RDA-NISO [Proposed] Working Group on Privacy Implications of Research Data Sets

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Agenda

- Introductions
- Birds of a Feather in San Diego (P5)
- Review of the scope and goals
- Discussion of the outputs and schedule as outlined
- Efforts to solidify the group within RDA and ensure its approval
- Working with other working/interest groups
- Ideas for planning next steps
- Discussion of NISO plans for a Symposium on Research Data & Privacy in September (11th?)
- **Other topics welcome**

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BoF during San Diego Plenary (P5)

- Meeting in San Diego on March 9, 2015

- 18 participants (had to change time, so limited)

- Discussion about ethics, privacy vectors, international legal implications

- Identified a set of areas of focus

BoF Topics Identified

- Personally identifiable information (PII), may exist within the data set; this is frequently reviewed in light of IRB or university policy.

- Data that does not contain PII, but could if the data set is combined with related data sets.

- Data that is historical in nature that contains PII, though subjects are presumed deceased, but could be linked to living subjects.

- Data from back-end usage of systems and the policies regarding tracking of researcher behavior by repositories or other intermediary systems.

- Security of data replication and interaction with other systems, for the purpose of preservation or reuse of data.

- Privacy metadata about the data set, related to provenance, minimum viable consent work, license or reuse information, legal jurisdiction, etc.

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Goals

- 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 which privacy is a part, this working group is focused specifically on privacy-related concerns and will support, where appropriate, the related work of other RDA working groups.

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Expected Outcomes (1)

The group will work to achieve the following specific outcomes:

- Development of a framework that explains, at a high level, the precautions that data creators, repositories, aggregators and scientists should use in creating, using, preserving, and providing access to research data.

- Definitions of key vectors where privacy issues are evident in the ecosystem of data sharing and reuse.

- An outline of situations where the privacy principles would be applied.

- Identification of key areas of variance in privacy laws or regulations at national and international levels that are significant when sharing data worldwide.

Expected Outcomes (2)

- Definition of a set of technical metadata that can be used to describe privacy-related information contained within a data set, parameters for use, and description of where it should be applied.

- Gather and share a bibliography of data-and-privacy-related materials for public use.

- Advancement of adoption of the principles through an outreach and communications campaign

Other ideas or suggestions for outputs welcome!

About the Working Group

- **Chair(s):** Todd Carpenter, Nettie Lagace, Bonnie Tijerina, Michael Zimmer, (others?)

- Working group members: Currently 43 (Mar 1, 2016)

- Currently under TAB review
  - Discussion of whether we should be a working group or an interest group

- Target participants
  - Researchers, Privacy/Legal Experts, Administrators, Repository Managers, Librarians,

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Timeline for the Working Group

DATE	Milestone
December 2015	Kicking off project – Submission of the Case Statement
Jan-Feb 2016	RDA Case Statement Review
March 2016	Project Approval
	First meeting of Working Group (Tokyo P7)
	Public webinar announcing launch
March —August 2016	Nine bi-weekly meetings with working group
September 2016	Second full-day meeting of Working Group (Denver P8)
	Public Teleconference about progress on project
	NISO public symposium on data & privacy
Oct 2016—March 17	Ten bi-weekly meetings with working group
January 2017	Public review of draft outputs for review
	Open Teleconference to discuss process
April 2017	Second in-person working group meeting (Barcelona P9)
	Report to RDA
	Public Webinar to announce products
April—July 2017	Six bi-weekly meetings with working group
May—June 2017	Promotional presentations about project and outputs
July 2017	Working group completes drafting work
	Drafting of final report to RDA
September 2017	Final WG Meeting and Report presented to RDA (at P10)

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Related RDA Working Group

Ethics and Social Aspects of Data IG

WG for Data Security and Trust (WGDST) (Under TAB Review)

Health Data IG (Under TAB Review)

RDA/CODATA Legal Interoperability IG (Nearly finished)

Metadata IG

BioSharing Registry: connecting data policies, standards & databases in life sciences WG

RDA/WDS Publishing Data IG

> **OTHERS?**

Outside RDA -- Lots of work going on

> Data & Society
>
> Harvard's Privacy Tools for Sharing Research Data Project
>
> NISO effort on patron privacy
>
> **Others?**

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How to engage

Sign up for the working group

> Go to: http://bit.ly/1WO6YUd

> Login to RDA system (or create a profile, if you don't have one)

> On the Right-hand column, select "Join this working group"

First teleconference will be in late March

> Doodle Poll to setup the date:

> http://doodle.com/poll/fra4bu6sevfx24ic

Additional meetings to follow, dates set during first teleconference

> Probably have set day/time for calls (Probably 10/11:00 EST)

Probably will setup sub-groups to address specific efforts

Comment on the case statement, start a conversation topic. Lets get ideas rolling

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Symposium on Research Data & Privacy

- NISO is planning a side event at the International Data Week in Denver, CO.

- Free, Public symposium will also be live-streamed/recorded

- Probably at the RDA Conference Hotel downtown Denver

- Probably on Sunday, September 11, 2016
  - From 9:30 to 4:30

- More details **will come soon**
  - If you would like to give a talk, email Todd

Force16 Pre-meeting session

- Accepted proposal to discuss the project at the Force16 Conference in Portland, OR
- Sunday, April 17, 2016
- Discussion forum to highlight some of the issues within the research, publishing and library communities that participate in Force11

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Next Steps and Contact Information

- Join the group

- Fill out the Doodle Poll

- Come to the first meeting

- Contribute your ideas, thoughts

- Help us get the word out

- For more information:
  - Todd Carpenter – tcarpenter@niso.org
  - Nettie Lagace – nlagace@niso.org
  - Michael Zimmmer - zimmerm@uwm.edu
  - Bonnie Tijerina - bonnie@datasociety.net

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