



## How should HTA agencies use stakeholders: An example from the United States



# U.S. Department of Health & Human Services

Administration for Children & Families (ACF)

Administration on Aging (AoA)

Centers for Medicare & Medicaid Services (CMS)

Centers for Disease Control & Prevention (CDC)

Agency for Toxic Substances & Disease Registry (ATSDR)

Agency for Healthcare Research & Quality (AHRQ)

Food & Drug Administration (FDA)

Health Resources & Services Administration (HRSA)

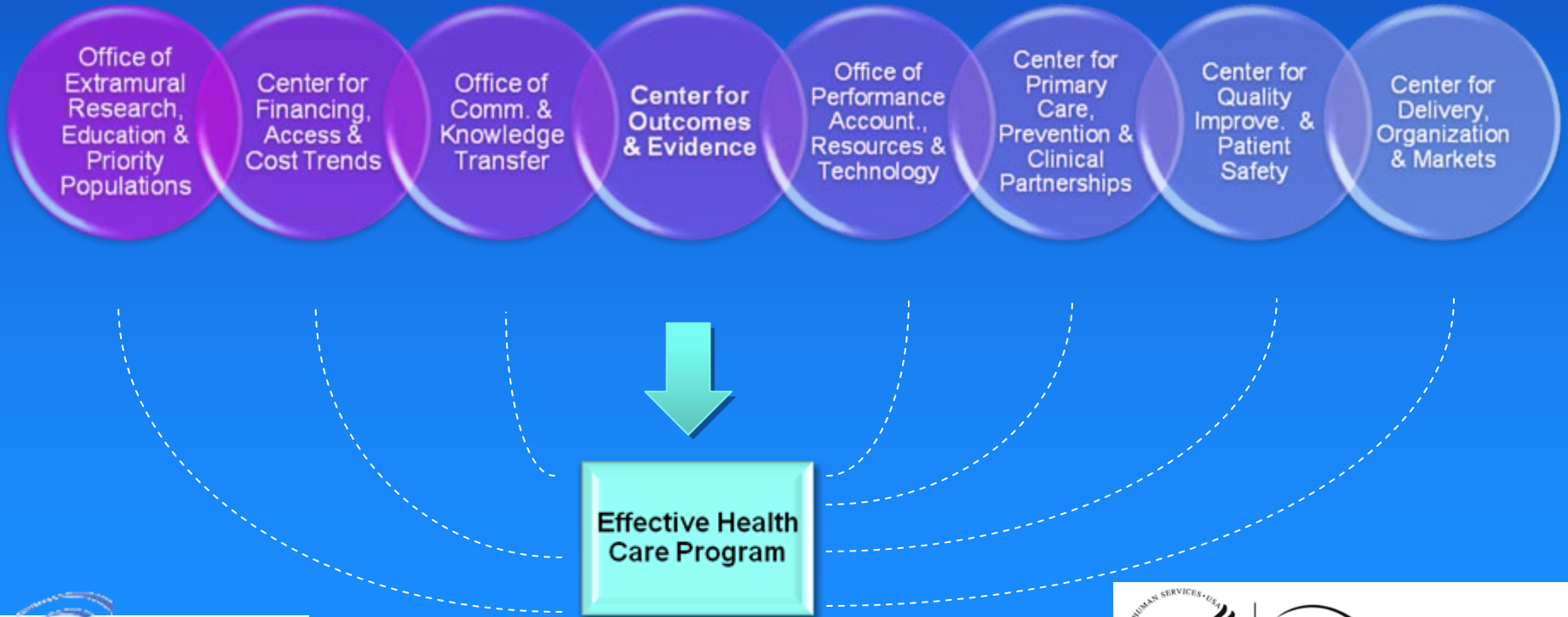
Indian Health Service (IHS)

National Institutes of Health (NIH)

Substance Abuse & Mental Health Services Administration (SAMHSA)



# Agency for Healthcare Research & Quality





# AHRQ and EHC Partners

- Directed by the Agency for Healthcare Research and Quality
- Effective Health Care Partners
  - ✧ Stakeholder Group
  - ✧ Scientific Resource Center
  - ✧ Evidence-based Practice Centers (EPCs)
  - ✧ Developing Evidence to Inform Decisions about Effectiveness Centers (DEcIDEs)
  - ✧ Centers for Education & Research on Therapeutics (CERTs)
  - ✧ John M. Eisenberg Clinical Decisions and Communications Science Ctr





# EHC Stakeholder Group

- 18-member volunteer committee representing clinicians, patients, government, payers, and industry
  - Provides input on research gaps and methods
  - Provides user perspective on program accountability and transparency
  - Identifies products most useful to decision-makers
  - Identifies opportunities for increased stakeholder involvement

# EHC Stakeholder Group

**Darrell Abernathy, MD, PhD**

**Wade Aubry, MD**

**Jennifer Bright, MPA**

**W. Gary Erwin, PharmD**

**Patricia Hart, MD, FACP**

**Maria Carolina  
Hinestrosa, MA, MPH**

**Peter Juhn, MD, MPH**

**Dick Justman, MD**

**Sharon Levine, MD**

**David Lorber, MD**

**Doris Lotz, MD, MPH**

**George Lundberg, MD**

**Newell McElwee,  
PharmD, MSPH**

**John Molina, MD, JD**

**G. Gregory Raab, MA,  
PhD**

**Alan Rosenberg, MD**

**Eric Wall, MD, MPH**

**Anthony Wisniewski,  
Esq.**



# Purpose and Context

- The EHC Stakeholder Group will serve as an “honest-broker” to AHRQ and the Effective Health Care Program
- The Stakeholder Group will provide context that:
  - Facilitates engagement of stakeholders
  - Maximizes short and long-term impact of the EHC Program
  - Challenges and improves the EHC Program
  - Emphasizes priority conditions

# Active Participation

- Serve on work groups
- Read and offer feedback on reports
- Assist to distribute reports
- Participate in select EPC / DEcIDE / Eisenberg Center meetings
- Host information session for membership
  - Example: U.S. Chamber of Commerce
- Link to related efforts
  - Example: Sharing NCI Consumer database

# Work Groups





# Program Priorities

---

- Advise process for selecting comparative effectiveness topics
- Develop a consumer involvement framework
- Discuss ways for stakeholders to be involved
- Increase transparency across EHC Program
- Begin selection process for new research topics

# Product Development

- Provide advice and guidance on EPC comparative effectiveness reports
  - Scientific methods and standards
  - Guidance for research
  - Transparency and controlling for conflicts of interest
  - Role of public in development of scientific reports
  - Quality and consistency of application
  - Future research needs
  - Effectively communicating results



# Product Dissemination

---

- Develop frameworks for dissemination to
  - Consumers
  - Clinician
  - Policymakers
- Advise on measuring impact of EHC Program

# Work Group Products

## ■ Program Priorities

- Consumer involvement framework
- Topic selection process
- Documenting processes to increase transparency

## ■ Product Development

- Disposition of comments
- Suggestions to improve reports and presentation of evidence, situations of low evidence, future research

## ■ Product Dissemination

- Consumer dissemination framework
- Website revisions



# AHRQ Adopts Suggestions

- Suggestions from Stakeholders
  - Improved topic nomination form
  - Posting research protocols
  - Disposition of public comments
  - Feedback to nominators
  - Revisions to website to increase transparency
  - Developing methods guidance for CERs
  - Proactive and targeting outreach efforts
  - Enhanced marketing and dissemination efforts

# Personal observations

- AHRQ genuinely wants frank and candid input
  - and is quick to act when it makes sense
- Some stakeholders were initially skeptical but have become “ambassadors” over time
  - Based on an appreciation for the bullet above
- The structure and organization of the group has facilitated this transition
  - Representation from diverse set of stakeholders
  - Meetings not open to public (more candid dialogue but may be perceived as not transparent)
  - Opportunities to interact with AHRQ staff and stakeholders outside of the meetings

# Considerations

- What value is placed on “consumer involvement?” Which stakeholders should be represented?
- What experience do you have working with industry? How is conflict of interest managed? What have been the key issues / concerns raised?
- What other processes do you use to gather input for improving your products and increasing applicability for decision makers?