What is Health Literacy and why is it important for Patient-Centered Research?

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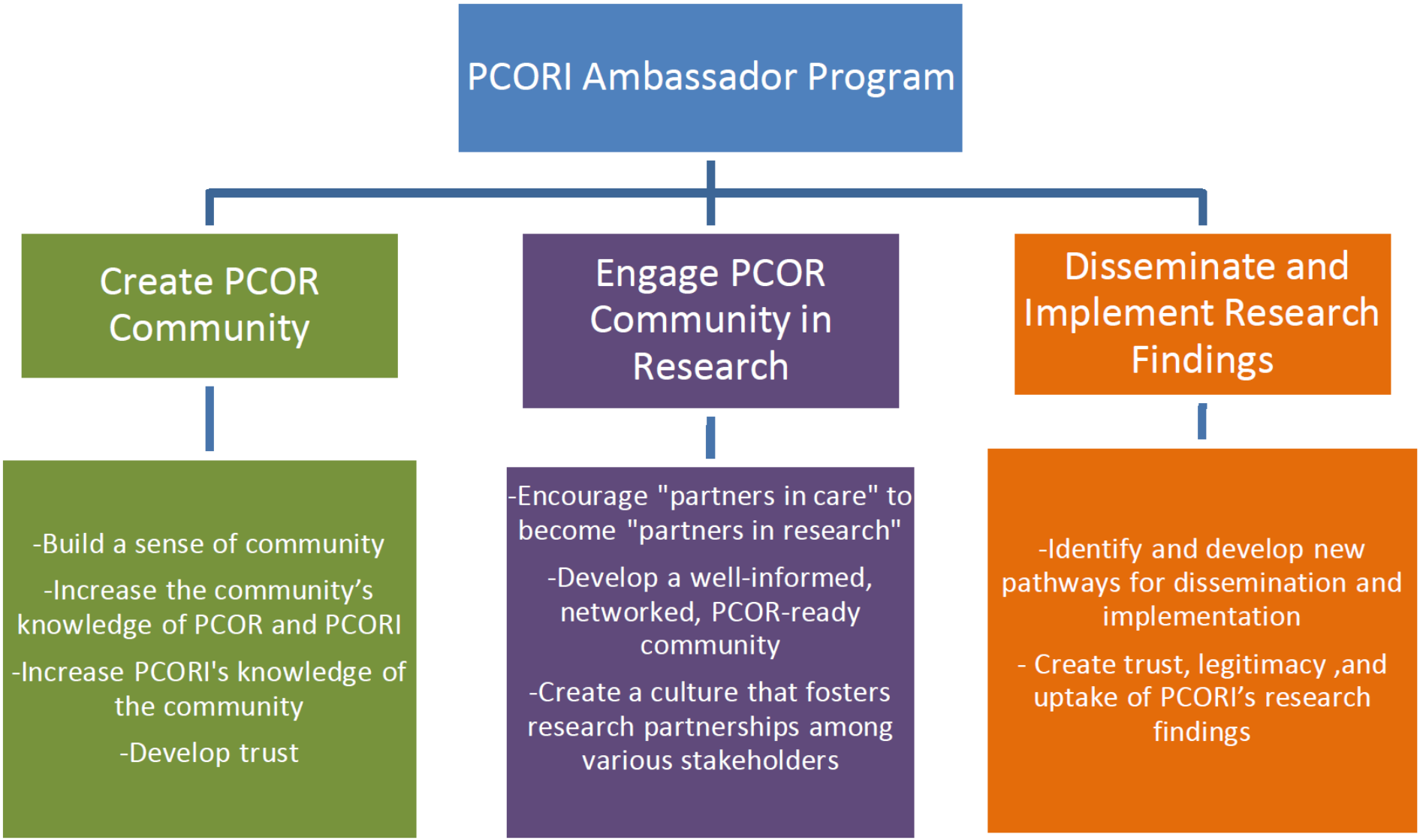
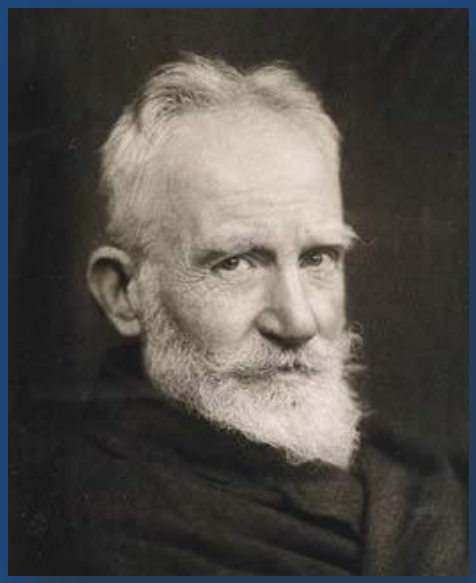
Main Points

- Low health literacy is common
- Don’t assume people will understand
- Health literacy critical to how we delivery health care
- Health literacy critical to using research


PCORI Ambassador Program
Create PCOR Community
-Build a sense of community
-Increase the community's knowledge of PCOR and PCORI
-Increase PCORI's knowledge of the community
-Develop trust
Engage PCOR Community in Research
-Encourage "partners in care" to become "partners in research"
-Develop a well-informed, networked, PCOR-ready community
-Create a culture that fosters research partnerships among various stakeholders
Disseminate and Implement Research Findings
-Identify and develop new pathways for dissemination and implementation
- Create trust, legitimacy ,and uptake of PCORI's research findings

17%-60%



The single biggest problem in communication is the illusion that it has taken place.

- George Bernard Shaw

Health Literacy

"The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."

Healthy People 2010

Key Points To Remember

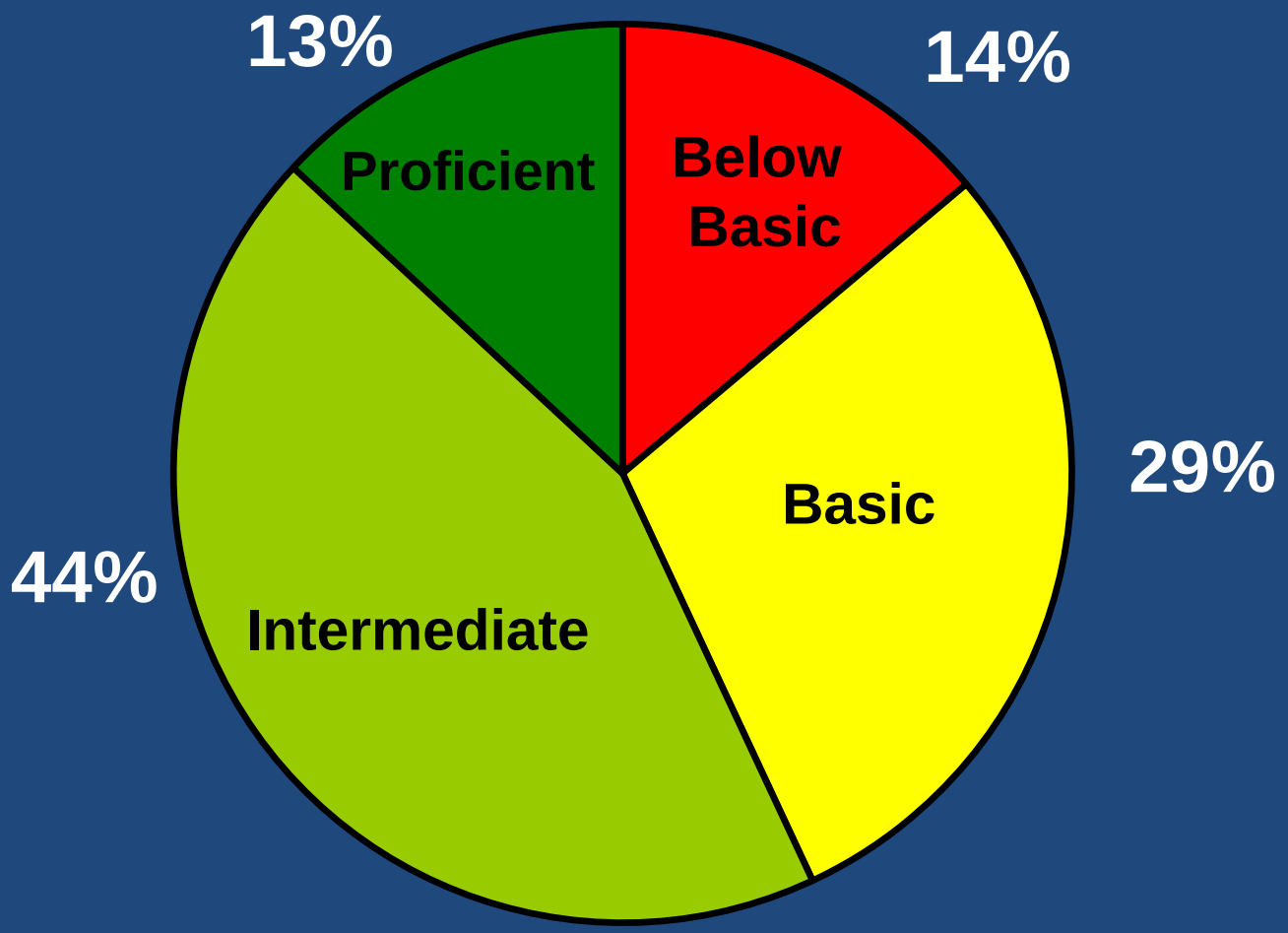
- Healthcare is complex, it is EASY to be confused
- Short term memory is limited
- Use the teach-back
- Mind the jargon
- How we present information matters

National Assessment of Adult Literacy (NAAL)

n = 19,714

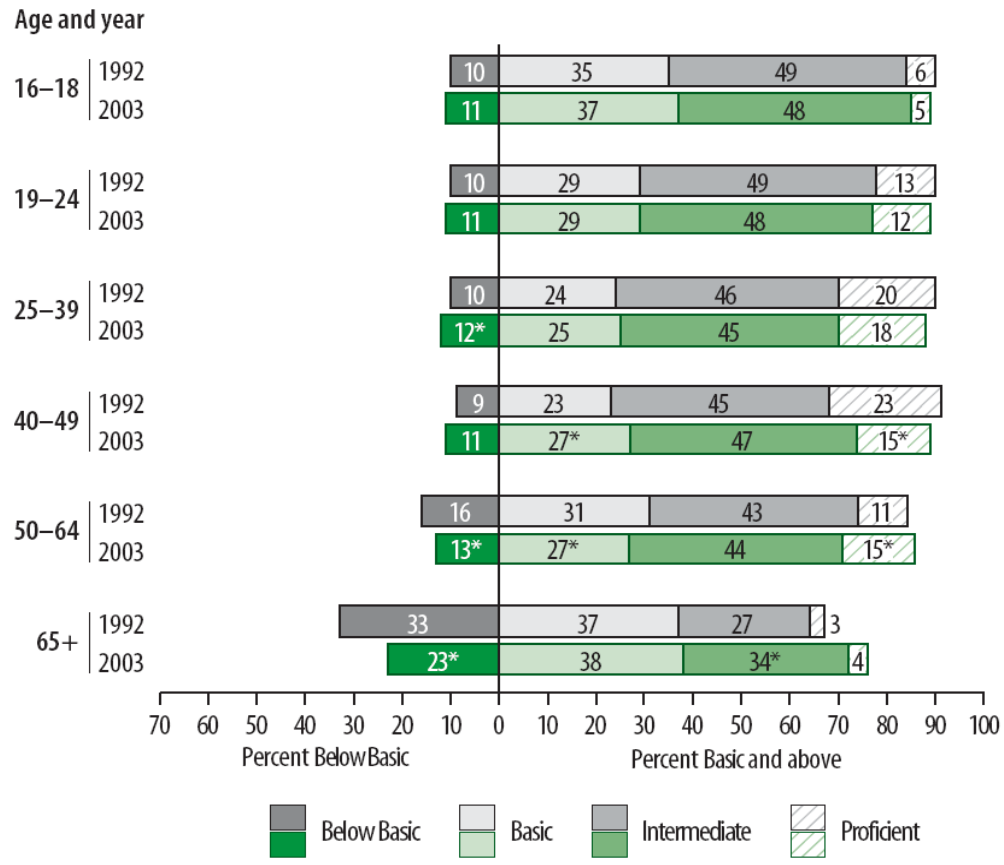
- Most up to date portrait of literacy in U.S.
- Scored on 4 levels
- Lowest 2 levels cannot:
  - Use a bus schedule or bar graph
  - Explain the difference in two types of employee benefits
  - Write a simple letter explaining an error on a bill

2003 National Assessment of Adult Literacy



Literacy and Age

Figure 12. Percentage of adults in each prose literacy level, by age: 1992 and 2003



Literacy and Aging

- Relationship between literacy and cognitive decline is murky
- Word recognition is often used as measure of pre-morbid intelligence
- Reading fluency can slow down with age, but other cognitive function remains good
- Remember that the skills needed to thrive 40 years ago are not the same skills needed now

APRIL 17, 2006

JOE KLEIN: HOW CONSULTANTS RUINED POLITICS

TIME

FLIGHT 93: THE MOVIE
EXCLUSIVE FIRST LOOK

SPECIAL REPORT

DROPOUT NATION

30% of America's high school students will leave without graduating. Here is what one town tells us about the crisis

BY NATHAN THORNBURGH

Christine Harden, 18, of Shelbyville, Ind.

www.time.com AOL Keyword: TIME

Video

It’s hard to be a patient

Health Outcomes Associated with Literacy

Health Outcomes/Health Services

- General health status
- Hospitalization
- Prostate cancer stage
- Depression
- Asthma
- Diabetes control
- HIV control
- Mammography
- Pap smear
- Pneumococcal immunization
- Influenza immunization
- STD screening
- Cost
- Mortality

Behaviors Only

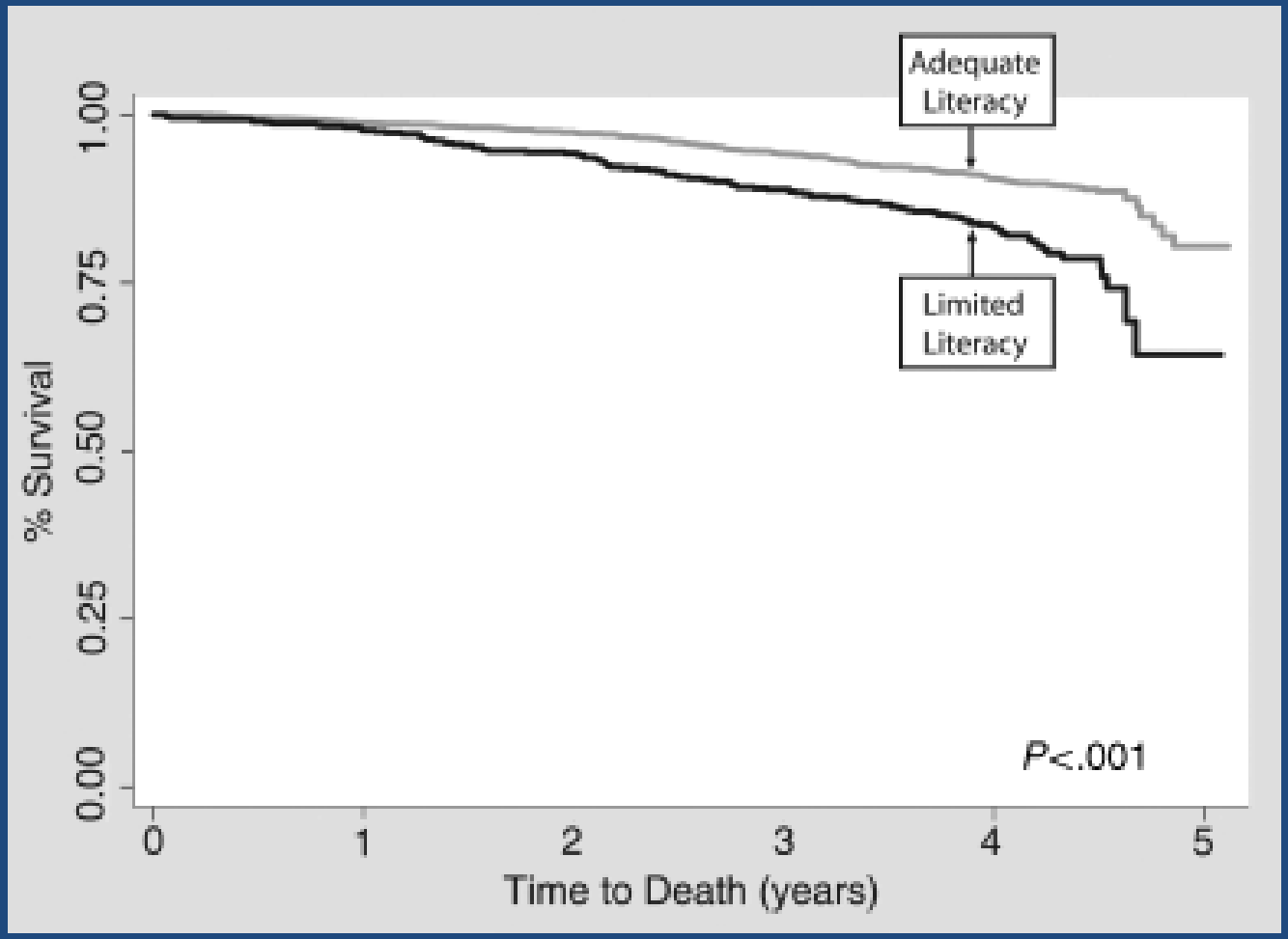
- Substance abuse
- Breastfeeding
- Behavioral problems
- Adherence to medication
- Smoking

Knowledge Only

- Birth control knowledge
- Cervical cancer screening
- Emergency department instructions
- Asthma knowledge
- Hypertension knowledge
- Prescription labels

DeWalt, et al. JGIM 2004;19:1228-1239

Literacy and Mortality



Health, Aging, and Body Composition Study

Sudore et al. JGIM 2006; 21: 806-812

Adult Hospitalization

- People with low literacy have 30-70% increased risk of hospitalization

- RR = 1.29 (1.07-1.55) Medicare Managed Care
- RR = 1.69 (1.13-2.53) Urban Public Hospital

*Adjusted for age, gender, socioeconomic status, health status, and regular source of care.

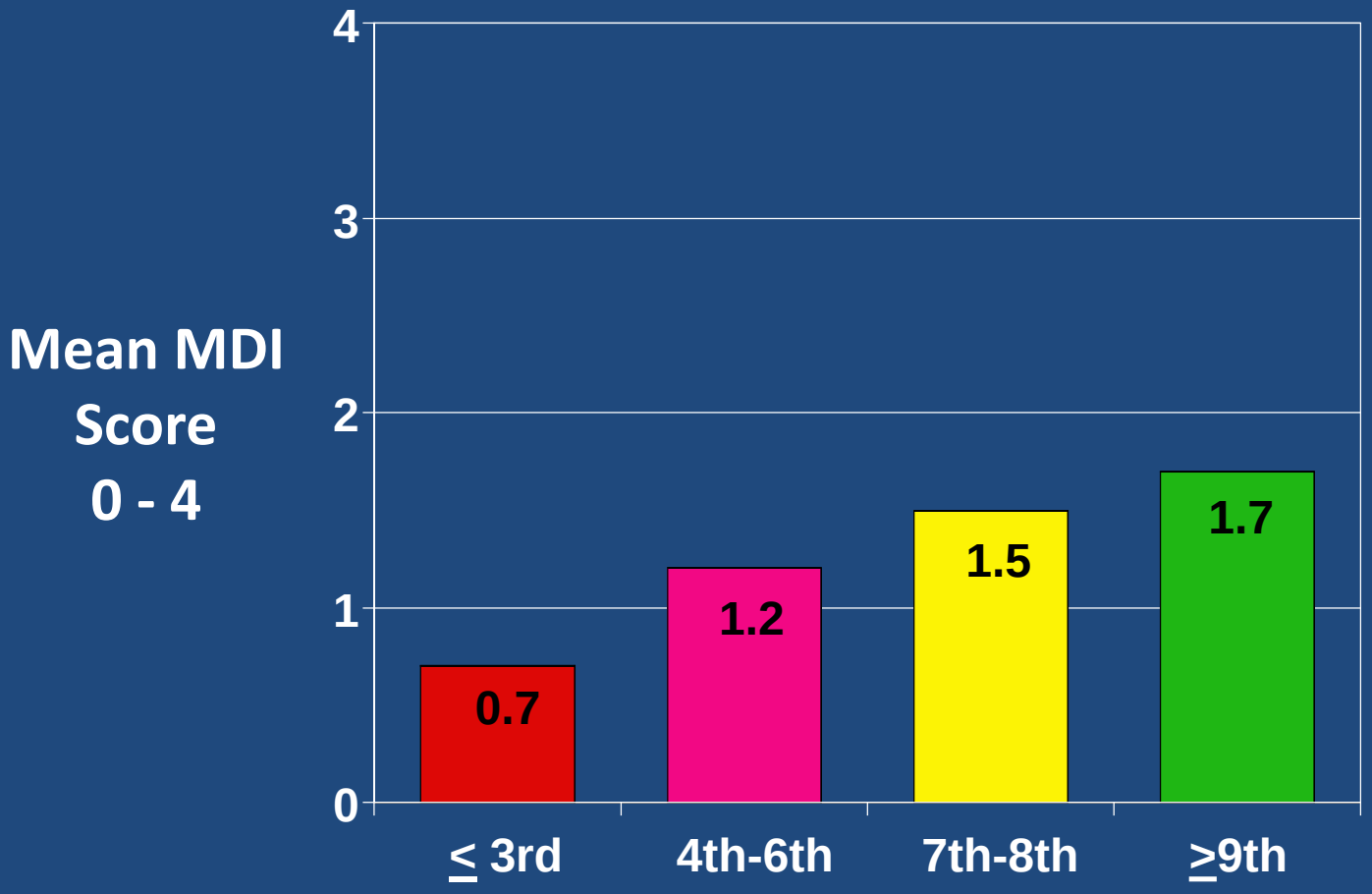
Baker et al. AJPH. 2002. 92:1278. Baker et al. JGIM. 1998. 13:791.

Cognitive Ability in the Hospital

- 50% of hospitalized elders have delirium
- 76% of hospitalized heart failure patients have mild cognitive impairment

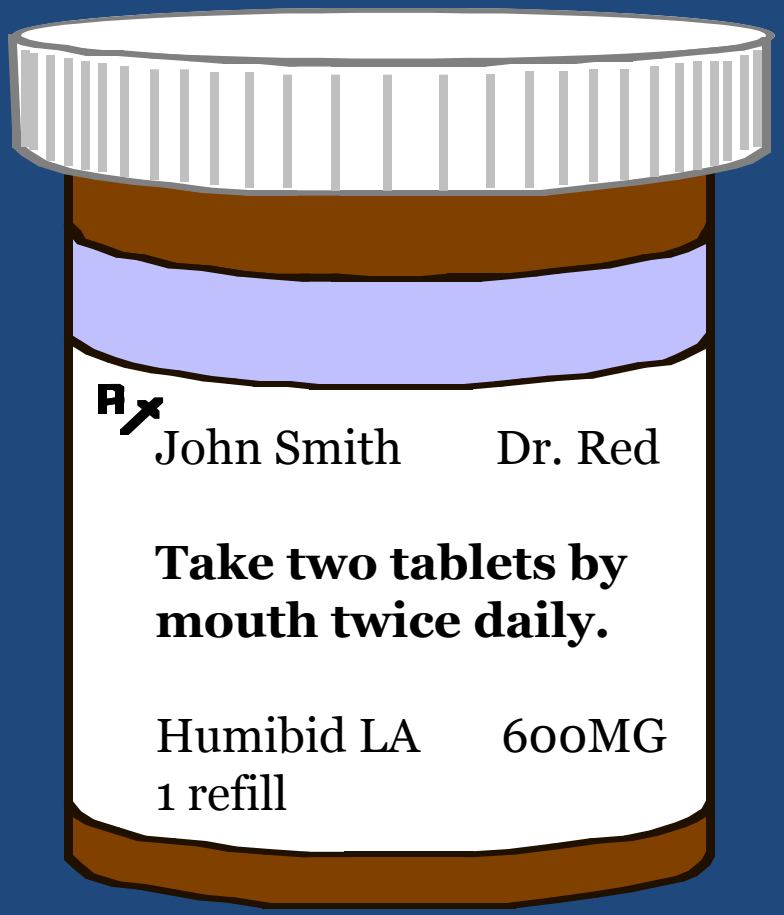
Inouye SK. *N Engl J Med* 2006;354:1157–1165.

Asthma Patients with Low Literacy have Poorer Metered Dose Inhaler (MDI) Skills

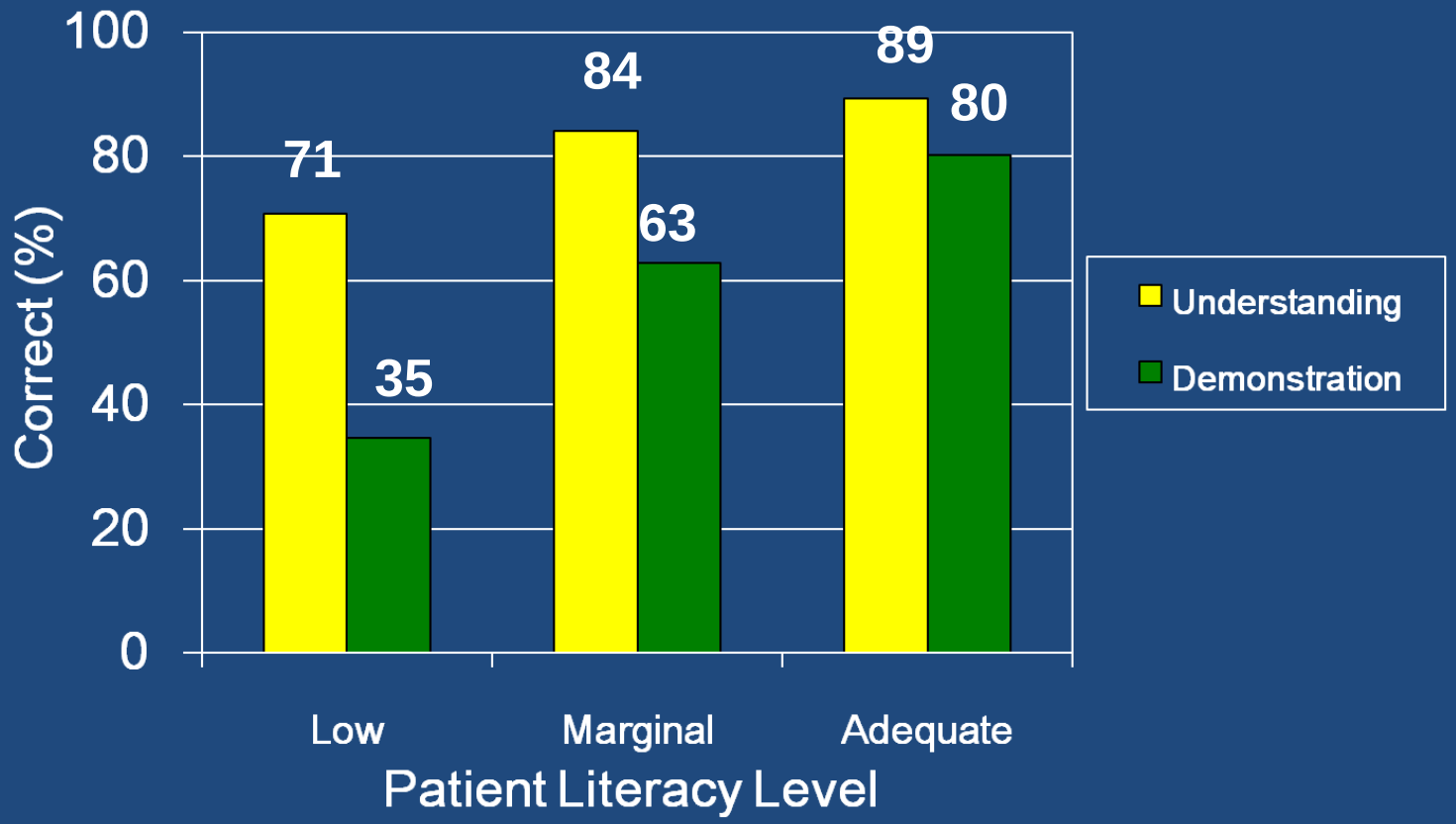


Williams et al. *Chest* 1998, **114**(4):1008-1015.

“Show Me How Many Pills You Would Take in 1 Day”



Rates of Correct Understanding vs. Demonstration "Take Two Tablets by Mouth Twice Daily"



Davis TC et al. Ann Int Med. 2006;145:887-894.

Can Patients Comprehend Rx Drug Warning Labels?

Davis et al. JGIM 2006; 21: 847-851

Simple Familiar Wording Understood by Most Patients

84%

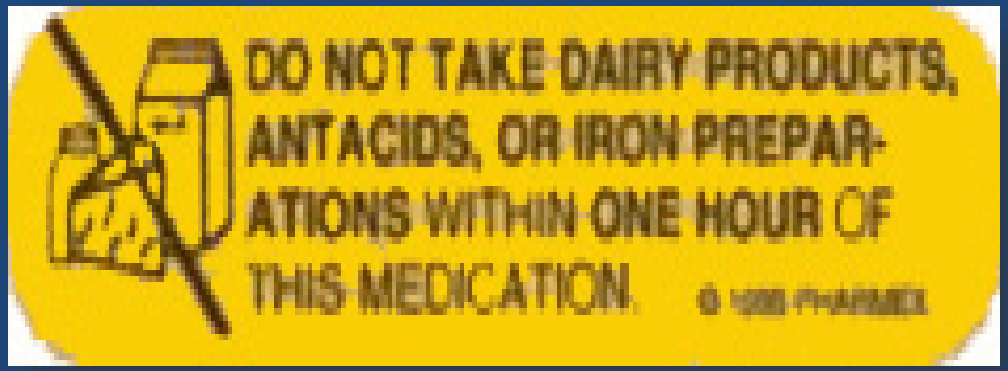
(1st grade.)

More Complex Message Limited Comprehension

59%

(4th grade.)

Unfamiliar Multi-step Instructions Rarely Understood



8%

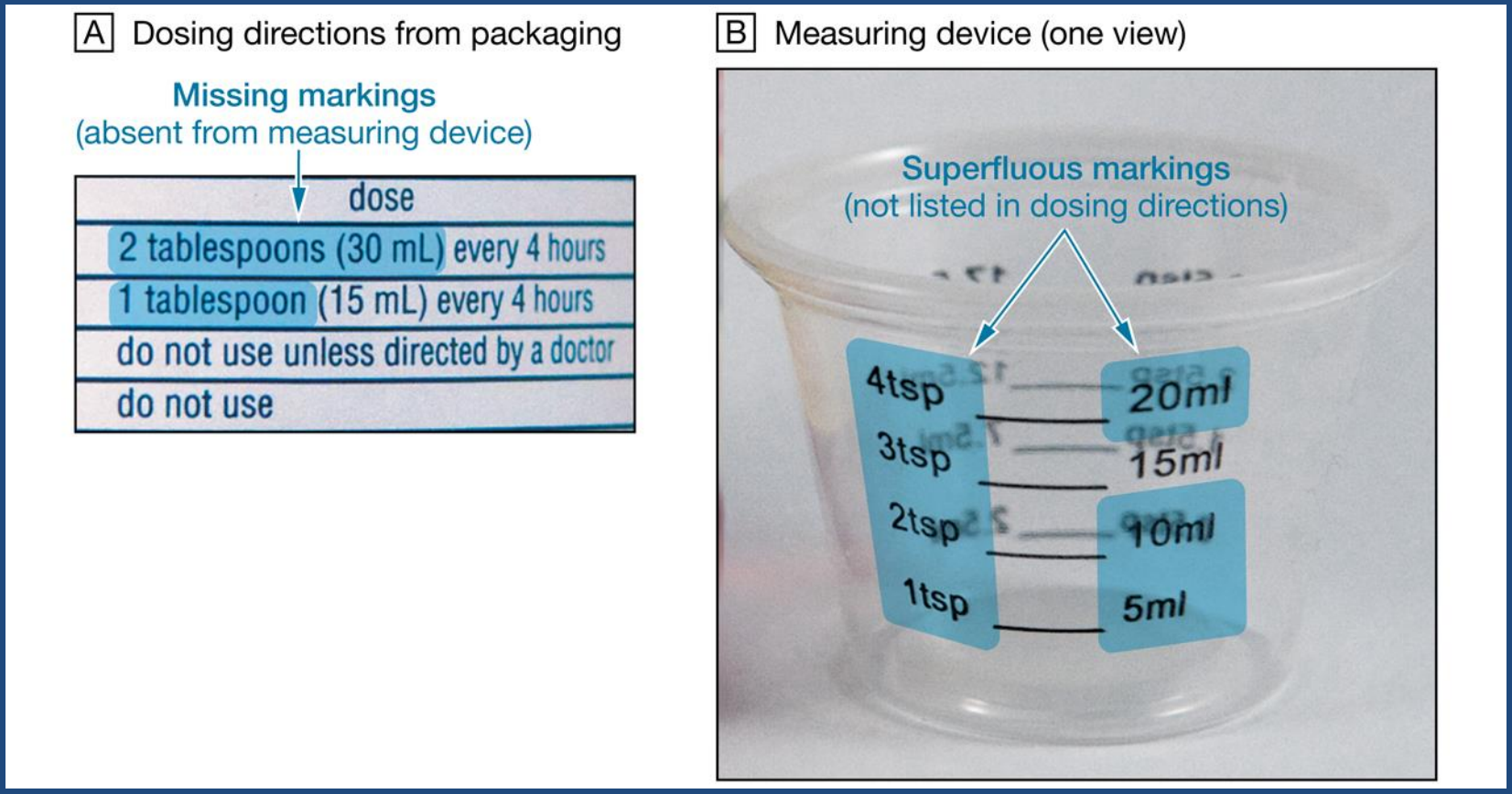
(12th-13th grade)

Visual Aids and Pictures Don’t Stand Alone

What does this mean?

- “Caution: May make you shaky”
- “Caution: May make you glow in the dark”
- “Caution: May make you shrink”

Figure 2. Inconsistencies Between Listed Doses and Markings on Measuring Device

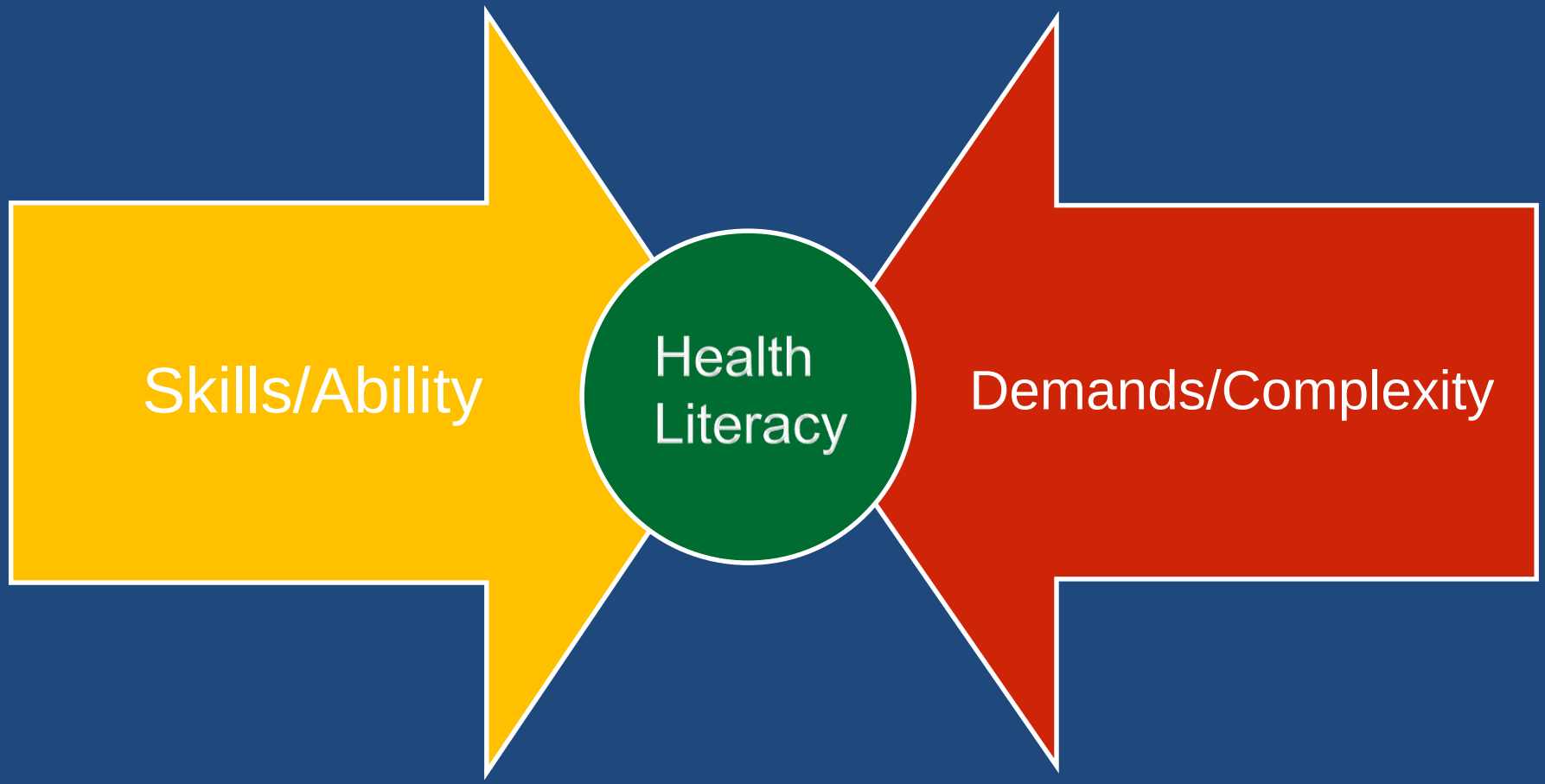


Yin, H. S. et al. JAMA 2010;304:2595-2602

Video

It’s easy to make a mistake

Improve Skills and Reduce Complexity



Slide by Ruth Parker, MD

Important Strategies

- Mind cognitive load
- Use the teach-back
- Mind the jargon

Strategy 1
Mind Cognitive Load
Limit the Number of Teaching Points

Comprehension is complex, how many things can one remember?

- Short-term memory:
  - Limited capacity
    - ‘Magic Number 7, plus or minus 2’?
  - Chunk information to maximize capacity
    - Once at capacity, we dump everything when the next is added
  - Short storage time

Miller, G. A. (1956). "The magical number seven, plus or minus two: Some limits on our capacity for processing information". *Psychological Review* 63 (2): 81-97.
Cowan, N. (2001). The magical number 4 in short-term memory: A reconsideration of mental storage capacity. Behavioral and Brain Sciences, 24, 87-185.
Doak, Doak, Root. 1996.

Example Draft Text—Patient Decision Aid

Men who choose radiotherapy were more likely to feel burning when they urinated, feel like their urine was blocked, or feel urgency to urinate than men who chose surgery or active surveillance. They were also more likely to feel like they needed to have a bowel movement more often, although those effects were uncommon.

• The sense of burning, urgency, or feeling blocked was more likely to improve by two years for men who had radiotherapy from an external beam than for those who had radiation given from pellets placed inside the body (brachytherapy).

• Around two out of ten men who had radiation reported problems having or maintaining an erection, but these problems happened much later than the problems experienced by men who had surgery. Men who had surgery developed sexual problems immediately, while men who had radiation had problems develop over time.

Grade level 14.9

Strategy 2

Teach-back Method

Explain

Assess

Clarify

Understanding

Let’s Practice

- Arrange yourselves in groups of 2
- Take 5 min to try scenario
- One person explains, the other learns
- Teach how to chew nicotine gum

Observations?
Did it seem normal/natural?

Strategy 3

Mind the jargon

Jargon Everywhere

How we present information matters

Table 2
Study 1: Unordered—Both Quality and Nonquality Hospital Information Is Presented Unordered

Indicators	Hospital X	Hospital Y	Hospital Z
Your out-of-pocket costs	$	$$$	$$
No. of general care beds	550	231	180
			2.0
			87%
			78%
			8
			29
			Limited
			Limited

1. Which hospital is most expensive for you?
2. Which hospital is most likely to follow the guidelines for heart attack care?
3. Which hospital has the least registered nurses per 100 patients?

Table 3
Study 1: Quality and Cost Only—Hospital Information Includes Quality Information Only and Is Highlighted

Measures	Hospital X	Hospital Y	Hospital Z
Your out-of-pocket costs	$	$$$	$$
No. of registered nurses per 100 patients	18	38	29
Has computer system to prevent medication errors	No	Yes	Limited
% of time guidelines for heart attack care are followed	82%	92%	87%
% of time guidelines for pneumonia care are followed	60%	89%	78%

Peters et al. Medical Care Research and Review. 2007.

Figure 1
Study 1. Mean Comprehension by Presentation Format and Numeracy

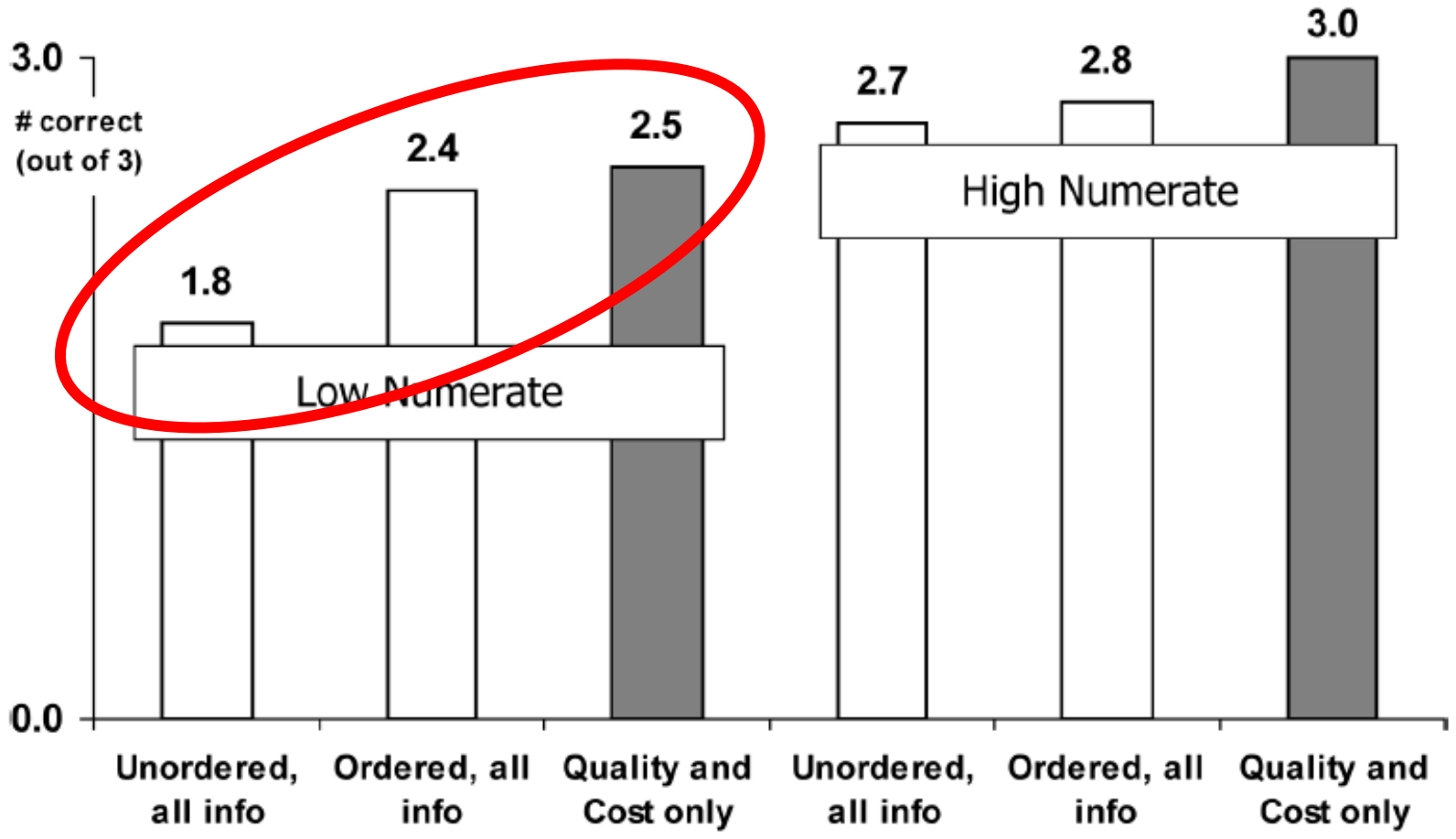


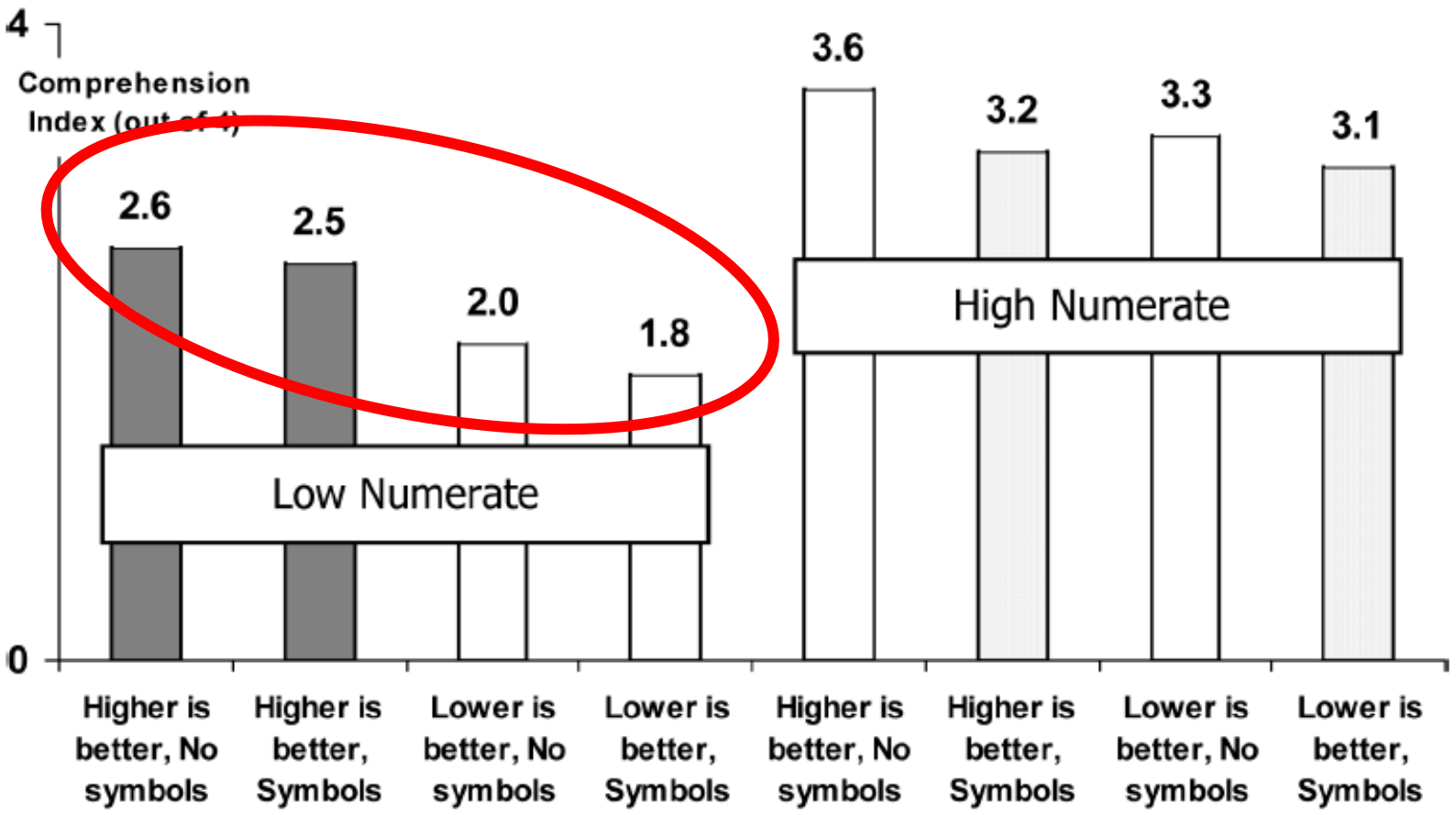
Table 5
Study 3: Patient-to-Nurse Ratio Is Presented as "Higher Is Better" with Easier-to-Evaluate Symbols

	No. of Registered Nurses per 100 Patients		Your Out-of-Pocket Cost
Hospital A	38	⊕	$$$
Hospital B	36	⊕	$$$$
Hospital C	32	⊕	$$$$
Hospital L	23	◯	$$$$
Hospital M	26	◯	$
Hospital N	24	◯	$$$
Hospital O	17	⊖	$$

Note: ⊕ = more registered nurses per 100 patients; ◯ = average number of registered nurses per 100 patients; ⊖ = fewer registered nurses per 100 patients.

1. Which hospital has the highest death rate for patients being treated for heart failure?
2. Which hospital has the lowest patient satisfaction with the hospital?
3. If you need to go to the hospital, is it better to choose one with a low number for its death rate or a high number?
4. If you need to go to the hospital, is it better to choose one with a low number for patient satisfaction or a high number?

Figure 4
Study 3. Mean Comprehension by Presentation Format and Numeracy



Tell me about your role

- How does health literacy cross paths with your goals as PCORI Ambassadors?
  - Research participation?
  - Informed consent?
  - Effectiveness of studies interventions?
  - Communication about results?

How can you incorporate HL into your work as an ambassador?

- Visit with another partner (someone different from prior exercise)
- Come up with 3 ways you can incorporate HL
- Take 5 minutes
- You will report out at the end.

Summary

- Healthcare is complex, it is EASY to be confused
- Health literacy issues permeate all aspects of medical care and research
- We present information in confusing ways
- We can help people understand