



Data Sharing and Communication Across Partnerships

GROUP TECHNICAL ASSISTANCE WEBINAR

SEPTEMBER 21, 2015 - CFPHE

Webinar Objectives

- ▶ Define data sharing and communication
- ▶ Describe what kind of data to share across partnerships
- ▶ Decide what is good data to share
- ▶ Know what not to share
- ▶ Know how to share sensitive data

What do we mean when we say data?

“Facts and statistics collected together for reference or analysis”

- ▶ What kinds of data exist?
 - ▶ Human subject data
 - ▶ **Personal Data** – data which relate to an individual who can be identified from the data and/or other information
 - ▶ Name, address, telephone, DOB
 - ▶ **Sensitive Information** – data which relate to an individual that doesn't identify them, but is sensitive in nature
 - ▶ Race/ethnicity, political opinions, religious beliefs, health condition, sexual health, illegal activities
 - ▶ **Anonymized Data** – individual data records from which personal and sensitive data have been removed
 - ▶ Zip code, county, employment, etc.
 - ▶ Non-human subjects data
 - ▶ **Publicly available data** (e.g. census data, geographic data) – data that is available publically and from which individuals cannot be identified
 - ▶ **Aggregate Data** – data which are processed to produce a generalized result and from which individuals cannot be identified
 - ▶ Be careful of small numbers!

Data Sharing Defined



- ▶ **Data sharing** is the practice of making data used for scholarly research available to other investigators, funding agencies, the scientific community, and (most importantly) the public.
- ▶ Data sharing can help eliminate duplicative work.
- ▶ The initial investigator can also share project data to build his or her reputation.

The Importance of Data Sharing

- ▶ Promotes scientific inquiry
- ▶ Encourages diversity of analysis and opinion
- ▶ Promotes new and innovative ways to test hypotheses and methods of analysis
- ▶ Facilitates education of new investigators
- ▶ Inspires others to investigate topics not explored by initial investigator
- ▶ Builds a body of data that promotes creation of new databases to house the information





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Data, in all its forms, newly created or re-used, should be maximized for use in order to improve health outcomes. Without a strong partnership with good communication, clear direction for a process, and well-developed content as part of a formal agreement, there are risks to the effective use, re-use and generation of meaningful information that is of value to all partners.”

PAIGE BACKLUND-JARQUÍN, *DATA SHARING: CREATING AGREEMENTS*

Consider the Context

Be able to recognize and diminish (as much as possible) power differentials regarding your project data

Community-Targeted Research

Enlists the “voice” of the community to engage participants in studies that the researcher has selected and to aid in the dissemination of the research findings

Community-Based Research

The community has a “vote” in the selection of research topics, but the researcher often determines the study design, method of data collection, and analysis of data

Community-Driven Research

All aspects of the research is shared, giving the community partner equal power, and hence the ability to “veto”

A strong community-academic partnership requires addressing the power differentials.

The Data to Share Across Partnerships

- ▶ **Human subjects** data can be shared
 - ▶ *If the identity and privacy of research participants can be protected*
 - ▶ *With a data use agreement in place*
 - ▶ *Typically requires IRB approval*
- ▶ **Non-human subjects** data can be shared
 - ▶ *In any circumstances the partnership deems necessary*
 - ▶ *Keep intellectual property in mind*



Sharing Sensitive Data – Tips & Tricks

- ▶ Strip all individual identifiers from data
- ▶ Research team should adopt standardized and effective methods of protecting participants' identities
- ▶ Withhold part of the data, statistically altering the data in ways that will not compromise secondary analyses
- ▶ Require researchers who seek your data to commit to protect precast and confidentiality
- ▶ Provide data in a controlled site (data enclave)

What not to Share

- ▶ Final research data do not include
 - ▶ lab notebooks;
 - ▶ partial datasets;
 - ▶ preliminary analyses;
 - ▶ drafts of scientific papers;
 - ▶ plans for future research;
 - ▶ peer-review reports;
 - ▶ communications with colleagues;
 - ▶ or physical objects like lab specimens.

Consider a Data Sharing/Use Agreement



- ▶ Both community and academic partners should benefit from the outcomes of the research process. Creating and adhering to a clear process for sharing data can help achieve this.
- ▶ Consider making this a part of your governance document.

Consider a Data Sharing/Use Agreement

- ▶ A clear process for developing and maintaining a Data Sharing/Use Agreement includes:

1. Develop a data sharing/use agreement early in the research project.
2. Use the data sharing/use agreement to develop shared vocabulary to use throughout the research partnership.
3. Formalize the agreement by writing it down and signing it.
4. Meet regularly and include revisiting the data sharing/use agreement as part of the meeting agenda.
5. Include flexibility within the agreement and make any necessary changes as they arise.
6. Identify clear termination dates within the agreement – termination of data collection, analysis and dissemination, for example.

Potential Elements of a Data Sharing/Use Agreement

- ▶ Subject matter
- ▶ Allowed uses for the data
- ▶ Who will receive the data and in what form
- ▶ How long the data can be used
- ▶ What must happen to the data once it is used
- ▶ How the data can be analyzed
- ▶ How the data can be aggregated/de-identified
- ▶ A process to allow review of publications or other forms of dissemination prior to public disclosure
- ▶ Statutory limitations on the use of the data and penalties for violations of the agreement

Resources

- ▶ http://grants.nih.gov/grants/policy/data_sharing/data_sharing_faqs.htm#926
- ▶ <http://www.icpsr.umich.edu/files/ICPSR/access/dataprep.pdf>
- ▶ <http://www.hsrmethods.org/PrivacyInResearch/Privacy%20Tools/Guidance%20on%20HIPAA%20Data%20Use%20Agreements.aspx>
- ▶ http://grants.nih.gov/grants/policy/hs/faqs_aps_definitions.htm#286
- ▶ http://www.northwarks.gov.uk/downloads/WDP_Data_Sharing_Protocol_v0.4.pdf
- ▶ <https://orra.rutgers.edu/data-use-agreements>



Questions? Comments?

Remember! Join us November 11, 2015 for the Group TA: *Working with IRBs, Grantsmanship, and Strategic Partnership Planning Specific to Potential Future Funding*