The Community as a Learning System for Health:
Using Local Data to Improve Community Health

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Are there limits to privacy preserving sharing of data?

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Take Home Point

Context: Sharing of patient information for research.

A general and purely technological solution to privacy preserving sharing of patient data might not be possible.

Current State

- Sharing of data
  - Complete (needs oversight)
  - Limited data set ("almost" de-identified, needs oversight)
  - De-identified data
- De-identification by HIPAA standard
  - Safe Harbor (removal of 18 predefined information items)
  - Statistical Standard (expert declares data re-identification risk as "very small")

Problems

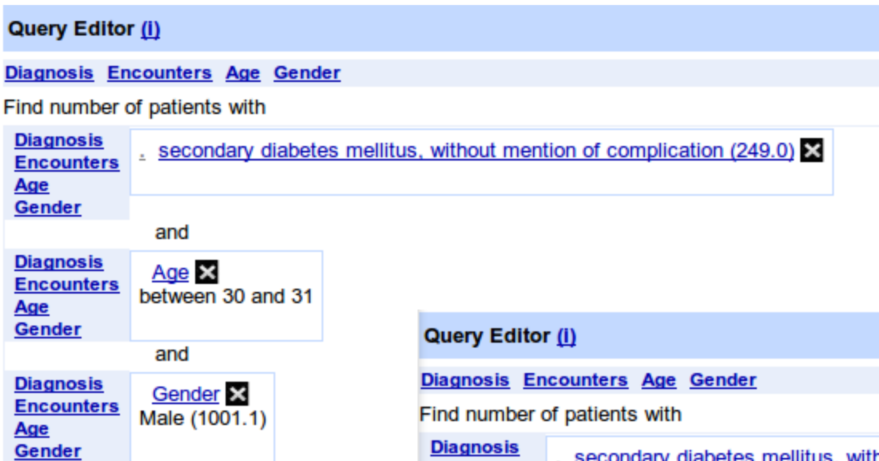
- Oversight (IRB)
  - Costly (administration, time)
    - Researcher: write IRB protocol and wait for approval
    - Institution: process protocol and administrate it
  - Difficult across institutions

Problems

- De-identification
  - by Safe Harbor yields data with limited utility[1]
  - by Safe Harbor does not prevent re-identification[2]
  - by Statistical Standard is vaguely defined:
    - "A person with appropriate knowledge" [...] "determines that the risk [of re-identification] is very small"
- Inferences about sensitive information can be made without re-identification

[1]Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research. IOM 2009
[2]The disclosure of diagnosis codes can breach research participants' privacy. Loukides G, Denny JC, Malin B. J Am Med Inform Assoc. 2010 May 1;17(3):322-7

Insufficiency of de-identification:
inferences about known individuals



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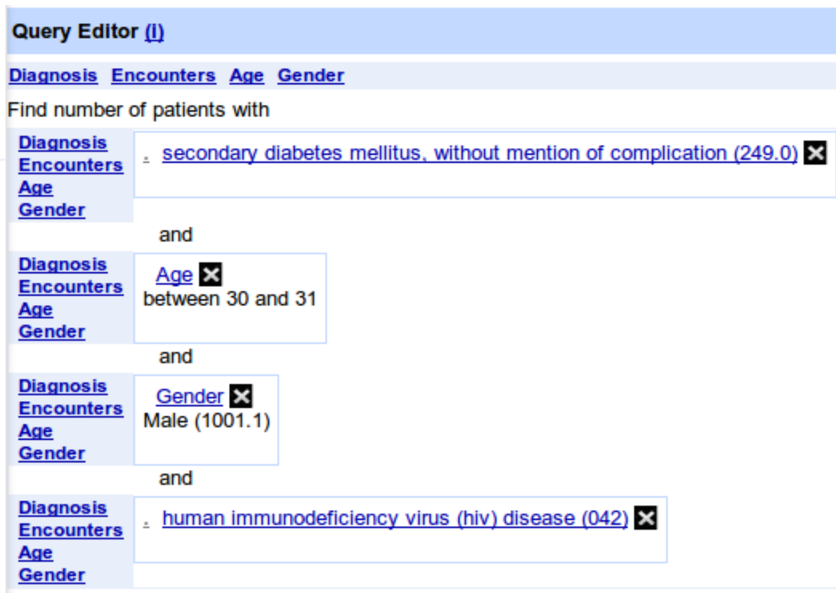

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(We know that neighbor Bob is 30 and has secondary diabetes)

Points of Discussion

- Are insufficiencies of de-identification too esoteric to be of practical concern?
  - Is heuristic and empirical risk assessment[1,2] convincing?
    - "we were able to re-identify x %": not a valid upper bound!
  - Can we use media attention as a guide?
    - Note:
      - HITECH breach reporting does not apply to de-identified data
      - There are no tracking requirements for de-identified data

[1]Evaluating re-identification risks with respect to the HIPAA privacy rule. K Benitez, B Malin. *JAMIA 2010;17:169-177*
[2]A method for managing re-identification risk from small geographic areas in Canada. El Emam et al. *BMC Medical Informatics and Decision Making* 2010, **10:**18

A possible alternative view?

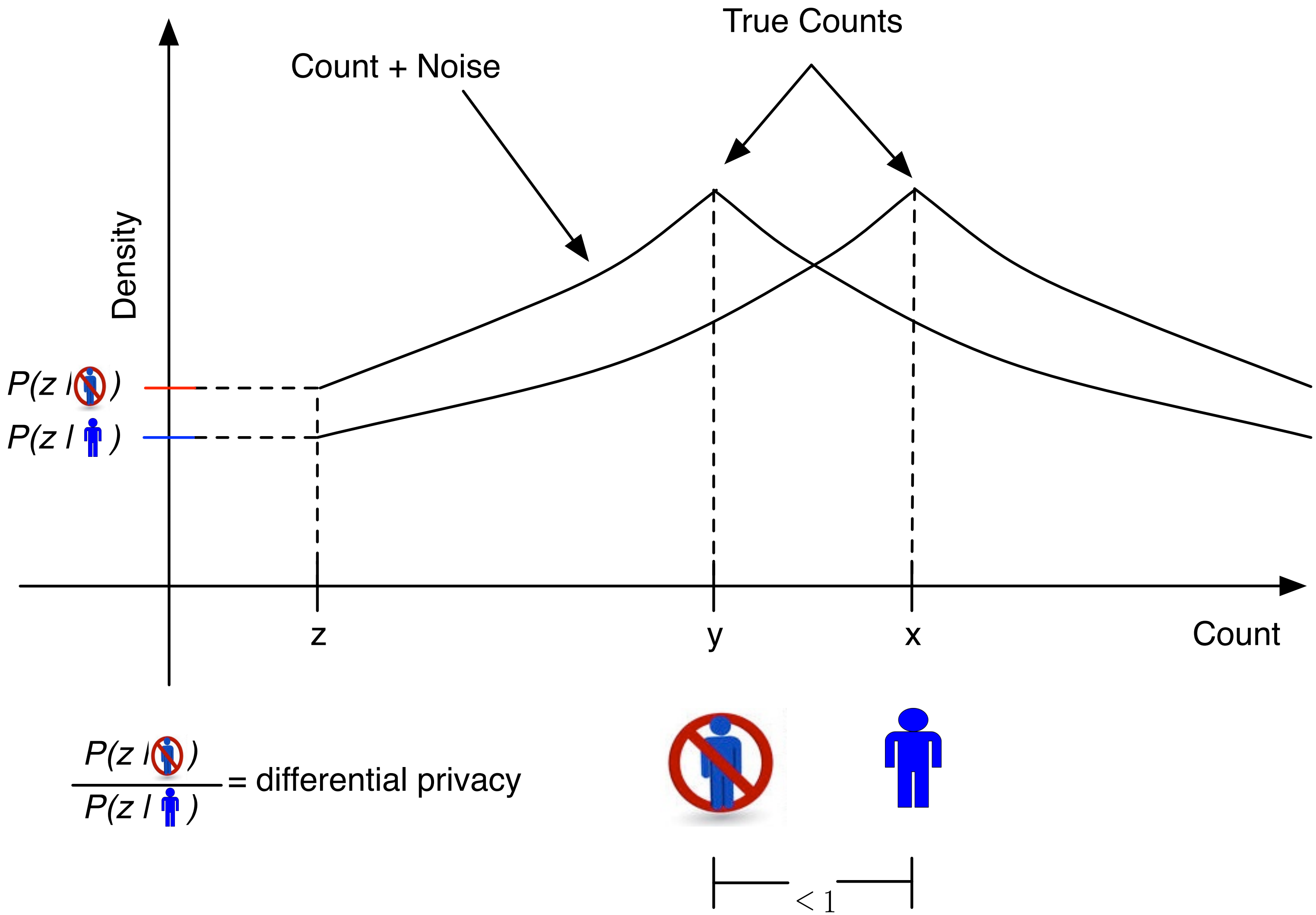
- Ideal for individual privacy: "*information is privacy preserving if what can be learned about any **individual** is independent of this information*"
- Consequence: we are allowed to share information about *populations.*
- Implies de-identification
- Complete independence not feasible: requires infinite populations

Towards the ideal: Differential Privacy

- Differential Privacy* bounds the change in likelihood of learning anything about an individual by his inclusion in the data
- Is a property of an access method (as opposed to a property of data)
- Access methods to data that provably guarantee differential privacy exist

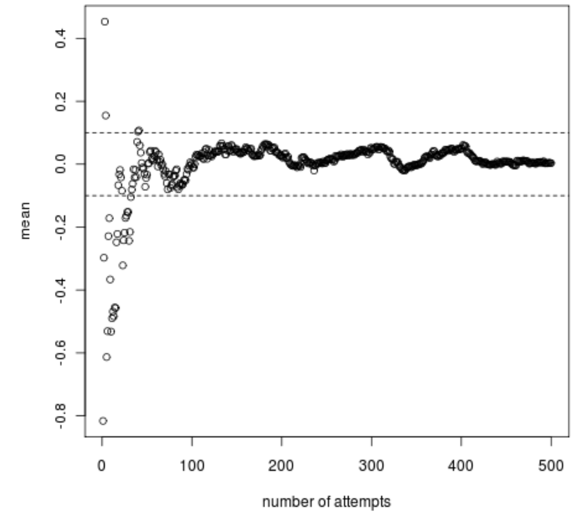
*Dwork, C.; McSherry, F.; Nissim, K. & Smith, A. Calibrating Noise to Sensitivity in Private Data Analysis Proceedings of the Conference on Theory of Cryptography, 2006

Differential Privacy and Noisy Counts



The Finite Privacy Budget

Example: Adding noise to counts does not Protect against averaging multiple trials



Suggests* a general property of a finite "privacy budget": only small # of privacy preserving accesses can be allowed, beyond which privacy can no longer be guaranteed

Increase information about each patient: decrease in budget!

*New Efficient Attacks on Statistical Disclosure Control Mechanisms. Cynthia Dwork and Sergey Yekhanin CRYPTO 2008

Dealing with a finite budget

- Use all allowed information accesses up front to extract all privacy preserving information
  - Never allow privacy preserving access again
  - Different uses might need different information
  - Very high-dimensional data: budget very small
- Leverage environment to “extend budget”
  - Principle: substitute some “treatment” (punishment) for some “prevention”
  - Requires:
    - Detection of misuse and perpetrator
    - Effective sanctioning of perpetrator (aka. “teeth”)

Conclusion

- De-identification as a definition of privacy seems insufficient for believable privacy
- Current theoretical research suggests that there are limits to truly privacy preserving sharing of data using technological means alone

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