

WHOSE DATA ETHICS DO YOU MEAN? BUILDING COMMON LANGUAGE WITH RCR

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Who am I?

And why are you listening to me?

- Nina Exner
 - » Researcher and Grant Support Services at NC A&T
 - Somewhere between liaison to and embedded with our Division of Research
 - » Also doctoral candidate at UNC SILS
- North Carolina Agricultural and Technical State University
 - 3 1890s land grant university, HBCU
 - » R2 6th in student FTE and 3rd in research \$\$ among NC public universities





Working with Responsible Conduct of Research

Definitions

Let me check our terminology so I don't waste your time

- Sponsored Research aka Division of Research, Vice-President of Research, Sponsored Programs, and may other names
- Research Development aka Proposal Development or pre-proposal
- Responsible Conduct of Research [RCR]
 - » Research Integrity Officer [RIO]
 - » Institutional Review Board [IRB] and other ethics committees



Discussing data with RCR

My story of data confusion

I was discussing data management with my RIO. We had done several general introduction to ethics trainings together already.

- We got to talking about data ethics and beefing up the data integrity training part of our intro to ethics sessions
- As we talked I realized what she was talking about as "data management" was nothing like what I thought of as data management! It was also not what the DMP emphasizes.



Data Management and Data Ethics

The data lifecycle versus data protection

- My RIO thinks in terms of the IRB's view of data ethics
 - » Subject protection and privacy: Ensuring access control for privacy and data integrity
- I and the DMP process focus on a different view of data management
 - » Reusability of data for the larger research community
 - » Data definitions and integrity for the next researcher, not the current researcher
- Imagine being a grad student or new faculty getting these trainings!



Discussion question

A pause to check in

- Do you think my experience is similar to what's happening at other campuses?
- Have you heard anything about your RCR department's view of data?





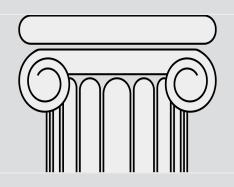
Combining and harmonizing these views of data to build consistent data training

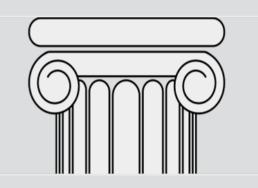
How we combined the issues

Looking at the IRB and the DMP

- Where is there overlap and where are there differences?
- How can it be made clearer for trainees so that all processes are presented as parts of one bigger process?
- Cross-promoting IRB and DMP within a larger data ethics concept
- Encouraging trainees (especially new ones) to start thinking of all everything they collect as data, and to think about all of those data objects in a more ethical way.







Respect for subjects, scholars, and society

Clarity for consistency and reusability

Support these pillars with the documents that you might have to write about your data:

- The ethics protocol, such as an IRB application
- The data
 management plan
 (DMP), for funded
 projects



THINKING ABOUT YOUR DATA

Collection

How will you collect data in a way that is safe for subjects, researchers, and the public?

Access (during the study)

Who will have access to the data?

How will you make sure of the right access levels?

Storage

Where is your data?

Who can get into it?

How is it preserved against loss?

Ownership

Who "owns" the data?

Who gets credit for it?

Who can have/keep a copy?

Sharing

How will you share it - *in a* reusable way - with the

with the research community and the public?

IRB, IACUC, Biosafety, etc.



Training with the new conceptual structure

Active reflection questions we ask in out training sessions

- "Do you know what happens with your data when you're not there?"
- "If you had to drop this study for two years and come back to it, would you be able to tell where you were?"



Data Sharing and Management Snafu in 3 Short Acts http://www.youtube.com/watch?v=N2zK3sAtr-4

- "What was Dr. Spot's goal with his research?"
- "Why did Dr. Panda give up on using the data?"
- "What things should Dr. Spot have done differently?"

Discussion question

Another pause to check in

- How do you get new researchers started thinking about both ethical and long-term views of data?
- We focus on the "Snafu" video more with graduate students, but on discussions about lab practices more with faculty.
 - » How do your graduate vs. faculty trainings differ?





Questions? Thanks for listening!

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