Cross-Cutting Themes: collaboration, scientific responsibility

**Overview questions:** What is at stake with data sharing? What are the trade-offs from your perspective? What are the most common practices you’ve encountered in your field or training? Who owns data? How and when should data be shared?

**Key points to consider:**

* NIH policy requires data sharing from federally funded projects. Why is this?
* Sharing data more openly can facilitate progress in research and minimize waste.
* However, some data is collected with certain restrictions and stewardship obligations. Open sharing, without restriction, risks violation of those trust agreements.
* Some investigators also worry that sharing data will minimize their ability to make an original contribution with the research.
* Some question whether the quality and veracity of the data can be trusted in open sharing sites, or with secondary use of existing data sets.

**Process for Thinking through Difficult Ethical Dilemmas**

**Recognition***: What are the issues being raised? What is the underlying ethical concern? How does this issue impact me?*

**Reasoning***: What values are at stake? Are there competing points of view? What are the potential benefits and harms of different actions? Are there any rules or guidelines that can help?*

**Responsibility***: What are my responsibilities? Do others have responsibilities also?*

**Response***: What should I do – and why?*

**Case Discussion:**

1. Are there data sharing or data management issues you have struggled with or worry about?

**Backpocket Case Study:**

You have been offered an exciting new position at another research institution. While in your current position, you were awarded an NIH grant involving secondary analysis of clinical data from your current research institution hospital. Both your current department/university and your new one are interested in a data sharing agreement if you are going to move your grant with you. Your research involves data from vulnerable populations and you are concerned about who will have access to the data if you leave a copy behind. What should you do? What are your considerations?

**Assigned Reading:**

1. International Consortium for Investigators for Fairness in Trial Data Sharing. NEJM 2016; 375(5): 405-7.
2. Trinidad et al. Research Practice and Preferences: The Growing Gulf. Science 2011; 331: 287-88.
3. **Additional Resource:** NIH FAQs on Data Sharing: http://grants.nih.gov/grants/policy/data\_sharing/data\_sharing\_faqs.htm