

HIPAA is a speedbump, not a barrier: Data Collection and Research in the Context of HIPAA

RETAIN Grantee Call

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Disclaimer and Promise

• We're not:

- Lawyers
- Giving legal advice
- Going to argue the finer points of the HIPAA reg

We are:

- Going to share lessons learned from hundreds of data collection and research efforts using HIPAA covered data
- Going to share strategies for data protection



Yes, you can share HIPAA covered data

Every organization that shares data has a process for sharing that data for research purposes as permitted by HIPAA Privacy Rule

Covered entity

Business associate

- Up front phone huddle that includes relevant stakeholders from states and from researchers
- Illuminates the process adequately for everyone!
 - Who needs to be in the loop?
 - Examples: Program
 champion, IT and data
 security staff (they know the
 data!), contracting, legal, IRB?

What is your state's business process for sharing data for research?

- Understand this process up front
- Saves a lot of time and effort (we can help you figure this out!)



Privacy and Security Paperwork

Individual consent is a component of this study

- Might involve a HIPAA Business Associate Agreement (BAA)
- Might involve a Data Use Agreement for a Limited Data Set
- Maybe IRB required (yours or ours?)



Forms

- Research request? Usually a comprehensive form, mix of yes/no, multiple choice, free form responses
- Data security/privacy questionnaire? Another form, we complete these all the time



Strategies we use to Protect Your Data



