

# PSWG Hearing: Big Data for Community Health Initiatives

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# Goals

- Overview of risks when communities use big data
- Stewardship framework and toolkit from NCVHS
- Problem areas less discussed (maybe because they aren't the "hi-tech" areas)

# Big data: let's assume the benefits; what are the risks?

- Surprise
  - Who has the data
  - What data they have
  - What they are using the data for
- Suspicion
  - Who has data that I don't know about and what do they have?
- Shut-down
  - Refusal to share data
  - Requests that data be destroyed

# So: Fair Information Practices and Data Stewardship

- NCVHS Privacy, Confidentiality and Security Subcommittee digest of FIPs since HEW Report: [Records, Computers, and the Rights of Citizens](#)
- Stewardship framework for community health data use: [Letter to the Secretary](#)
- Toolkit for Communities Using Health Data (draft copy provided to work group)

# Tools in the Stewardship Kit

- Accountability
  - Openness, Transparency, and Choice
  - Community and Individual Engagement and Participation
  - Purpose Specification
  - Data Quality and Integrity
  - Data Security
  - De-identification
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- Appendices include case studies and sample data use agreements

# Problem areas

- Assuring accountability and identifying the entity who is responsible for each element of stewardship.
  - Where can community members go if they have concerns?
- Assuring transparency:
  - How can community members find out who has what data and for what purposes?
  - How can suspicions be answered?
- Following data chains:
  - Data lifecycles and what to do when data are no longer being used
  - Data transfers and data use agreements: problems with contract law as a method for enforcement