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# Consumer's View of Comparative Effectiveness Research

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AIR Center for Patient & Consumer Engagement

# Our Experience with Patients, Consumers & CER

- Formative research and product testing of CER summary products with patients, caregivers, and clinicians for AHRQ.
- Public comment analysis and patient research for PCORI Methodology Report.
- Currently researching patient engagement through public deliberation on CER.
- Literally thousands of interviews and surveys with patients and health consumers over past 10 years.

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# Evidence That Consumers Are Skeptical About Evidence-Based Health Care

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**ABSTRACT** We undertook focus groups, interviews, and an online survey with health care consumers as part of a recent project to assist purchasers in communicating more effectively about health care evidence and quality. Most of the consumers were ages 18–64; had health insurance through a current employer; and had taken part in making decisions about health insurance coverage for themselves, their spouse, or someone else. We found many of these consumers’ beliefs, values, and knowledge to be at odds with what policy makers prescribe as evidence-based health care. Few consumers understood terms such as “medical evidence” or “quality guidelines.” Most believed that more care meant higher-quality, better care. The gaps in knowledge and misconceptions point to serious challenges in engaging consumers in evidence-based decision making.

## Patient and Consumer Beliefs

- Majority of patients are still unclear of the role that research evidence plays in making decisions about their care.
- Majority of patients still believe that a treatment must be safe and effective if it is being offered to them.
- Uncertainty makes little sense and indicates a lack of concern for certain groups.
- The number of patients engaging at some level in their health care is growing, though many still defer to their doctor

## “Passengers on a Plane”

- Don't know aviation science, but haven't needed to learn to take the trip.
- Would like the flight to be comfortable, but are far more interested in the destination, and the many decisions that come AFTER the arrival.
- Wish someone would ask where they want to go instead of just inviting them to go on their trip.
- Trusting organizations like the FAA to ensure that the ride is safe and the pilots are competent.

## Consumer Complaints About CER

- Evidence on interventions that are not available to me.
- Evidence of outcomes that are not important to me.
- Unequal amounts of evidence to compare options.
- Limited evidence on side effects and harms.
- Evidence that contradicts my doctor's beliefs or practices.

# Illustration



- “For the majority of interventions, sparse data are available, which precludes firm conclusions for any single approach or for the optimal overall pain management following non-pathological hip fracture due to low energy trauma.”
- “Overall, the evidence shows that most interventions result in improvements in short-term pain scores; however, few differences of long-term clinical importance are noticeable when comparisons between interventions are available.”

**CONSUMER read:** They don’t know, but you have to try something. You can’t stay in pain. Too hard for me to make sense of; I’ll go with whatever my doc says.

## Decisional Dilemmas: Trade Offs

- Which choice will allow me to work to support my family?
- Which choice will allow me to meet my obligations to the family or community?
- Which choice will allow me to cure or live comfortably with this condition?
- Which choice will least change my life and activities as I now enjoy them?
- Which choice can I afford?



## Key Tensions to Resolve

- Current research methods and practices that are unable to produce answers to consumer questions.
- Research products that are primarily academic or support academic promotion but have limited utility in clinical practice.
- Limited consumer involvement as key informants to established research projects.

## Where are we headed?

- Consumers need to see pay-off in new tools, information.
- Patient engagement research is needed to quantify, qualify, and guide consumer engagement practice.
- Connections needed to bridge disparate silos of patient and consumer engagement efforts across health care.

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