Patient-Centered Outcomes Research: Evidence-Based System Transformation

Carolyn M. Clancy, M.D.
Director
Agency for Healthcare Research and Quality

Third National Comparative Effectiveness Summit
Washington, DC – October 12, 2011
“Our criteria and standards need to be more flexibly adaptable to the finer clinical peculiarities of each case. In particular, we need to learn how to accurately elicit the preferences of patients to arrive at truly individualized assessments of quality.”

The quality of care: How can it be assessed? JAMA 1988;260:1743-1748
Current Challenges

- Translating scientific advances *into actual clinical practice*
- Translating scientific advances *into usable information* for clinicians – and for patients
- Delivering information in the right places
Evidence-Based System Transformation

- The Landscape: 21st Century Health Care
- The Growing Role of Patient-Centered Outcomes Research
- Where to From Here?
- Q&A
AHRQ’s Strategic Goals

- **Quality**: Deliver the right care at the right time to the right patient
- **Safety**: Reduce the risk of harm by promoting delivery of the best possible health care
- **Efficiency**: Enhance access to effective health care services and reduce unnecessary costs
- **Effectiveness**: Improve health care outcomes by encouraging the use of evidence to make more informed health care decisions
AHRQ Priorities

**Patient Safety**
- Health IT
- Patient Safety Organizations
- Patient Safety Grants (incl. simulation)

**Effective Health Care Program**
- Comparative Effectiveness Reviews
- Patient-Centered Outcomes Research
- Clear Findings for Multiple Audiences

**Ambulatory Patient Safety**
- Safety & Quality Measures, Drug Management, & Patient-Centered Care
- Patient Safety Improvement Corps

**Medical Expenditure Panel Surveys**
- Visit-Level Information on Medical Expenditures
- Annual Quality & Disparities Reports

**Other Research & Dissemination Activities**
- Quality & Cost-Effectiveness, e.g., Prevention & Pharmaceutical Outcomes
- U.S. Preventive Services Task Force
- MRSA/HAI
Reports Indicate that Quality Is Improving, but at Slow Pace

- 2010 reports indicate quality is up 2.3 percent
- Biggest gains in acute illness and injury
- Disparities remain unacceptably high
- Of 22 measures of access to care, 60 percent showed no improvement and 40 percent got worse

www.ahrq.gov/qual/qrdr10.htm

Today, Progress is Uneven in Eight National Priority Areas

- **Two are improving**: Palliative and End-of-Life Care, and Patient and Family Engagement
- **Three are lagging**: Population Health, Safety and Access
- **Three require more data to assess**: Care Coordination, Overuse and Health System Infrastructure
- **Disparities in all 8 areas** related to race, ethnicity and socioeconomic status
Some Areas Merit Urgent Attention

- Cancer screening and management of diabetes
- States in the central part of the country
- Residents of inner-city and rural areas
- Disparities in preventive services and access to care
Patient-Centeredness: The final frontier?

- Patient-centeredness may be the most challenging of all 6 domains of quality, because it is so difficult to define and measure.

- But, it is also likely the most important, because it includes elements of all other domains.
AHRQ’s Effective Health Care Program created by Medicare Modernization Act of 2003

From 2005-2009, AHRQ received $129 million from Congress for patient-centered outcomes research

Program has published more than 100 products, including guides for clinicians and consumers, with plans for 75 more over the next two years

Emphasis on synthesis of existing evidence and creation of new evidence
A Framework for Patient-Centered Outcomes Research

Horizon Scanning → Evidence Synthesis → Evidence Need Identification → Evidence Generation → Translation → Dissemination → Implementation → Improvements in Health Care

Research Platform
Infrastructure – Methods Development – Training
Priority Conditions

- Arthritis and non-traumatic joint disorders
- Cancer
- Cardiovascular disease, including stroke and hypertension
- Dementia, including Alzheimer Disease
- Depression and other mental health disorders
- Developmental delays, attention-deficit hyperactivity disorder and autism
- Diabetes Mellitus
- Functional limitations and disability
- Infectious diseases including HIV/AIDS
- Obesity
- Peptic ulcer disease and dyspepsia
- Pregnancy including pre-term birth
- Pulmonary disease/Asthma
- Substance abuse
Dissemination Goals

- Foster awareness and use of patient-centered outcomes research findings, products, and tools by a wide range of audiences
- Inform professional and consumer audiences about AHRQ’s Effective Health Care Program
- Drive toward greater degree of shared decisionmaking between clinicians and patients
Target Audiences

- Physicians, nurses, pharmacists, and other health professionals
- Consumers, patients, and their caregivers
- Health care system decision makers and business leaders
- Regional, State, and Federal policymakers
- Advocates for improvements of health care systems and patient outcomes
Growing Recognition of the Importance of Patient-Centeredness

- Improving health outcomes by developing and disseminating evidence-based information to patients, providers, and decision-makers
- Investments in robust systems and infrastructure to inform everyday clinical decision-making
- More opportunities to evaluate patient-centered outcomes research among diverse populations and patient subgroups that are not always adequately represented in studies
Recovery Act
Dissemination Contracts*

- Publicity Center – $18M
- Regional Offices – $8.6M
- Online Continuing Education – $4M
- Academic Detailing – $11.7M
- Systematic Program Evaluation – $2.4M

*September 2010 – September 2013
Recovery Act
Grants by Priority Condition*

* Grants by Priority Condition, AHRQ Effective Health Care Program
Patient-Centered Outcomes Research Institute

Created by the Affordable Care Act

- An independent, nonprofit Institute with public- and private-sector funding
- Sets priorities and coordinates with existing agencies that support patient-centered outcomes research
- Prohibits findings to be construed as mandates on practice guidelines or coverage decisions
- Contains patient safeguards
The Patient-Centered Outcomes Research Institute and AHRQ

- Provides funding for AHRQ to disseminate research findings of the Institute and other Government-funded research, and to train research on patient-centered outcomes research and build capacity for research
  - Up to 20 percent of the Patient-Centered Outcomes Research Trust Fund can be used to support research capacity building and dissemination activities
    - 80 percent may be used by AHRQ for dissemination and establishing grants for research methods training
    - 20 percent can be used by the Secretary to coordinate relevant federal health programs to build data capacity for patient-centered outcomes research
Future Directions

Promote value by seizing opportunities emerging with the increasing attention being paid to transforming the nation’s health care system

- Form alliances, partnerships and other strategies that promote collaboration
- Further integrate quality into the broader health care transformation effort
- Address the gaps that exist between our ability to generate data and having the capacity to produce actionable information that can be used right now
Questions?

AHRQ Mission
To improve the quality, safety, efficiency, and effectiveness of health care for all Americans

AHRQ Vision
As a result of AHRQ's efforts, American health care will provide services of the highest quality, with the best possible outcomes, at the lowest cost

www.ahrq.gov