

Topic for Discussion: Data Sharing, Data Management

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?

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?*

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.

Additional Resource:

NIH FAQs Data Sharing: http://grants.nih.gov/grants/policy/data_sharing/data_sharing_faqs.htm

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, which you expect to transfer with you. As you get ready to relocate, the university contacts you to find out your data management plans and asks for either the original data or a copy (with access to the original data if requested). 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. You had assumed that the data collected in your study would remain solely with you.