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Supporting Patient and Consumer Involvement in Patient-Centered Outcomes Research

Danielle Lavalley

AHRQ Community Forum

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Logo: Effective Health Care Program, Community Forum

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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

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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.

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Community Forum Project

- 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

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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

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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

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Supporting Patient and Consumer Involvement

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

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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