



CONSUMER ATTITUDES ABOUT COMPARATIVE EFFECTIVENESS

Evidence as an essential—but insufficient—
ingredient for medical decision-making

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Today's Takeaways

- People like compared effectiveness, with reservations
- The best way to communicate medical evidence is as part of shared decision-making
- The language to use when presenting evidence



A FEW WORDS ABOUT LANGUAGE

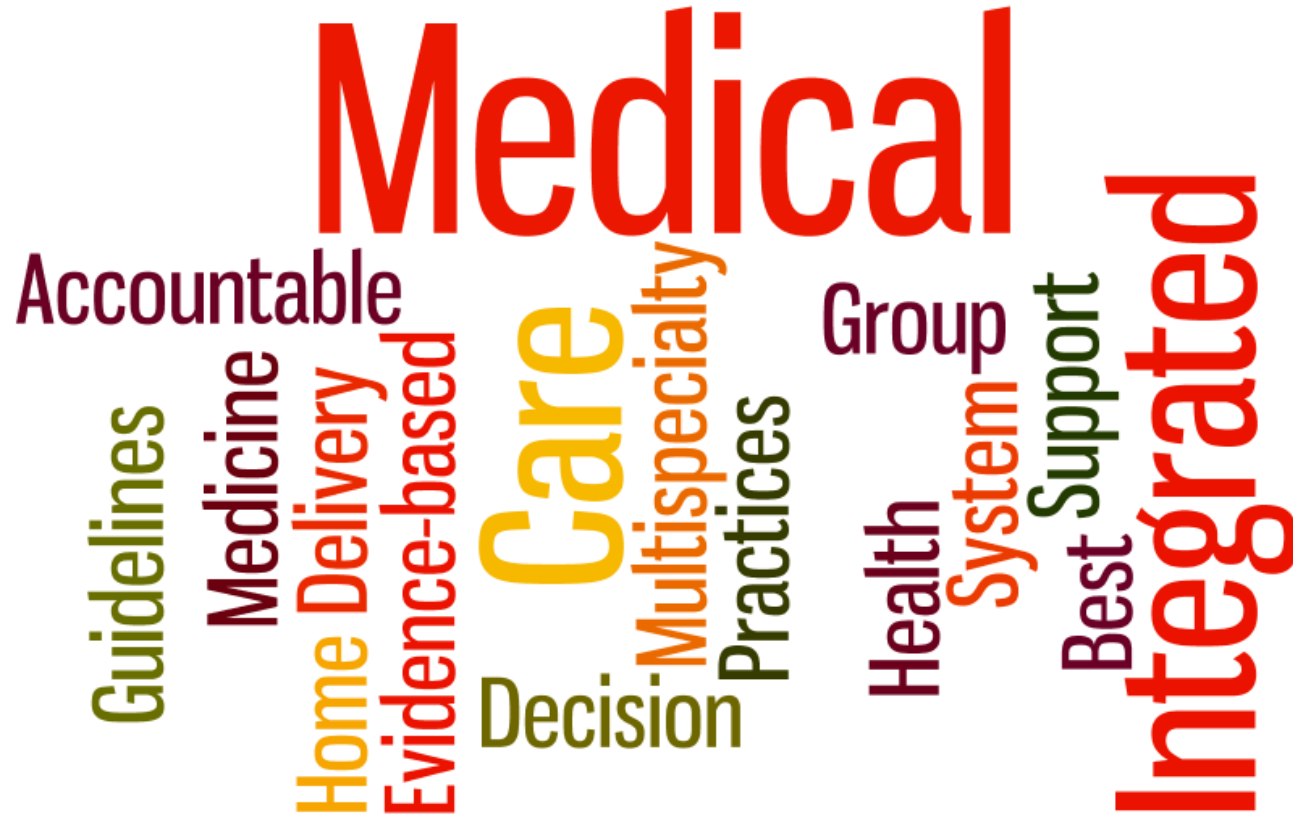
Do They Hear What You (Think You) Say?



The new landscape of delivery and payment reform is covered with language landmines



The Way “We” Talk About Health Care



Come Again?

What You Say	What They Hear
Medical home	Nursing home, home health, end of life
Medical decision support	End-of-life decisions
Guidelines or treatment guidelines	Restrictive, rigid, limited, driven by cost
Integrated health care delivery system	Bureaucratic, industry language, meaning unclear
Integrated care	Bureaucratic, industry language, meaning unclear
Multispecialty medical group	Bureaucratic, industry language, meaning unclear, trying to do too much, low quality, limited choice of specialists to choose from
Best practices	Bureaucratic, meaning unclear, insincere, cookie-cutter care, not tailored to the individual
Evidence-based medicine	Impersonal, one size fits all
Accountable	Something will go wrong, minimal care, buzz word

Source: Ross M, Igus T and Gomez S. "From Our Lips to Whose Ears? Consumer Reaction to Our Current Health Care Dialect." *The Permanente Journal*. 13(1):8-16. 2009.



What Value Looks Like



People equate value with “bargain-basement pricing,” not high-quality care



VALUE = Rationing, Poor Quality

- “Eliminating waste,” “increasing efficiency” or even “saving money” sparks fear of rationing care that they want — and feel they need — but that may be expensive
- Feelings that care will be cheapened, or that time with physician will be cut or — worst of all — that the care that they want could be curtailed is threatening. It shuts down the conversation
- The premise of VBID programs — the use of high quality providers or evidenced-based procedures leading to lower costs — is counterintuitive to employees’ perceptions that lower cost equals lower quality

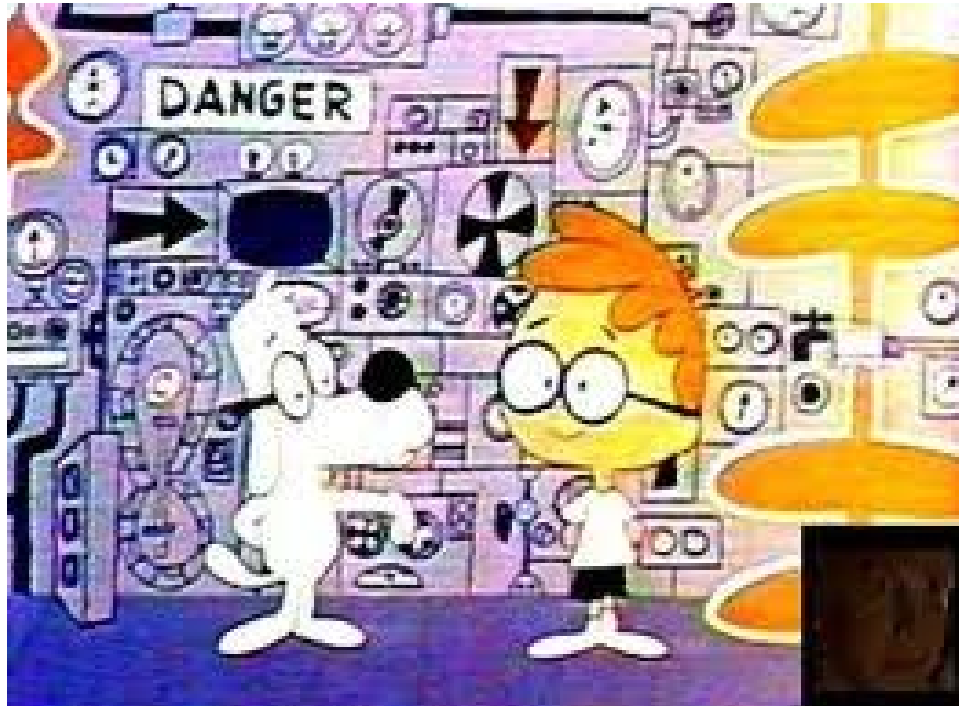


HOW TO TALK ABOUT EVIDENCE

The IOM and Evidence Communications

In 2009, the IOM charged its Evidence Communications Innovation Collaborative to “improve public understanding, appreciation, and discussion—between and among patients and providers—on the nature and use of evidence to guide clinical choices”





Remember Death Panels?

A few choice words about federal oversight of comparative effectiveness research:

- *A national health care rationing board*
- *An agenda that will destroy the doctor-patient relationship and set us on a course for government-administered health care*
- *Handing personal medical decisions over to the federal government*
- *Lays the groundwork for a permanent government rationing board prescribing care in place of doctors and patients*



The World According to Dr. Luntz

- **One-size-does-NOT-fit-all.** The idea that a “committee of Washington bureaucrats” will establish the standard of care for all Americans and decide who gets what treatment based on how much it costs is anathema to Americans
- “Science and research should be used to enhance and improve healthcare quality, not limit a patient’s choices or options. We should encourage doctors and healthcare professionals to share best practices and learn from each other’s experiences, but we need to recognize that every patient is different and every illness needs an individualized, personalized approach. Statistical analysis can help, but healthcare requires a human approach, timely decisions, and the right of patients to try an innovative approach if everything else has failed.”

Dr. Frank I. Luntz - The Language of Healthcare 2009



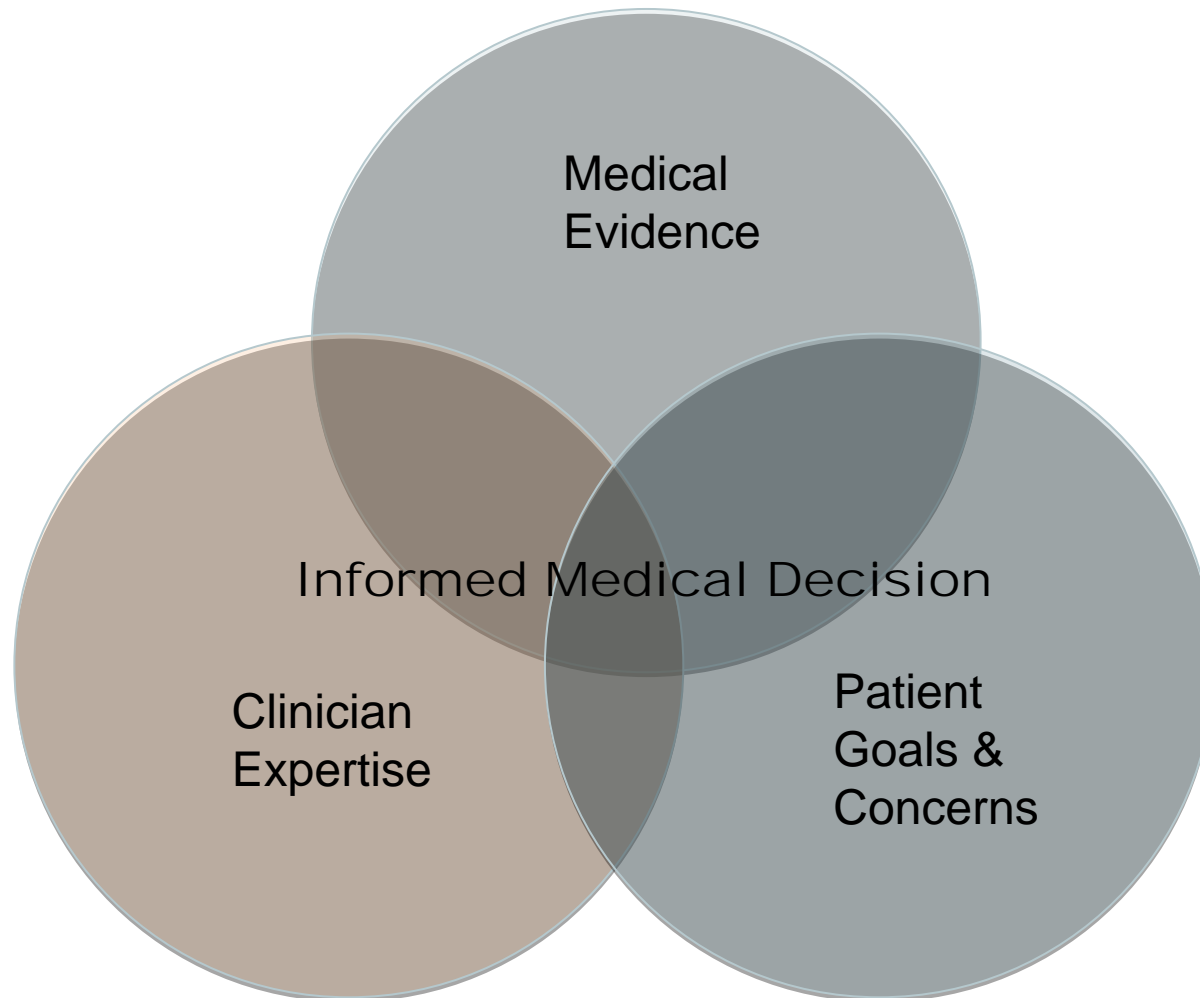
Put Evidence Under An Umbrella Concept



**Making an informed decision
about the care that's right for you**



Elements of an Informed Medical Decision



Source: Alston C, et al. "Communicating with Patients on Health Care Evidence." Washington, D.C.: Institute of Medicine. September 2012



Research

Qualitative

- MSLGROUP, GYMR, PerryUndem Research & Communications (formerly Lake Research Partners)
- Chronically ill patients
- Mix of genders, education levels and incomes
 - One-on-one interviews
 - Charlotte, NC
 - Focus groups
 - Bethesda, MD
 - Indianapolis, IN
- Fall 2011

Quantitative

- An online survey was conducted by Consumers Union
- 1,068 non-institutionalized adults age
- March 2012



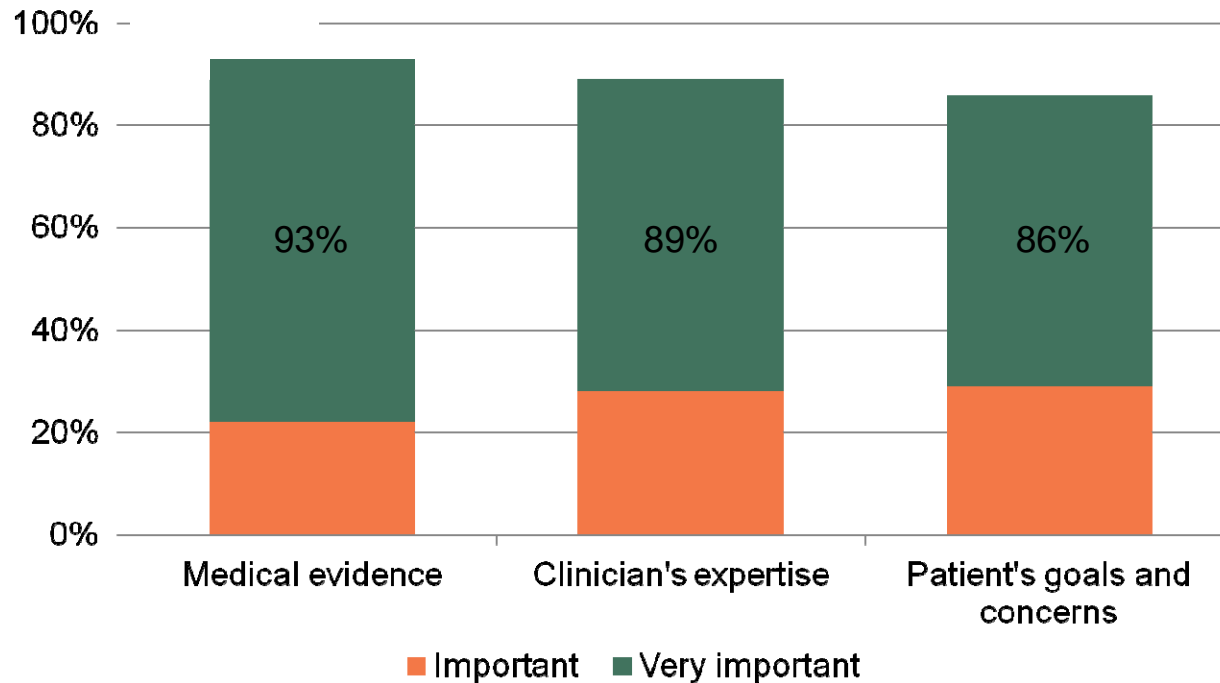
3 Core Findings

- People want to be involved in decision-making
 - Results in the best care possible
 - Esp. for decisions about surgery or medications
- Patients want doctors to communicate options
 - People trust their doctors and want more time to talk/listen
- People value comparative effectiveness research
 - Regardless of politics, patients see deep value in CER
 - Their fear, however, is that money will ultimately drive decisions and/or their preferred treatment will be off limits



People Value All 3 Elements Strongly

Figure 4. Strong support for the three parts of informed medical decisions



- For most subgroups, personal preferences were less important than the medical evidence and the providers opinion.
 - Females (64% very important) indicate that their personal preference and goals are more important than males (50% very Important)



Perceptions of Physicians

- Patients trust that the doctor is up on the latest medical info - but don't know for sure
 - They think the doctor is up on research if he/she ...
 - Mentions a pharmaceutical or treatment before it is advertised or in the news
 - Went to a prestigious medical school
 - Cites journal articles
 - Looks up information in front of the patient
 - Doesn't rush the patient and takes time to answer questions



Where Patients Get Information

- The Internet is the main source of health information
 - Most people use the Internet before their medical appointment in order to “speak the doctor’s language” and/or after to interpret what the doctor said
 - Google
 - WebMD
 - Sites that include patient experience information
- Patients turn to women as health care gatekeepers
 - Wives, mothers, sisters, daughters, friends ...



What Patients Want to Hear

- When discussing treatment options, patients want their doctor to use clear language and listen to them
- Patients want to hear:
 - The truth about the diagnosis - no sugar-coating
 - All options for treatments
 - Risks and side effects of treatment options
 - What the diagnosis and treatment mean for future quality of life
 - Recommendations for a website or literature where the patient can learn more
 - Next steps
- And for some:
 - How the illness or condition developed
 - A willingness for the patient to get a second opinion



When Patients Want to Hear It

- Participants are mixed about *when* they want to have the discussion about treatment options
 - Some say at the point of diagnosis (mostly men)
 - Some say a few days later (mostly women)
 - Some say BOTH at diagnosis and a follow-up appointment a few days later



Language That Resonates With Patients

"As you know, you have low back pain caused by a herniated disc – meaning one of the discs cushioning the bones in your back has ruptured. There are a number of options for treating it, including surgery or just giving your back time to heal. Most of the scientific evidence shows that low back pain like yours will get better on its own without surgery. If given enough time, the back can usually heal itself, but it could take weeks or maybe months. Surgery can relieve the pain more quickly but also carries risks. You'd have to go under anesthesia, and there is no guarantee that the surgery will work. Outcomes for either option will be better if you lose a bit of weight and take appropriate pain medications for a limited time while you heal. My opinion is that you should let your back heal on its own, but the decision needs to be yours. Is there information I can give you to help you decide between treatment options?"



Why Certain Language Resonates

"meaning one of the discs..."	Participants appreciate the explanation of what is wrong—describing what a herniated disc means.
"number of options"	Participants like options, particularly when it comes to surgery. If there are options for treatment, they want to hear about them. A few crossed out "a number of" because only two options were presented.
"scientific evidence"	Many like that the physician reports on the scientific evidence—they want to know what evidence exists. "Medical evidence" tends to work better than "scientific evidence", however. Also, adding "recent" or "up-to-date" modifiers may help for some who wonder how recent the evidence is.
"carries risk"	Risks are a key component of treatment options that consumers want to hear.
"no guarantees"	Knowing that there is "no guarantee" is a key factor that would weigh in the decision process. Additionally, the phrase resonates with participants who appreciate the honesty in a discussion.
"outcomes...will be better if you lose a bit of weight"	Some participants like this because it is truthful, while others like it because they prefer to take steps on their own prior to medical intervention.
"my opinion is..."	The doctor's recommendation is key, although a few do not like the word "opinion", which feels uncertain. "My experience" or "my recommendation" may be a better word choice.
"the decision needs to be yours"	Again, participants want to be integrally involved in making decisions, so many like hearing this from their doctor
"is there information I can give you"	Participants like this gesture, and feel it is an opening to ask questions. An improvement might be asking directly: "Do you have any questions right now that I can help answer?" "How do you feel about all of this?" "What are your thoughts and concerns?"



Best Framing Language

Making sure you get the best possible care starts with you and your doctor making the best decision for you.

Your doctor can help you understand what types of care work best for your condition, based on medical evidence.

Because there are always new treatments, doctors use this evidence to keep up with which work best.

Your doctor's experience helps him/her evaluate and apply the evidence to your situation.

The doctor also needs to listen to you so he/she understands your values, preferences and goals.

This is important because every patient is different, and when there are options, it is important for the doctor to know what is important to you.



Second Best Framing Language

When you and your doctor sit down to talk about what tests or treatments to do, the conversation should involve the best medical evidence.

But the research is constantly changing as we learn more, so the recommendations may change over time, too.

As new treatments are developed, they are compared to the ones that exist today to determine if they're really better.

This is all part of the process of continuously improving our health care choices.



How to Describe the Evidence

- Yes
 - Medical evidence
 - Recommendation
 - Best practice
 - Guideline
 - What is proven to work best
- Maybe
 - Medical science
 - Evidence-based medicine
 - Comparative effectiveness
- No
 - Research - *"Research changes every day"*
 - Standard - *"But I'm different"*



Talking About Evidence

For the following statements, tell me how confident you are that it describes information you need to help you and your provider make a decision about the treatment for your condition



5 Final Recommendations

1

Talk about CER as “determining what care works best for your condition, based on the most up-to-date medical evidence”



5 Final Recommendations

2

Avoid talking about the negative
(It's not "preventing the wrong care," it's "getting the right care")



5 Final Recommendations

3

Talk about it in the context of what patients want most: A conversation with your doctor in which he/she clearly reviews treatment options, listens to you, and answers your questions



5 final recommendations

4

Use evidence of choices involving surgery as examples for communicating CER



5 Final Recommendations

5

Use key elements in a successful message:

- Making sure you get the best possible care starts with you and your doctor making the best decision for you.
- You and your doctor can better understand the best type of care for you by looking at the most recent medical evidence.
- Every patient is different.
- Your doctor will listen to you, understand your needs and concerns, and answer your questions as you make this decision.



To Learn More

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To Follow Up

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