m. - 5:00 p.m. (MT)
Sheraton Denver Downtown Hotel
Denver, Colorado**

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About the Symposium

Even as the opportunities presented by offering access to and re-use of scientific data sets become more apparent, sharing human subject data in particular is hampered by lack of a framework to address privacy and security concerns. The Research Data Alliance (RDA) and the National Information Standards Organization (NISO) are working to address that challenge through a joint interest group building a global consensus framework that will support both privacy and scientific data sharing.

The generous support of the Sloan Foundation is enabling the RDA/NISO interest group to host a free public symposium in Denver on privacy implications of research data, gathering, sharing and reuse, as a stepping stone towards that goal.

Attendees will hear from experts on the following:

- The feasibility of balancing research requirements with the need for privacy protections
- The limits of anonymization in the context of personally identifiable information
- The demands of security, privacy, and trust
- Privacy, policy, and data governance in university research practice
- Privacy and legal frameworks in the European Union