

# Challenges in Using Administrative Data: Legal, Technical and Political

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# Someone's Singing...

**The first data sharing meeting**



**All is good....**



# Then the Discussions Begin on Data Access

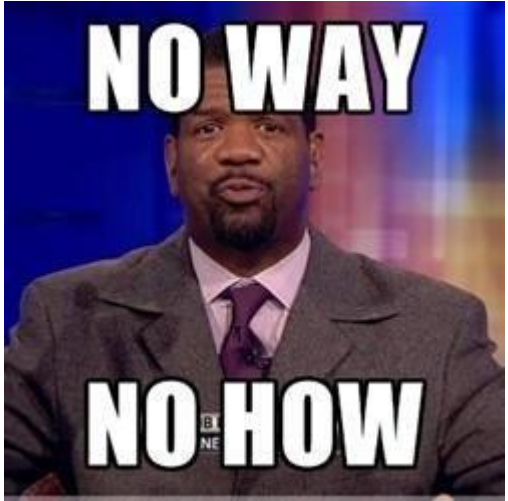
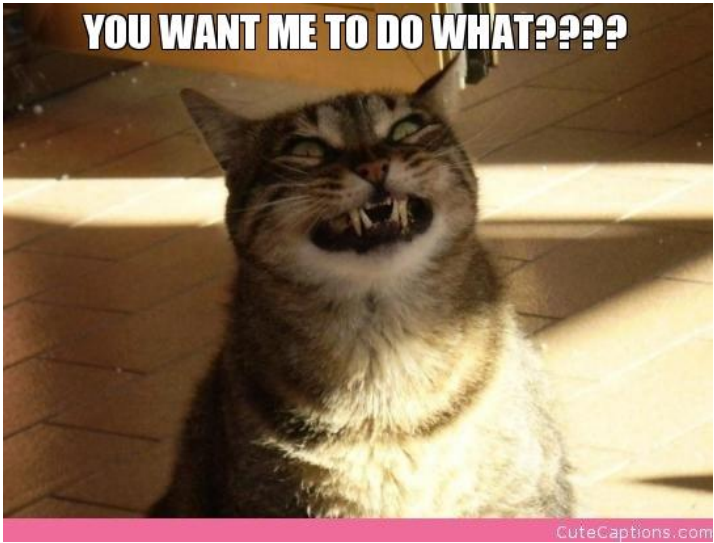
## The Data Request



## The Response



And then the party ends....



# What Barriers Do We All Face?

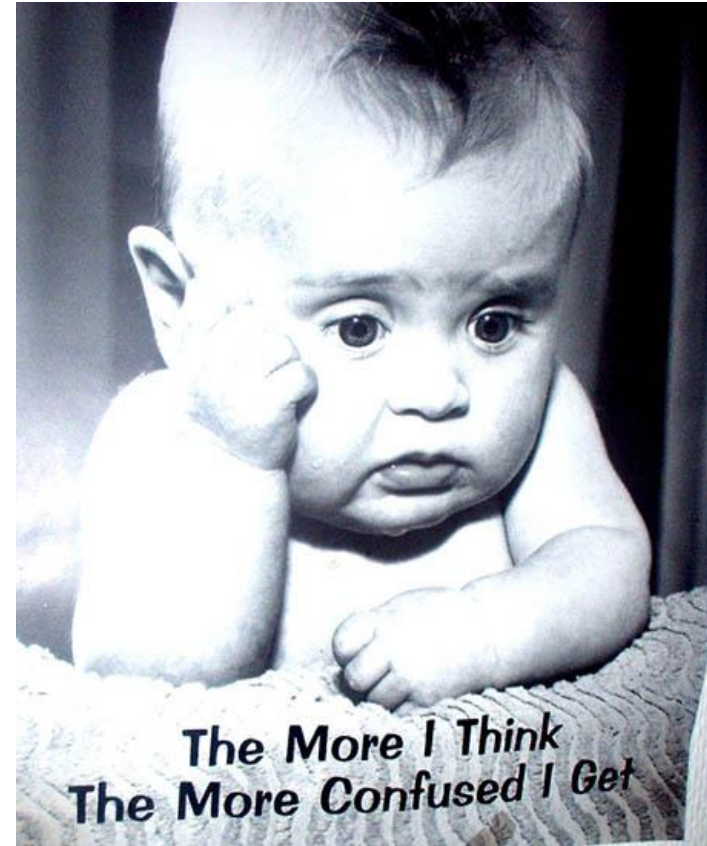
- A question of identity
- I'd like to but the law just won't let me
- Technology
- Politics

# What/Who Are You?

- A data center?
- Loosely associated researchers?
- A program evaluator?
- Substantive focus?
- A data user?
- A data source?
- What is the purpose of the enterprise?
- Data access v. repository
- Full data set or data pull?
- Identifiable or deidentified data?
- Who is your audience/customer/target?

# Legal Issues: Or, Life Without Lawyers is Hardly Worth Living

- There are a *lot* of relevant laws:
  - HIPAA
  - FERPA
  - 42 CFR Part 2
  - Privacy Act of 1974
  - HMIS
  - State laws
- There is a *lot* of confusion about such laws



# Some Questions To Ask

- Is there *really* a legal issue or is the lawyer just really anxious?
  - Many “legal” issues are really political issues
  - Which law applies (preemption, federalism, different standards)
  - Do you need everything you think you do?
  - Are there methodological resolutions?
- 
- A resource: [http://impact.sp2.upenn.edu/aisp\\_test/wp-content/uploads/2012/12/0033\\_12\\_SP2\\_LegaT\\_Issues\\_Data\\_Systems\\_000.pdf](http://impact.sp2.upenn.edu/aisp_test/wp-content/uploads/2012/12/0033_12_SP2_LegaT_Issues_Data_Systems_000.pdf)





# “Technical” Issues: Human Factors

- Can the data answer the question you are asking?
- Can you make the data answer the question?
  - Who prepares the data?
  - Are your analysts adequately trained? How do you know?
  - Can you answer a question the first answer raises?
- Managing the data
  - Who assures the data are secure?
  - Who does your use agreements? Your policies? IRB?
  - Governance structure

A potential resource: [http://impact.sp2.upenn.edu/aisp\\_test/wp-content/uploads/2012/12/0033\\_12\\_SP2\\_Ethical\\_Admin\\_Data\\_001.pdf](http://impact.sp2.upenn.edu/aisp_test/wp-content/uploads/2012/12/0033_12_SP2_Ethical_Admin_Data_001.pdf)



For My Next Magic Trick I Will Link All of  
These Different Data Sets...



# Technical Issues: Non-Human Kind: Architecting the System

- Where are the data?
- Do you have enough room?
- “...developers face the challenge of scaling their development approach beyond fixed, predefined data silos, to encompass large numbers of data sets with heterogeneous data models and access methods”
  - <http://tomheath.com/papers/bizer-heath-berners-lee-ijswis-linked-data.pdf>
  - <http://aboutsqlserver.com/2014/12/02/size-does-matter-10-ways-to-reduce-the-database-size-and-improve-performance-in-sql-server/>

# “Technical” Issues: Non-Human Kind

- Interoperability:

the extent to which systems and devices can exchange data, and interpret that shared data. For two systems to be interoperable, they must be able to exchange data and subsequently present that data such that it can be understood by a user.

<http://www.himss.org/library/interoperability-standards/what-is-interoperability>



# Technical Issues: Can You Retain the Data?

- To complete the following protocol upon separation from Institution or the expiration of Investigator's contract:
  - Destroy all Data Files at the originally approved site
  - Submit a letter stating that all Add Health Data Files have been securely erased with the secure erasure program listed in the security plan for the originally approved site.
  - Return all CDs containing Data Files, within thirty (30) days of the expiration of the Contract Period, as specified on the Institutional Signatures page, or to submit a renewal application.
- <http://www.cpc.unc.edu/projects/addhealth/data/restricteduse/RestrictedUseContractApplication.pdf>

# Politics

- Not everyone wants to let you look inside the box
- Not everyone wants to know if their program “works”
- Urgency is a matter of perspective
- Who decides what the findings are?
- Are you free to disseminate the findings?



# Some Concluding Thoughts

- A foothold is not a bad thing
- Does someone important care about your work?
- “The law won’t let me” is not always “the law”
- Infrastructure matters; knowing someone who knows about infrastructure matters even more
- Administrative data is even more fun with mixed methods