Supporting Patient and Consumer Involvement in Patient-Centered Outcomes Research

Danielle Lavallee
AHRQ Community Forum
October 13, 2011
Overview

- Provide a brief overview of the Agency for Healthcare Research and Quality (AHRQ) Community Forum
- Describe Community Forum efforts to broaden patient and consumer involvement in the EHC Program
- Presentations
  - Outreach to Patient and Consumer Representatives
    - Carolyn Branson, SRA International
  - Support for Patient and Consumer Representatives
    - Amy Bonoff, NBCC Project LEAD
  - Partnering with Patients to Disseminate Research Products
    - Lawrence Sadwin, American Heart Association
- Q & A
Goals

- Understand approaches to effectively and efficiently identify patient and consumer representatives;

- Describe approaches to best support and train patient and consumer representatives; and

- Understand strategies for partnering with patients and consumers in the translation and dissemination of research products.
Part One: Explore the use of public deliberation as a method for eliciting input from the public on health care issues, particularly in the conduct and use of CER.

- Assess what is known about public deliberation
- Conduct a large randomized controlled experiment of alternative methods of public deliberation
Community Forum Project

Part Two: Support and enhance stakeholder involvement in all aspects of AHRQ’s expanded Effective Healthcare Program.

Collaborative partnership:

- American Institutes for Research
- Center for Medical Technology Policy
- Consumers Union
- AcademyHealth
Community Forum Project: Support patient and consumer participation

- Understand best approaches to support patient and consumer involvement
- Develop capacity building resources for patients, consumers and researchers
- Identify and learn from other organizations who successfully involve the patients and consumers
## Supporting Patient and Consumer Involvement

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<tr>
<th>Technical Expert Panel (TEP) Members</th>
<th>Affiliation</th>
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<tr>
<td>Amy Bonoff</td>
<td>National Breast Cancer Coalition Project LEAD</td>
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<td>Carolyn Branson</td>
<td>SRA International</td>
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<td>Deborah Collyar</td>
<td>Patient Advocates in Research (PAIR)</td>
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<td>Virna Elly</td>
<td>Patient Advocate</td>
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<td>Nancy Fitton</td>
<td>Consumers United for Evidence-Based Healthcare CUE)</td>
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<td>Peg A. Ford</td>
<td>Patient Advocate, <em>Ovarian Cancer Advocacy Alliance</em></td>
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<td>Andrea Furia-Helms</td>
<td>FDA Patient Representative Program</td>
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<td>Lawrence Sadwin</td>
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<td>John Santa</td>
<td>Consumers Union</td>
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<td>Jennifer Sweeney</td>
<td>National Partnership for Women</td>
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Today's Presenters

- Outreach to Patient and Consumer Representatives
  - Carolyn Branson, SRA International

- Support for Patient and Consumer Representatives
  - Amy Bonoff, NBCC Project LEAD

- Partnering with Patients to Disseminate Research Products
  - Lawrence Sadwin, American Heart Association