

Why We Need Shared Decision Making



FOUNDATION FOR
INFORMED MEDICAL
DECISION MAKING

Jack Fowler
Senior Scientific Advisor

Three Foundations of Shared Decision Making

- Ethics
- Variation in medical care
- Studies of medical effectiveness and outcomes

In 1982, Presidential Commission on Medical Ethics Concluded:

- *“Patients who have the capacity to make decision about their care must be permitted to do so voluntarily and must have all relevant information regarding their condition and alternative treatments, including possible benefits, risk, costs, other consequences, and significant uncertainties around any of this information.”*

When Rates of Interventions vary Widely, what is the Right Rate?

- Since patients are the ones who have to live with the consequences, one reasonable answer is:
 - The rate at which informed patients would choose the intervention

In the 1990s, Patient Outcome Research Teams Observed:

- Major mismatches between the evidence about how treatments work and the way medicine was practiced
- 3 particularly critical examples:
 - Surgery for benign prostate hyperplasia disease
 - Surgery for lower back pain
 - Cardiac interventions

For BPH

- Some physicians were operating on BPH with early symptoms under the theory that they were preventing progression
 - There was little or no evidence about rate of progression

For Low Back Pain

- Fusions and insertion of screws were common, and continue to be common, when the evidence suggests no benefit— and possibly more harm than good
- Also, patients often unaware most herniated discs will heal themselves

For Coronary Artery Disease

- Stents were being inserted, and still are, for patients who were unlikely to derive any survival benefit
- Patients routinely assume procedure critical to survival

For all Three Interventions:

- Trials have been done using balanced decision aids that reduced the interventions when patients were informed and invited to have a say in the decision process

Foundation Began Making Decision Aids in 1989

1. Laid out the reasonable alternatives
2. Spelled out what was known about the pros and cons of alternatives, including doing nothing at all
3. Provided interviews with patients who had made different choices, as they explained their rationales and how their treatments had worked out
4. Encouraged patients to play an active role in decision making

A Good Decision Process Requires 3 Things

1. Patients need to be informed
2. Patients need to think through their goals and concerns, and how they relate to decision
3. Patients and doctors need to talk together
 - a) Doctors need to be sure patients have accurate information about their options
 - b) Patients need to make sure doctors know their goals and concerns and preferences

In the Abstract, this all seems like the Right Thing to do

- So how are we doing 20+ years later?
 - Not so well

National Survey of Medical Decisions

- Telephone interviews with 3,010 persons 40 and older
- Screened for discussions in the past two years related to nine common medical decision
- Detailed questions on up to two discussions, among those who had a discussion

National Survey of Medical Decisions

- Cancer screening tests:
 - Colorectal Cancer
 - Breast Cancer (mammography)
 - Prostate Cancer (PSA testing)
- Prescription medication decisions:
 - Hypertension
 - High Cholesterol
 - Depression
- Surgical interventions:
 - Knee/hip replacement
 - Cataracts
 - Lower back pain



Discussions Initiated by HCP

Medication Initiation:



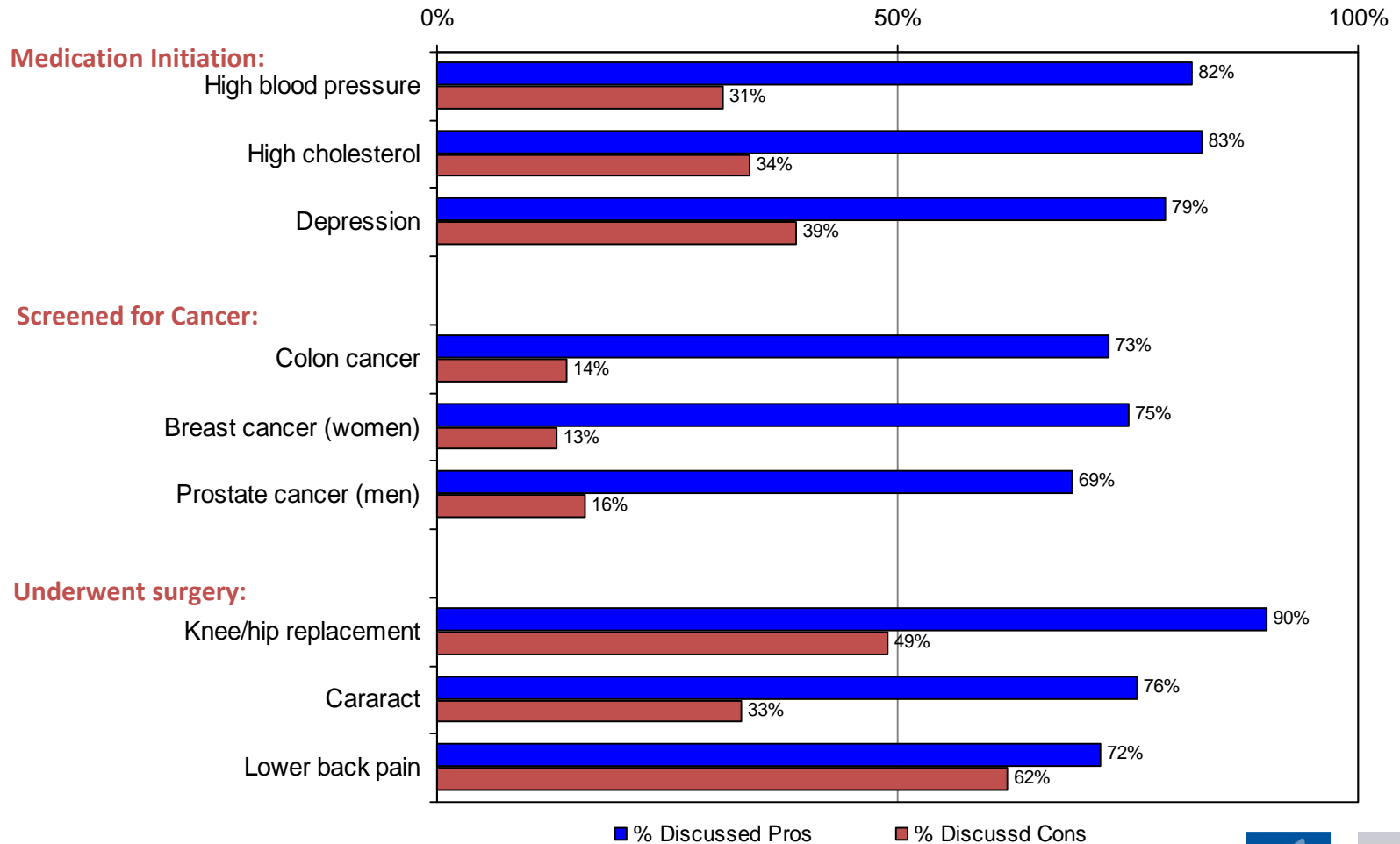
Cancer screening:



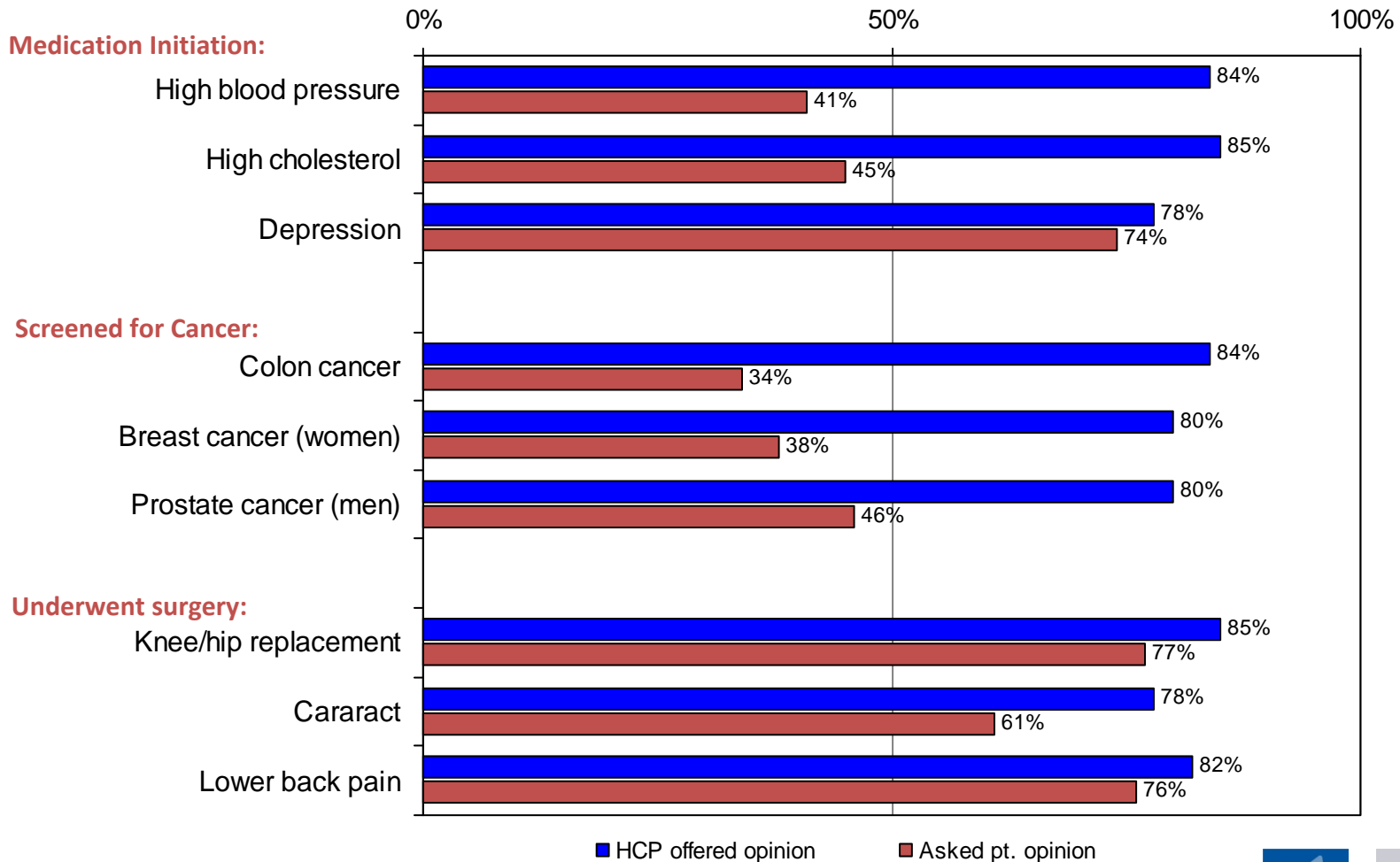
Elective surgery:



Discussion of Pros and Cons- “some” OR “A lot”



Did HCP Offer an Opinion and Ask for Patient's Own Opinion?



What did the Physicians Recommend?

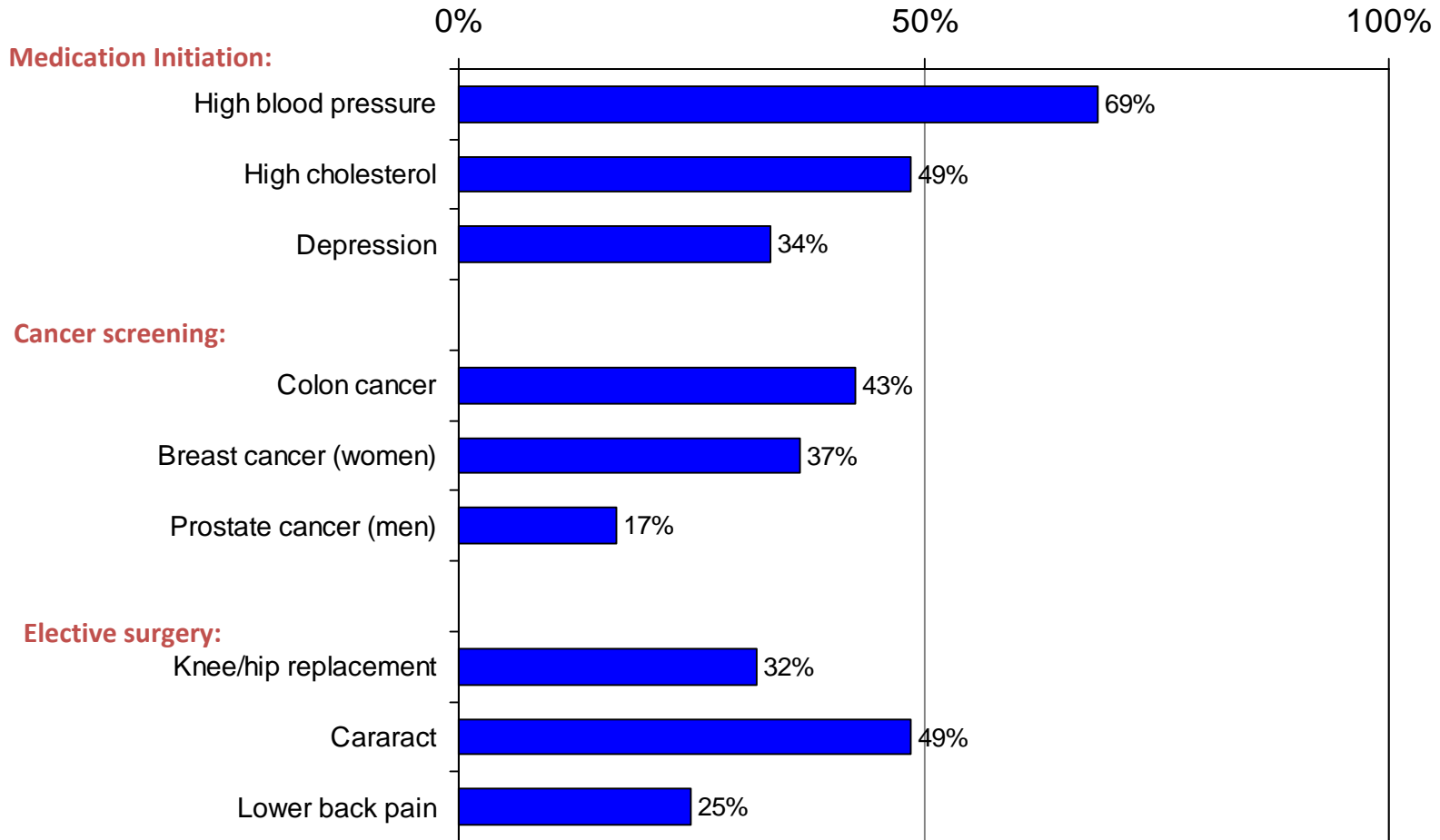
- Surgical decisions
 - About 65% of recommendations were to do it
- Medication decisions
 - Over 90% of recommendations were to take it
- Cancer screening (including PSA testing)
 - About 95% of recommendations were to do it

How Much do Patients Know about their Conditions and Treatments?

- Not so much!
- We had clinical experts specify 4-5 key items they thought a patient faced with each of the decisions should know, for example:
 - Diagnosis and death rates
 - Key side effects
 - Duration of medication
 - Etc.
- For all decisions except high blood pressure:
 - On average, patients answered half or fewer of the questions correctly



Mean Proportion of Knowledge Items Answered Correctly



What is Wrong with Delegating Decisions to Physicians?

- Some research by Karen Sepucha illustrates one important aspect of the problem

Example: Early Stage Breast Cancer

- NIH consensus conference in 1990 concluded that, “*breast conservation treatment...is preferable because it provides survival equivalent to total mastectomy...while preserving the breast.*”

Validating Key Facts and Goals

- Mailed survey to determine accuracy, importance and completeness of items
- Providers AND patients in sample
 - How important was each item?
(Not at all; Somewhat; Very; Extremely)
 - Pick top three
 - Anything missing?

Top Three Goals and Concerns for Breast Cancer/Herniated Disc Decisions

Condition: Goal	Patient	Provider	p
Surgery: Keep your breast?	7%	71%	P<0.01
Chemotherapy: Live as long as possible?	59%	96%	P=0.01
Reconstruction: Look natural without clothes	33%	80%	P=0.05
Reconstruction: Avoid using prosthesis	33%	0%	P<0.01
Herniated Disc: Avoid taking medicine	39%	5%	P<0.01



Types of Information Most Important Across a Range of Conditions

Fact	% top 3 Patient	% top 3 Provider	p
About 30 of 100 adults with depression get better without active treatment	23%	0%	P<0.01
Continuing usual activities will not make herniated disc worse	58%	27%	P=0.03
Between 2 and 5 of 100 men will eventually die of prostate cancer	41%	7%	P=0.02
If a PSA test gives a high reading, a prostate biopsy is usually done	59%	21%	P=0.03

So what is the Problem with Delegating Decisions to Physicians?

- The physician is very likely to have different ideas about what is important to the patient than the patient does
- And, currently, the physician is not that likely to ask patients what is important to them

Decision Aids are a Proven Way to Inform and Involve Patients

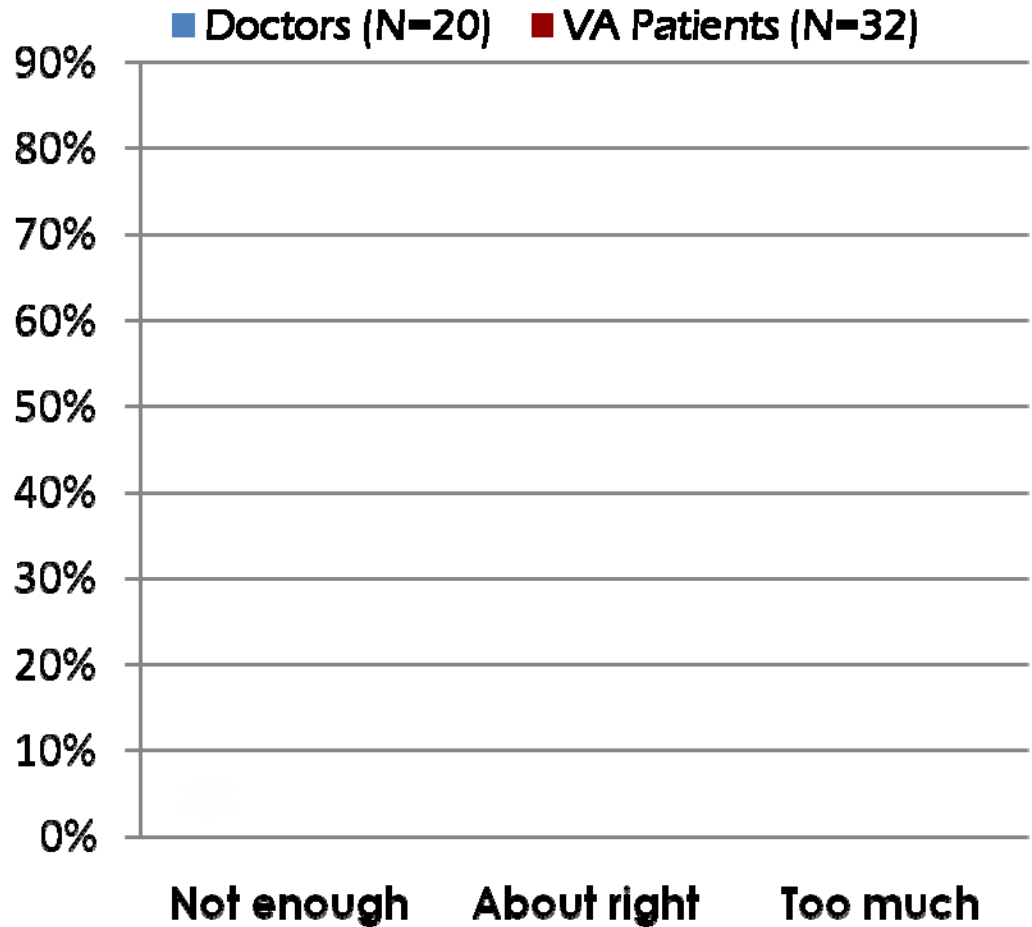
- There are almost 90 randomized trials
- They show clearly that patients seeing well-designed decision aids
 - Know more
 - Participate more in decisions

Two Most Cited Reasons that all Decisions are Not Shared

- Providers can't or won't do it
- Many patients don't want to be informed and share in decisions, or they are unable to

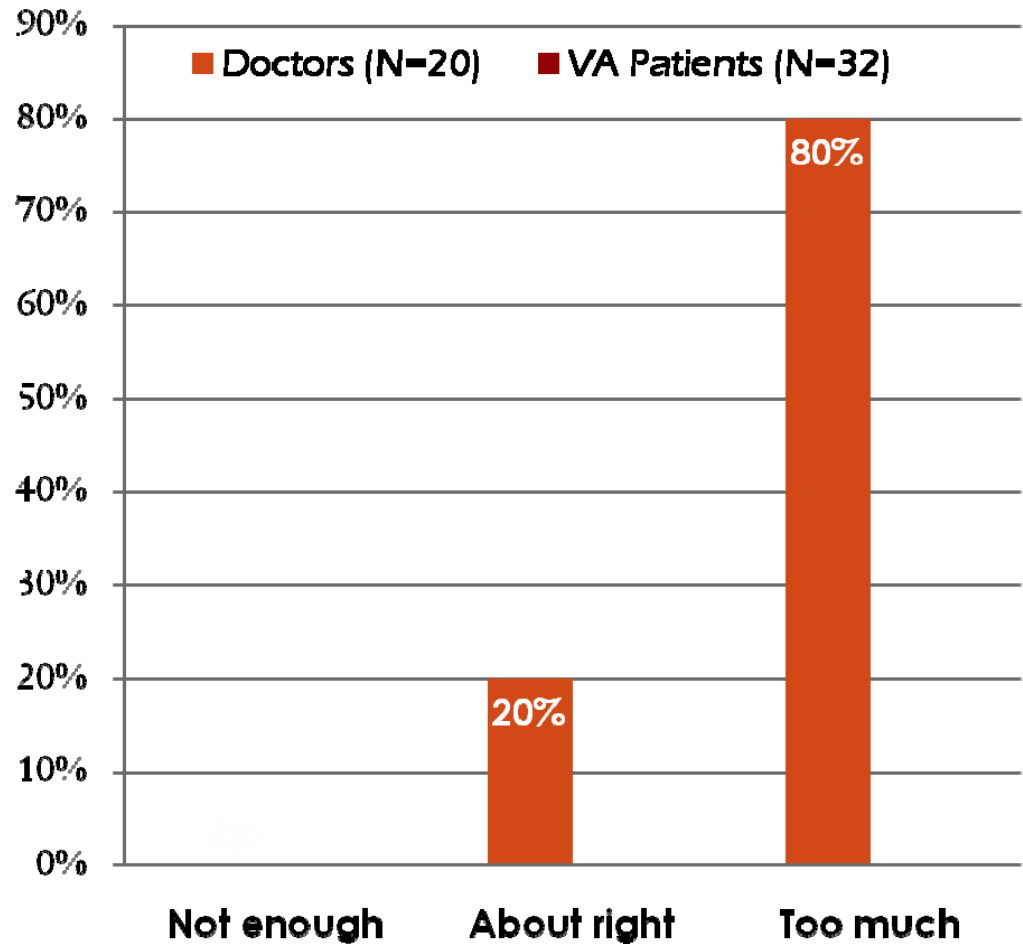
Testing our First 30-Minute BPH Program

How would you rate the
amount of information?



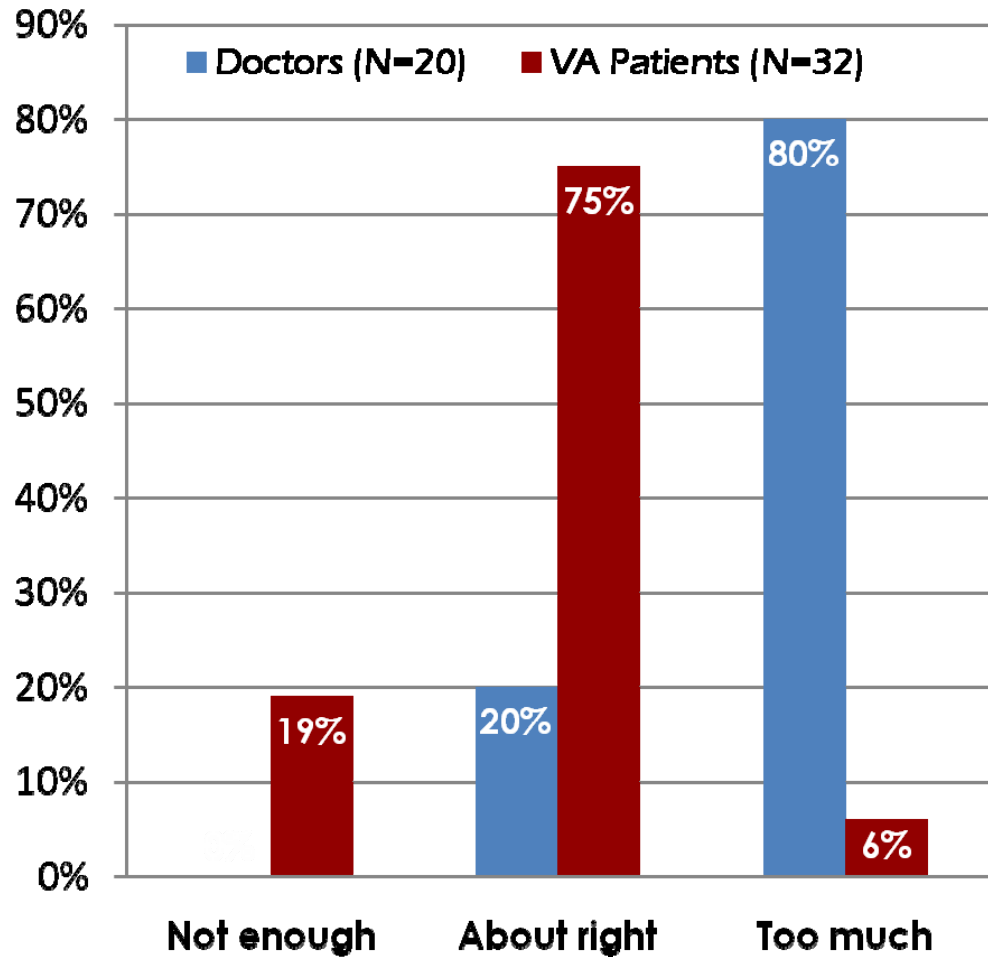
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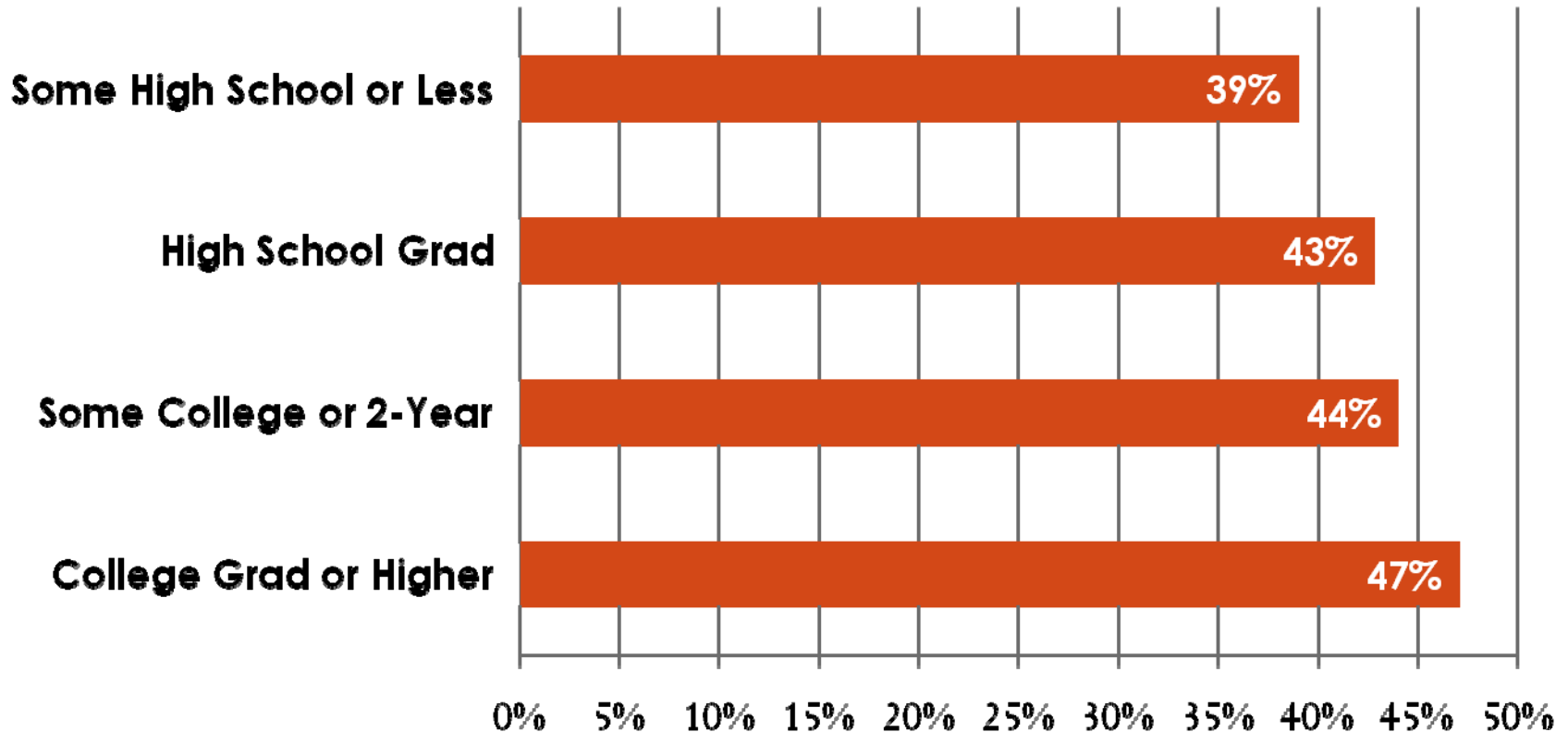
One Universal Truth

- Every time we ask, people (particularly physicians) underestimate how much patients value getting information about their medical conditions and being involved in decisions.

A Particular Concern

- Certain groups can't absorb material—
 - Those over 65
 - Those with less education
 - Those with lower literacy of numeracy skills

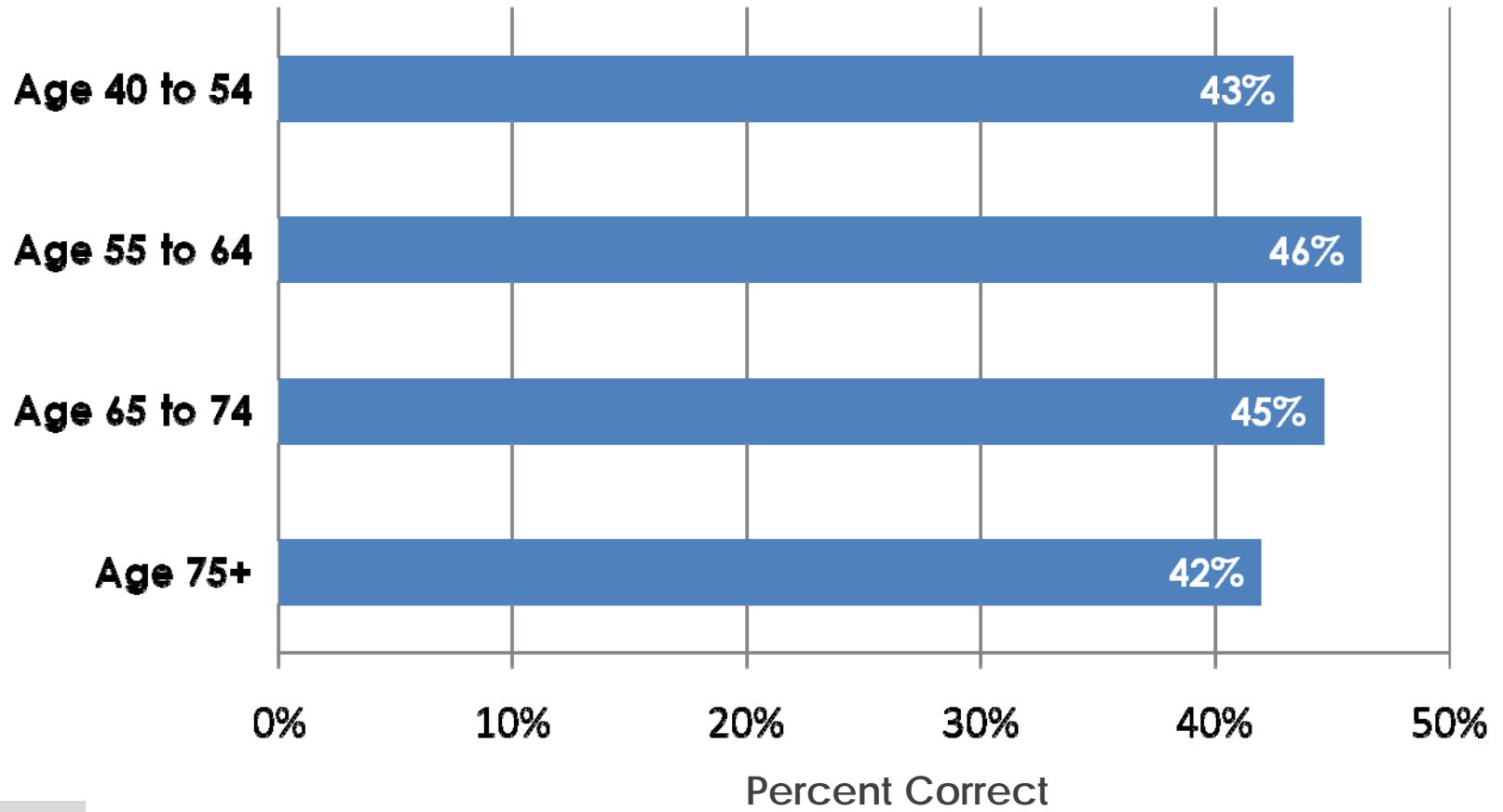
Mean Knowledge Score by Education



N=4935



Mean Knowledge Score by Age



N=4946

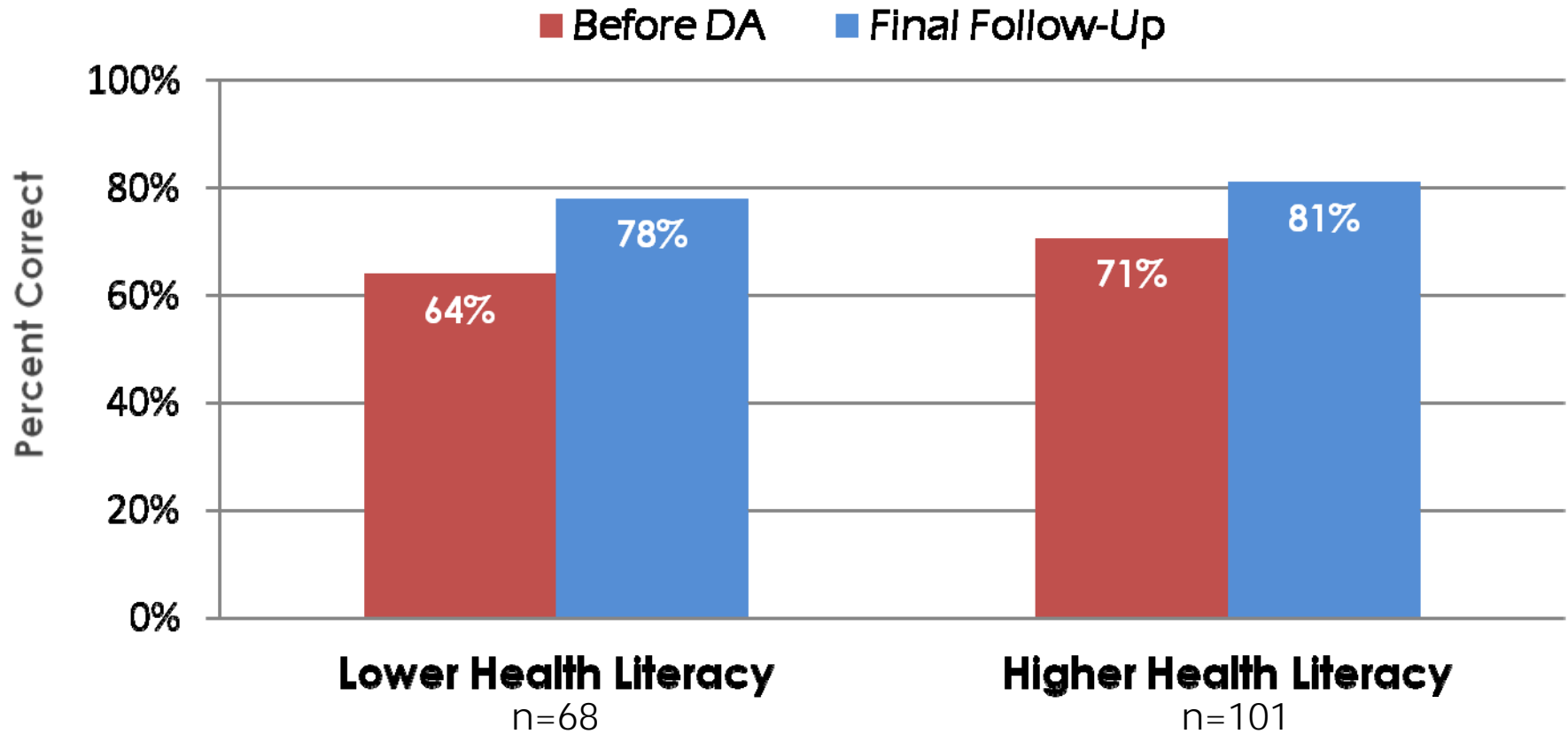
However the evidence is:

- Those with less education and those over 65 do start out with less information and therefore particularly need extra help to understand their options
- However, good decision aids help them as much as anyone – and sometimes more

Eckman Studies Effects of Decision Aid on Managing Heart Disease

- Compared knowledge before and after audio-visual program
- Analysis compared responses of patients with high and low health literacy levels

Mean Cardiac Knowledge Scores by Health Literacy Level



Knowledge Changed, but what about Behavior?

		Higher Health Literacy	Lower Health Literacy
Body Weight	↓	1.7%	2.8%
# of Smokers?	↓	27%	21%
Daily Cigarettes?	↓	23%	46%

Note: Percent of change from Pre-Intervention to Final Follow-up

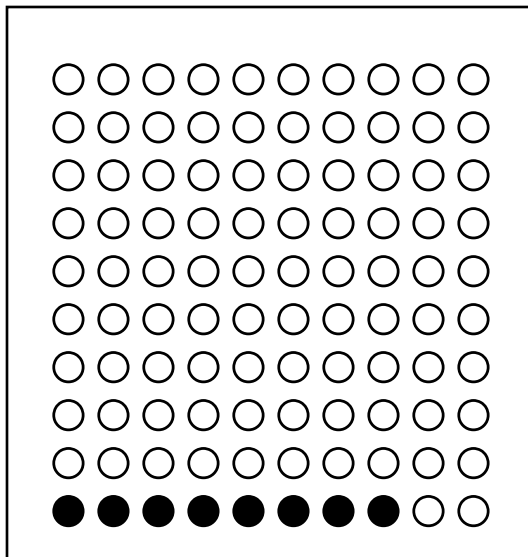
Understanding Risks

- Galesic et al. studied different ways of communicating risk:
 1. Statement of **relative** risk reduction
(“Reduce risk by 13%)
 2. Statement of **absolute** risk reduction
(“8% have stroke without aspirin; 7% with aspirin”)
 3. Add 100-person charts to Statement 2

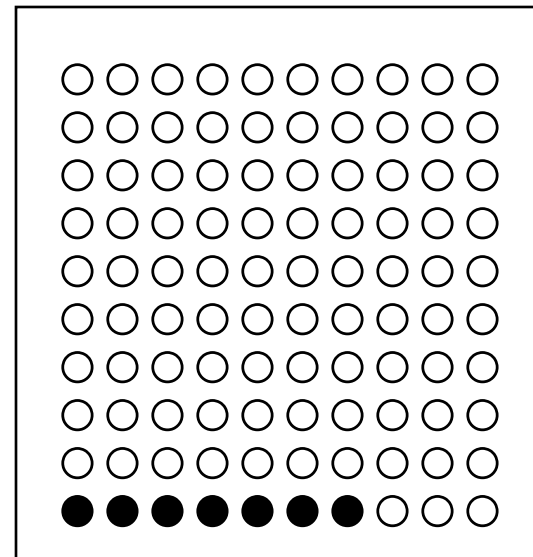
Understanding Risks

3. Add 100- person charts to Statement 2 ("8% have stroke without aspirin; 7% with aspirin")

Without Aspirin



With Aspirin



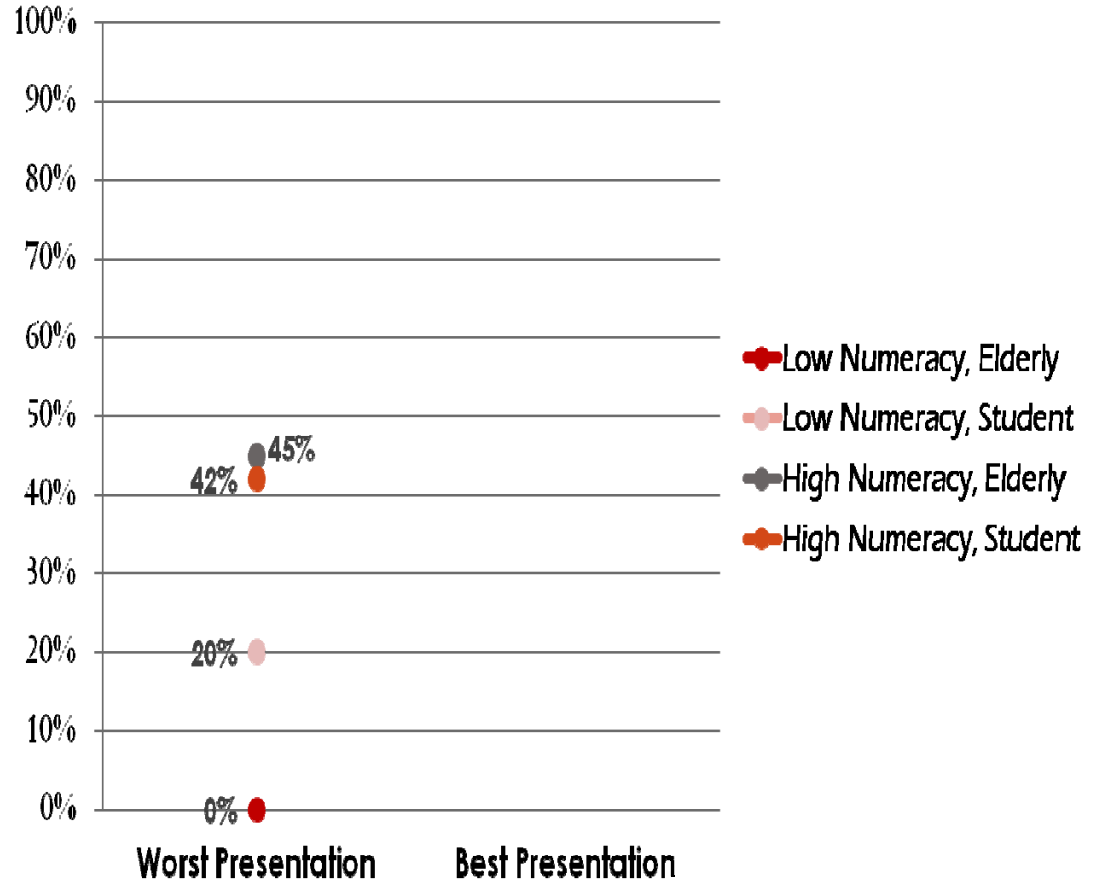
Findings

- Absolute risk statement produced much better understanding of risks than relative risk reduction statement
- The icons added considerably to understanding over just the statement

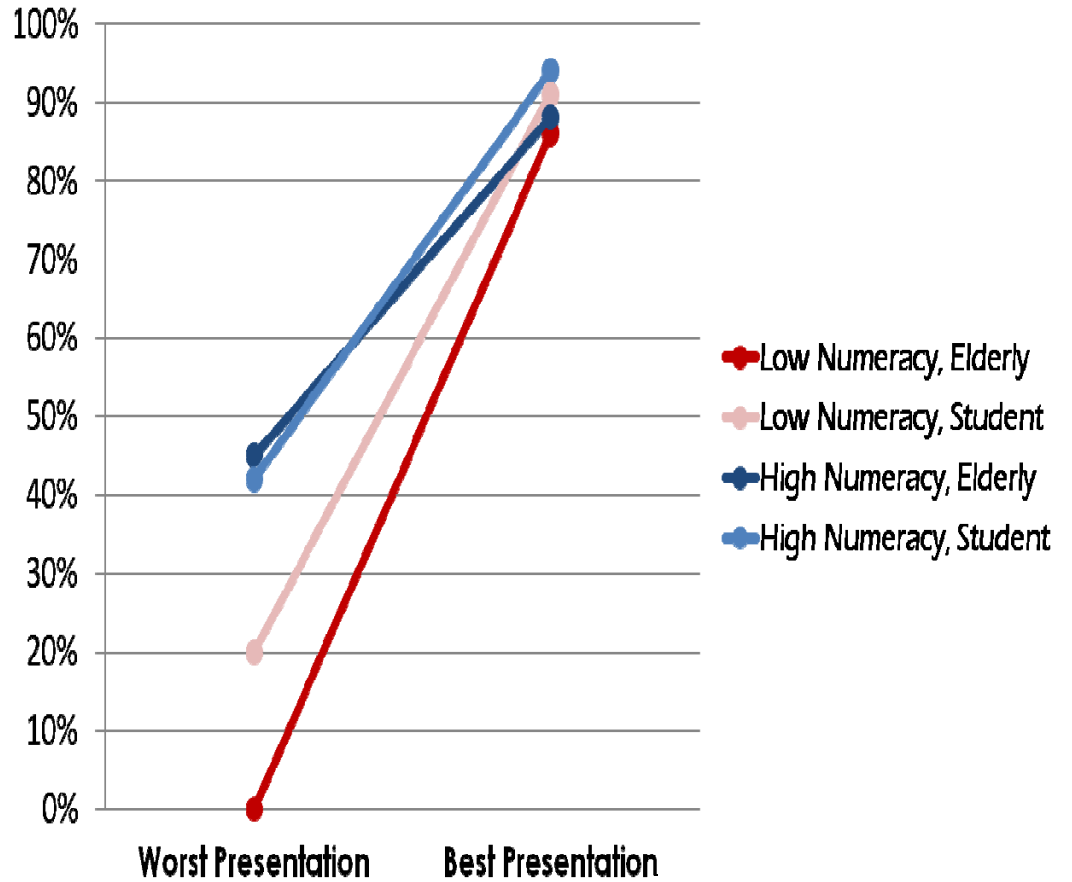
Findings with Respect to Literacy

- Compared understanding of risk reduction for samples of college students and senior citizens recruited from community centers
- Both groups were stratified by score on a numeracy test

Percent of Respondents Who Understood Risk Reduction by Numeracy Level and Quality of Data Presentation



Percent of Respondents Who Understood Risk Reduction by Numeracy Level and Quality of Data Presentation



What about Interest in Sharing Decisions?

- Various surveys have asked questions about interest in sharing, and the results depend heavily on how the question is asked
- The best evidence comes from patients who have actually experienced decision aids and shared decision making

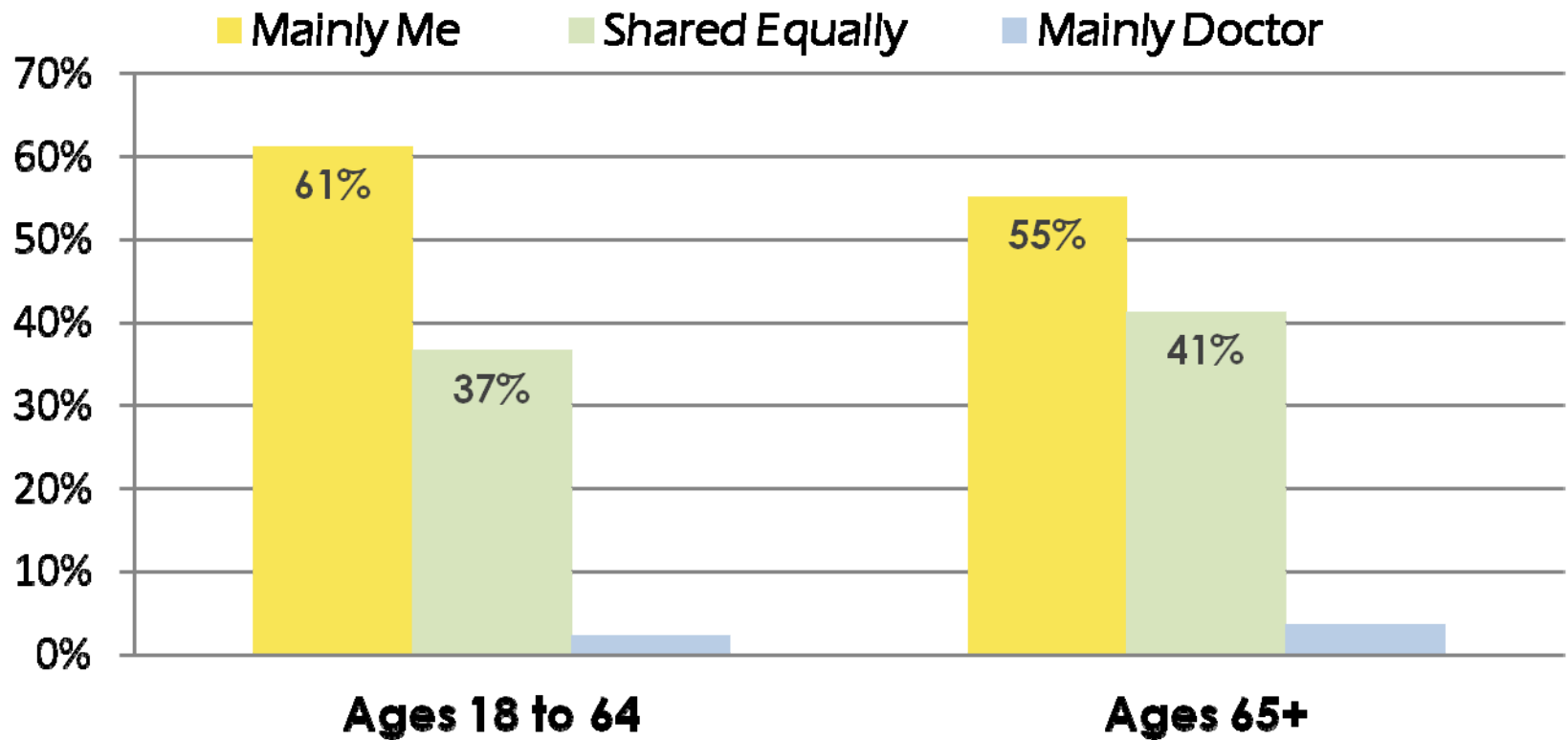
At Dartmouth-Hitchcock

- Patients routinely see decision aids for at least 11 different decisions
- They are surveyed after they see them

Results for those Aged 65+

- Asked who should make the decision:
 - Mainly the doctor
 - Shared equally
 - Mainly the patient

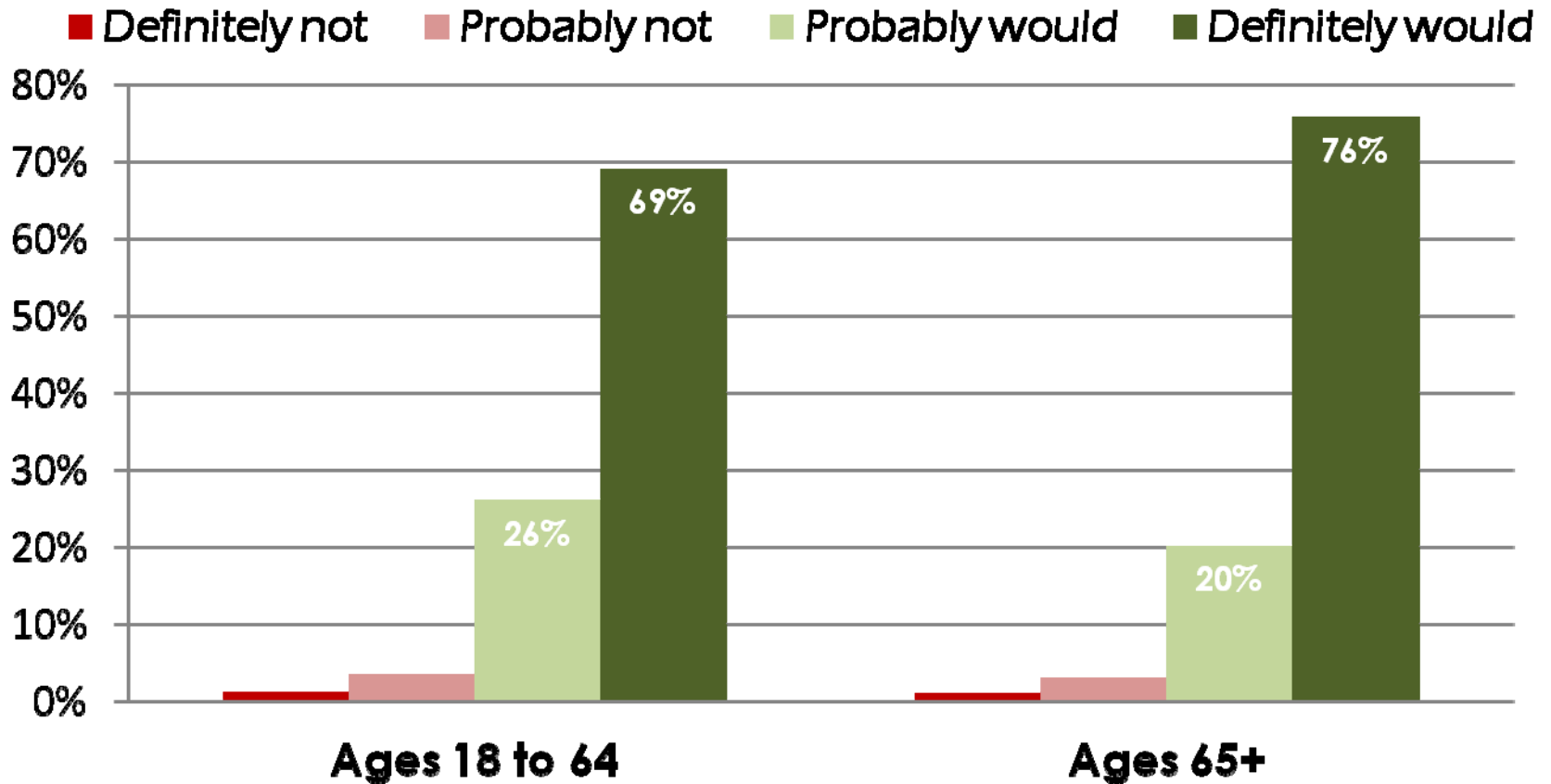
Who Should Make Decisions?



Would patients recommend decision aids to others?

- Definitely
- Probably
- Probably Not
- Definitely Not

Would You Recommend DA for Others



We have Looked Since 1989

- We have never seen evidence that older or less educated people push back against shared decision making when they are given encouragement and decision support

In Conclusion- Why Shared Decision Making?

- I. Informing and involving patients in their medical care is the right thing to do
 - a) Patients have a right to know about the reasonable options and their pros and cons
 - b) They certainly have a right to have a major say in their own medical care

In Conclusion- Why Shared Decision Making?

2. Existence of practice variation (under and over treatment)
 - a) The variation literature clearly shows the effects of physician-driven decision making
 - b) Having patients make informed decisions is the obvious path to the right rate and to allocating treatments to those who will benefit most

In Conclusion- Why Shared Decision Making?

3. Patients benefit from shared decision making and they value it
 - a) Decision aids increase knowledge:
 - i. For virtually all patients
 - ii. Often, particularly for those who start out with the least knowledge
 - b) Virtually all patients give their care high ratings when they are offered decision aids and encouragement to participate in their medical decisions



Our Challenge

- To create environments, support systems and incentives so that informing and involving patients in decision making is the routine standard of care

THANK YOU!