

# The Changing Landscape of Data for Health Services and Policy Research

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Association of Public Data Users (APDU)

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# Bio

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AcademyHealth

# 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:

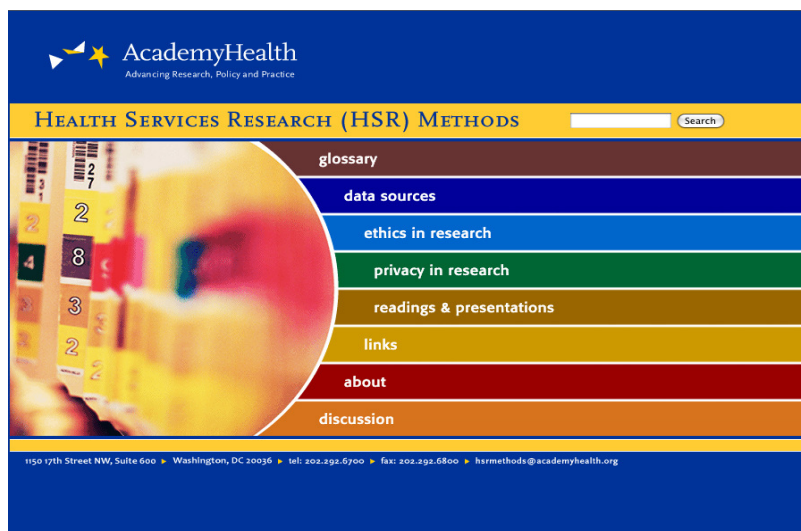
1. Support the development of health services research
2. Facilitate the use of the best available research and information
3. Assist health policy and practice leaders in addressing major health challenges



## In Other Words...

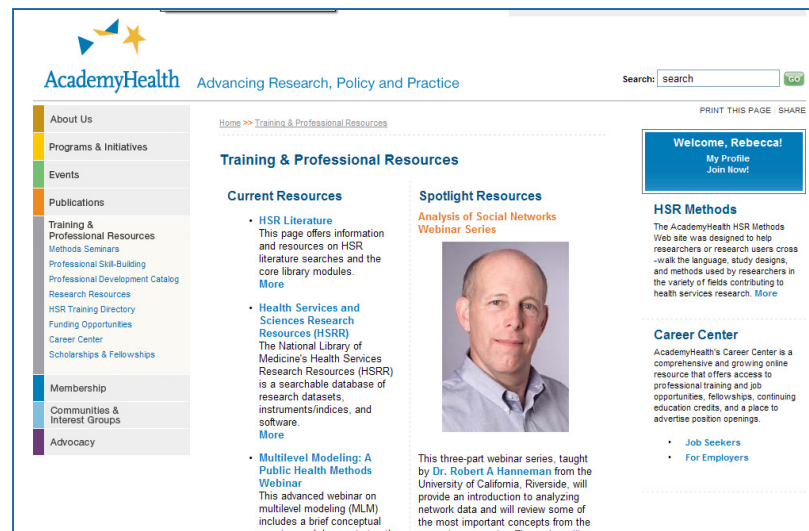
*We help **build** the knowledge base  
AND  
move knowledge into **action**  
through programs and services for  
research **producers** and research  
**users.***

# Resources for the Field



- AcademyHealth Methods Council
- HSR Learning Consortium
  - HSR Core Competencies
  - State of the Field Brief

[www.HSRMethods.org](http://www.HSRMethods.org)



- Research on trends in the field
- Seminars on methods and data
- Fellowships and funding opportunities

[www.academyhealth.org/edcatalog](http://www.academyhealth.org/edcatalog)

# Evidence Infrastructure Goals

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

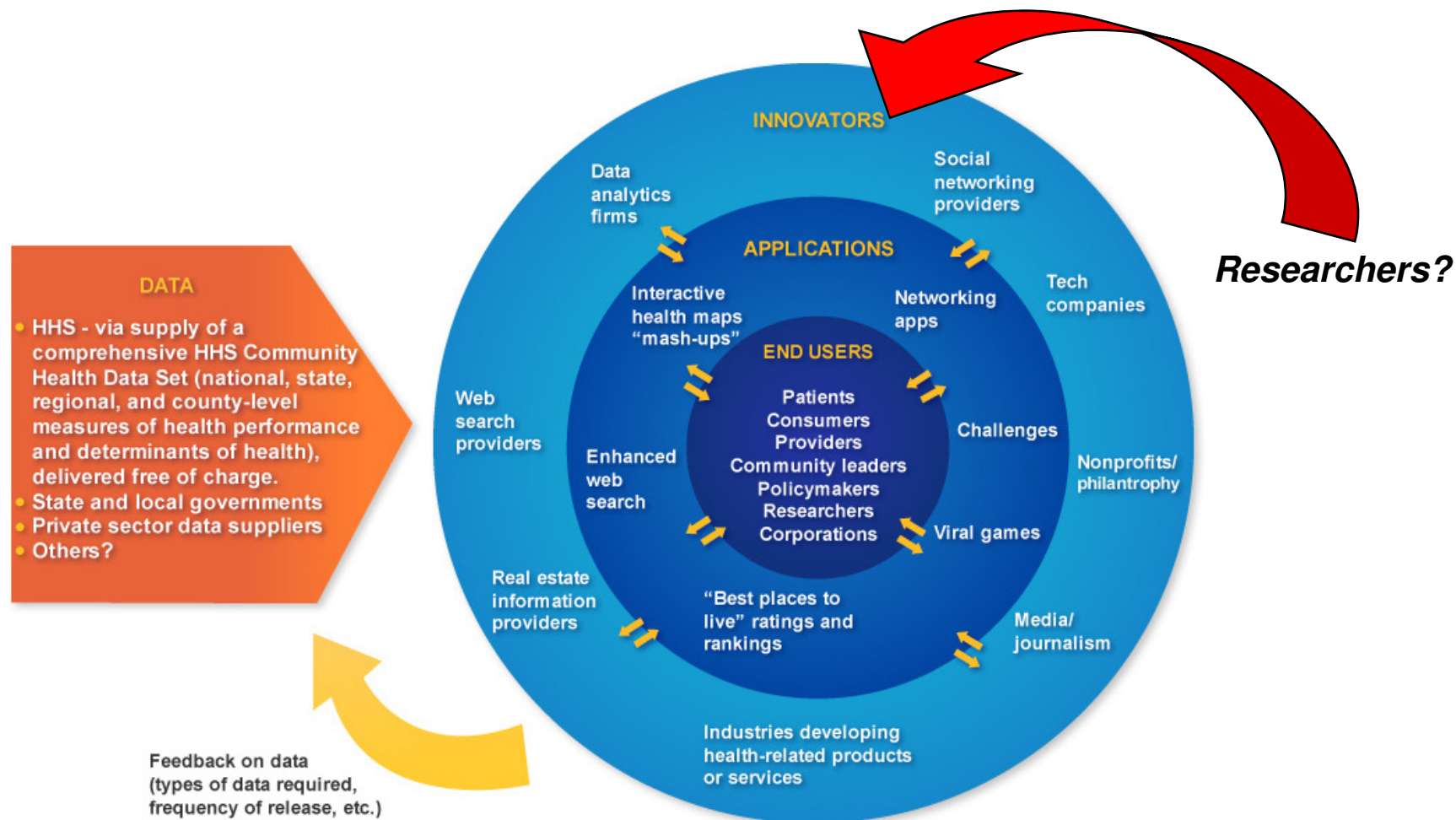
- Data Governance (security, privacy, access)
- Community and Stakeholder Engagement
- Data Capture, Integration, and Exchange
- Emerging Methods & Best Practice
- Continuous Professional Development
- Collaborative Science

# 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



[www.hhs.gov/open/datasets/communityhealthdata](http://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](http://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

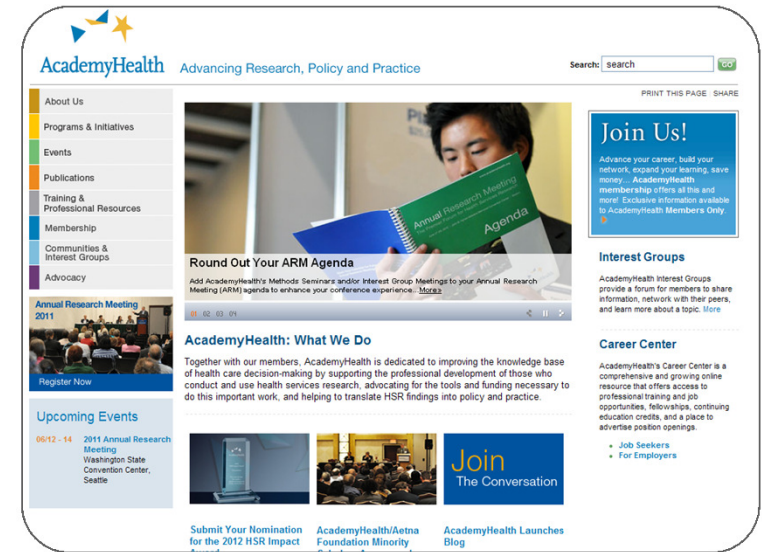
## Coming Soon:

- 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](http://www.AcademyHealth.org)
- Participate in Events
  - Live Webinars
  - Free Archived Sessions
- Stay Connected
  - Methods Minute
    - Sign up at [hsrmethods@academyhealth.org](mailto:hsrmethods@academyhealth.org)



# Thank you!

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