The Changing Landscape of Data for Health Services and Policy Research

Erin Holve, PhD, MPH, MPP
Association of Public Data Users (APDU)
September 22, 2011
Bio

Erin Holve, PhD, MPH, MPP
Director, Research and Education in HSR
AcademyHealth
erin.holve@academyhealth.org
@hsrher
@academyhealth
@edm_ah
Learning Objectives

→ Describe efforts to bolster the evidence infrastructure for health services and policy research to improve the “3R’s” of HSR
→ Increase awareness of trends in open government, collaborative science, and open access
→ Provide information on resources to get involved
AcademyHealth: Improving Health & Health Care

As the professional society for health services researchers and health policy analysts, our mission is three-fold:

1. Support the development of health services research
2. Facilitate the use of the best available research and information
3. Assist health policy and practice leaders in addressing major health challenges
In Other Words…

We help **build** the knowledge base
AND
move knowledge into **action**
through programs and services for
research **producers** and research
**users**.
Resources for the Field

- AcademyHealth Methods Council
- HSR Learning Consortium
  - HSR Core Competencies
  - State of the Field Brief
- Research on trends in the field
- Seminars on methods and data
- Fellowships and funding opportunities

www.HSRMethods.org
www.academyhealth.org/edcatalog
Evidence Infrastructure Goals

Build an Evidence Infrastructure for the 21st Century that supports a Learning Healthcare System. This includes the core domains of:

- Data Governance (security, privacy, access)
- Community and Stakeholder Engagement
- Data Capture, Integration, and Exchange
- Emerging Methods & Best Practice
- Continuous Professional Development
- Collaborative Science
Value of Building the Evidence Infrastructure

→ Improve health care and population health by enhancing HSR’s:
  – Relevance
    • Stakeholder engagement
    • Privacy protections
  – Reliability
    • Methodologically Rigorous
  – Responsiveness
    • Timely: faster turnaround for traditional approaches
    • New approaches to dissemination and translation
      – Open science? Open access?
Researchers in the Health Data Ecosystem

DATA
- HHS - via supply of a comprehensive HHS Community Health Data Set (national, state, regional, and county-level measures of health performance and determinants of health), delivered free of charge.
- State and local governments
- Private sector data suppliers
- Others?

Feedback on data (types of data required, frequency of release, etc.)

Researchers?

www.hhs.gov/open/datasets/communityhealthdata
Emerging Data Resources

- Expanded Claims Data
- Electronic Health Records (EHRs) and Registries
- Patient Contributed Data
  - Patient Reported Information
  - Biomonitoring
  - Crowd-sourced Data
- Incidental Data
* Mashups
Interactive and Patient Contributed Data

→ New Approaches
  – Mashups and Challenges
  – Participatory Sensing, Mobile or “mHealth”
  – ePatients & Citizen Science
  – Community of “Quantified Selves”

→ May need to re-think a few things…. 
  – Meaningful Community Engagement
  – Privacy 2.0
Collaborative Science in HSR

» Collaborative Research Environments
  - Research Networks
    • AHRQ ARRA Grants to Build Infrastructure for CER:
      - PROSPECT Studies
      - Enhanced Registries
      - Distributed Research Networks
      - Electronic Data Methods (EDM) FORUM
        » Provide input at www.edm-forum.org
    • DARTNet
    • Mini-Sentinel
    • OMOP
    • HMORN
  - AHRQ Effective Healthcare Program (DEcIDE, CERTs, EPCs)
  - Dartmouth Care Collaborative
  - VA Informatics and Computing Infrastructure (VINCI)
  - NORC Data Enclave
  - NIH Collaboratory
  - NCRR - CTSA projects: Physio-MIMI, i2b2, TRIAD, REDCap
www.edm-forum.org

Current Features:
- EDM Updates
  - Twitter: @edm_ah
- Presentation Recordings
- Library of relevant literature
- Call for Comments
- Annotated Bibliography

Coming Soon:
- Commissioned Papers
- Issue Briefs
- Literature Review
- Interactive Online Community
- Glossary of terms
Opportunities to Get Involved and Stay Connected

→ Join the discussion
  – www.AcademyHealth.org

→ Participate in Events
  – Live Webinars
  – Free Archived Sessions

→ Stay Connected
  – Methods Minute
    • Sign up at hsrmethods@academyhealth.org
Thank you!

Erin Holve, PhD, MPH, MPP
Director
AcademyHealth
erin.holve@academyhealth.org
@hsrher
@academyhealth
@edm_ah