

Patient Group Concerns about Comparative Effectiveness Research

November 5, 2012



- **ASSIGNMENT**

- **ASSIGNMENT**
- **CURIOSITY**

The Role of Health Advocacy Organizations
and Evidence-Based Medicine
Sheila Rothman.

JAMA. June 22/29 Vol 305, No. 24 p 2569-2570

- **ASSIGNMENT**
- **CURIOSITY**
- **SYSTEMATIC
OBSERVATION**

- **ASSIGNMENT**
- **CURIOSITY**
- **SYSTEMATIC
OBSERVATION**
- **NEW AUDIENCE**

Approach

20 < until SQ

large / small

specific disease / general

American Liver Foundation
Annie Appleseed Project
Center for Healthcare Decisions
Center for Medical Consumers
Childbirth Connection
Cystic Fibrosis Foundation
Dia de la Mujer Latina
Mothers Against Medical Error
National Alliance for Caregiving
National Coalition for Cancer Survivorship
National Committee to Preserve Social Security
and Medicare
Our Bodies Ourselves
Parkinson's Pipeline
Pulse of Colorado

AARP

Consumer Reports

Easter Seals

Epilepsy Foundation

Mental Health America

National Coalition of Aging Organizations

QUESTIONS

- 1. Tell me about yourself and your organization.**
- 2. How does CER fit in the effort to improve the effectiveness of health care?**
- 3. How does your organization view the relationship between CER and PCOR?**
- 4. What is an example of how your constituents have been affected by CER?**

QUESTIONS (cont.)

5. How do you see the increased attention to CER affecting future care of your constituents?
6. Some professionals believe that patients are opposed to comparative effectiveness research. Is this accurate? What's behind this view?
7. What are your fears and hopes for CER?

Observation:

Research

-- CER specifically --

rarely highest priority

Observation:

Agreement:

**The public / their constituents
don't know what CER is. They
think it's already governing
what's available**

Observation:

**Among interviewees,
knowledge about CER ranged
from very high to negligible**

Observation:

**Leaders' experience with
patient involvement in
research similarly variable**

Observation:

**Worries / concerns about CER
found mostly among large,
disease-specific groups**

Observation:

**Among those familiar with
CER, strong positions, good
illustrations of pros and cons**

Observation:

**Curiosity?
Rothman gross
generalization**

Implications for Researchers

1. Assume nothing

Implications for Researchers

1. Assume nothing
2. There is value in every level of experience

Implications for Researchers

1. Assume nothing
2. There is value in every level of experience
3. Collaboration with patient groups **ALWAYS** a strain on group

CER in the service of our aim:

***To live as well as we
can for as long as we
can***