

Enabling Research Use of Clinical Data

Workshop Methods



*NIH Big Data to
Knowledge (BD2K)*

Advancing Health and Discovery through Big Data



General schema

- Four 90 minutes sessions, each with a session leader charged with envisioning a Utopian ‘best achievable’ future state and how it differs from today
 - 3 research scenarios
 - Pragmatic Trials & Interventional Studies
 - Genome-Phenome Correlation
 - Observational Studies
 - Cross-cutting issues of policy, technology, and infrastructure
- Presenters then become discussion leaders for:
 - Is the vision plausible, desirable, achievable?
 - Actionable steps NIH can take to facilitate progress toward that better future

In what ways can NIH take action?

1. Fund investigator-initiated research (e.g., R01's)
2. Fund coordinated R&D (e.g., Human Genome project, research consortia, cooperative group clinical trials)
3. Create and sustain infrastructure (e.g., PubMed, Cancer Genome Atlas, standardized metrics)
4. Create or amend NIH policies (e.g., data and resource sharing)
5. Create and convene professional communities (e.g., BD2K workshops, CTSA working groups, consensus development conferences)
6. Advocate an agenda for change and innovation from a 'bully pulpit'
7. Partner with other federal agencies and/or industry

Getting there

- Brainstorming session rules: all ideas are potentially good and useful ones.
- Southwest Airlines approach: this will be a non-complaining, non-whining flight. You were hand picked because you are talented, experienced and already know some of this is very hard to do.
- Last session on Day 2 will be overall summary and first outline of a workshop report, which will be a white paper to NIH leadership on actionable steps, and perhaps a manuscript.