

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

Darren A. DeWalt, MD, MPH

Chief, Division of General Medicine and Clinical Epidemiology

University of North Carolina

Introductions

- Name
- Why are you a patient ambassador?
- What do you hope to accomplish at HARC?
- One thing you hope to get out of this session

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

PCORI Ambassador Program

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graph TD; A[PCORI Ambassador Program] --> B[Create PCOR Community]; A --> C[Engage PCOR Community in Research]; A --> D[Disseminate and Implement Research Findings]; B --> B1[-Build a sense of community]; B --> B2[-Increase the community's knowledge of PCOR and PCORI]; B --> B3[-Increase PCORI's knowledge of the community]; B --> B4[-Develop trust]; C --> C1[-Encourage "partners in care" to become "partners in research"]]; C --> C2[-Develop a well-informed, networked, PCOR-ready community]; C --> C3[-Create a culture that fosters research partnerships among various stakeholders]; D --> D1[-Identify and develop new pathways for dissemination and implementation]; D --> D2[-Create trust, legitimacy, and uptake of PCORI's research findings];
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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

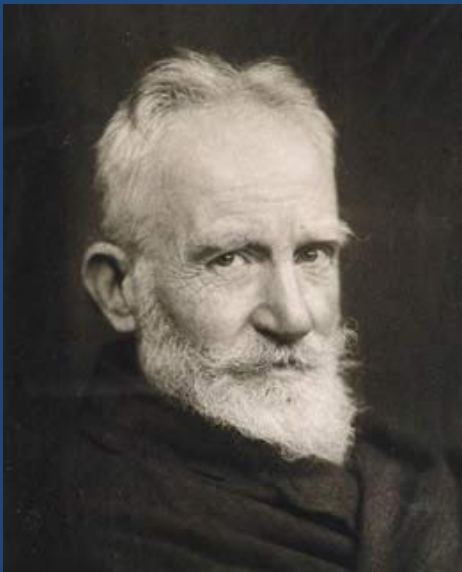
Disseminate and Implement Research Findings

- Identify and develop new pathways for dissemination and implementation
- Create trust, legitimacy, and uptake of PCORI's research findings

Answers to the Survey

- Understand role in conference
- Meet others
- Understand health literacy from professional or research point of view
- What populations are most at risk
- What strategies can help people understand medical stuff

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

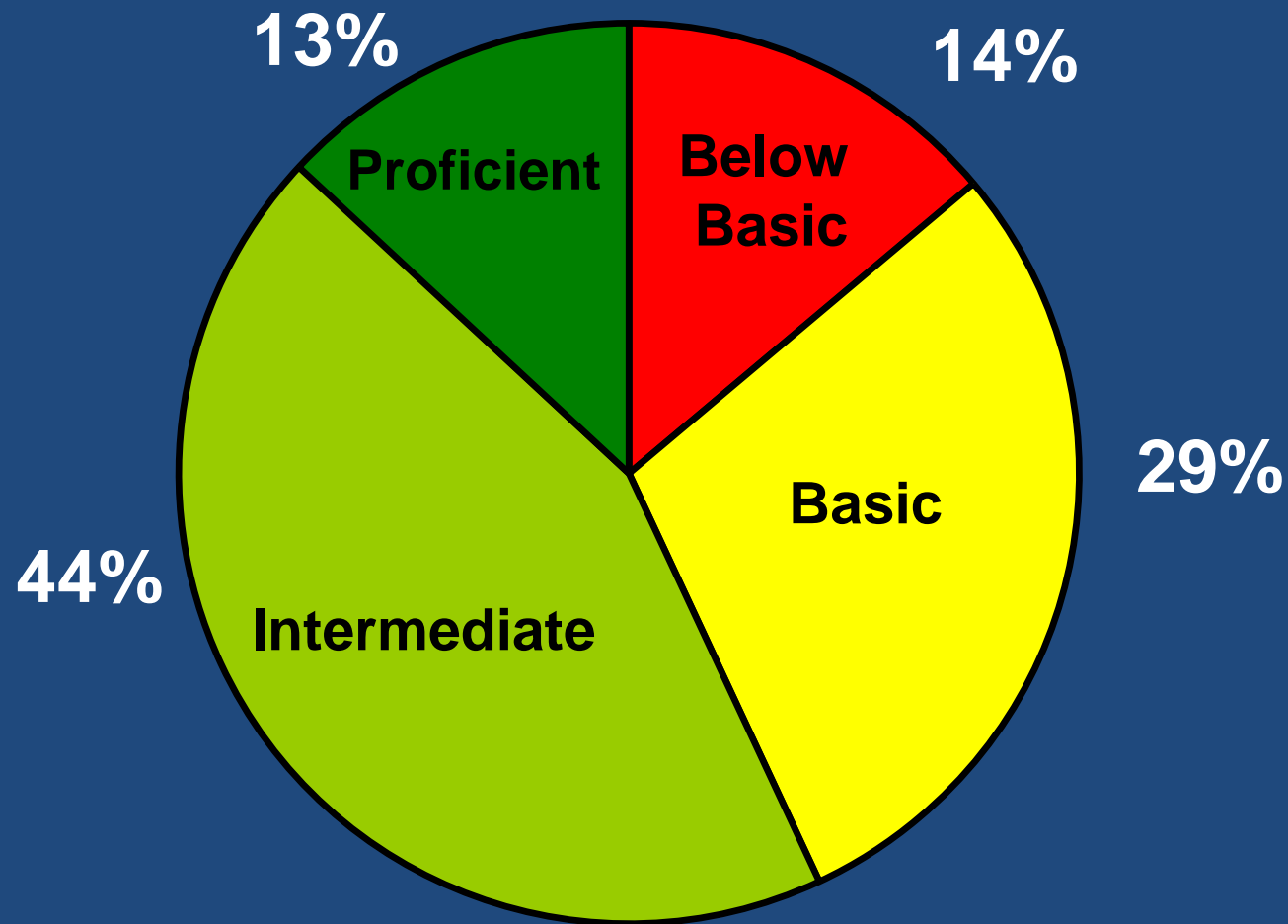
- Healthcare is complex, it is EASY to be confused
- Short term memory is limited
- Use the teach-back
- Mind the jargon
- How we present information matters

National Assessment of Adult Literacy (NAAL)

n = 19,714

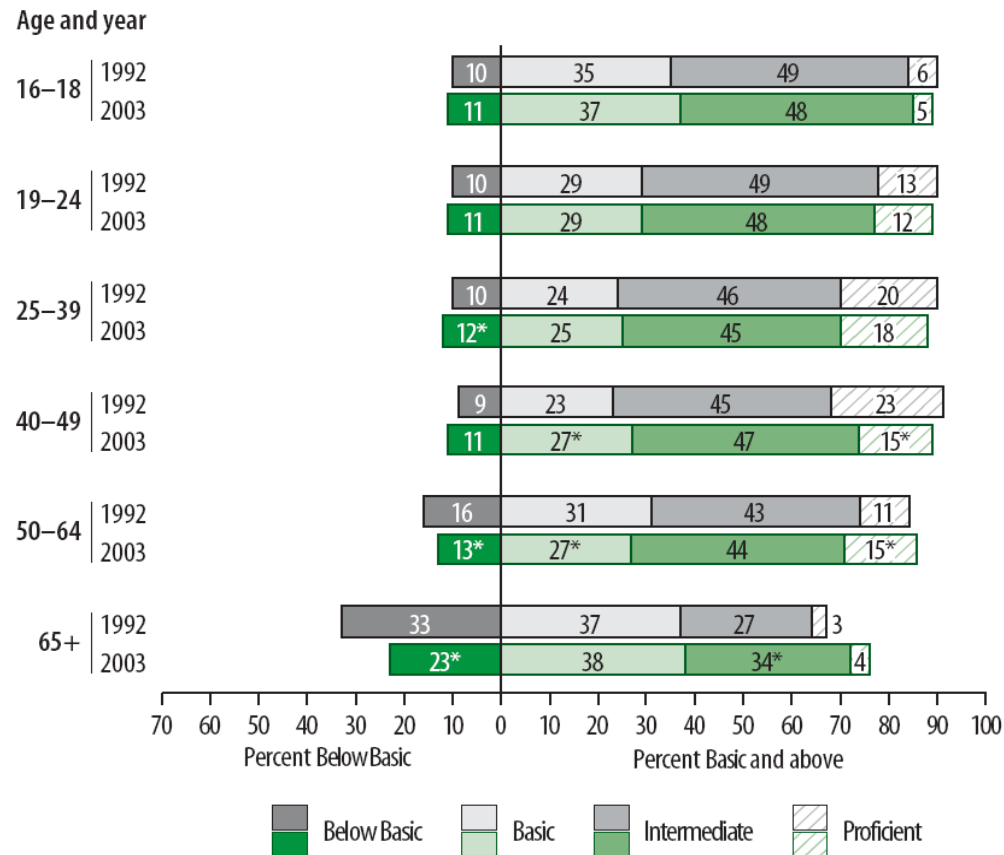
- Most up to date portrait of literacy in U.S.
- Scored on 4 levels
- Lowest 2 levels cannot:
 - Use a bus schedule or bar graph
 - Explain the difference in two types of employee benefits
 - Write a simple letter explaining an error on a bill

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

What Populations are Most at Risk?

- Elderly
- Poor
- Did not graduate high school
- Some racial and ethnic groups, but may be more related to socioeconomic status

Figure 11. Average prose, document, and quantitative literacy scores of adults, by age: 1992 and 2003

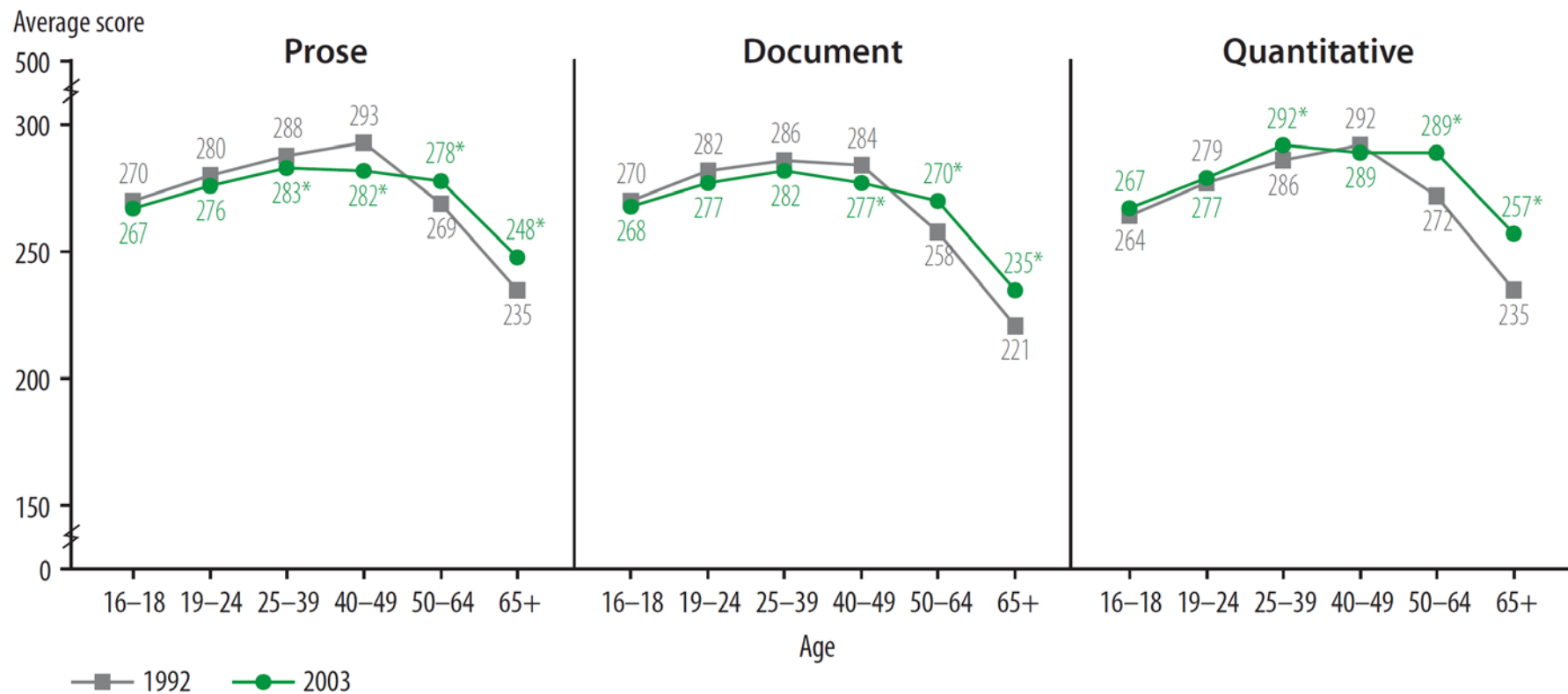


Figure 8. Percentage of adults in each prose literacy level, by race/ethnicity: 1992 and 2003

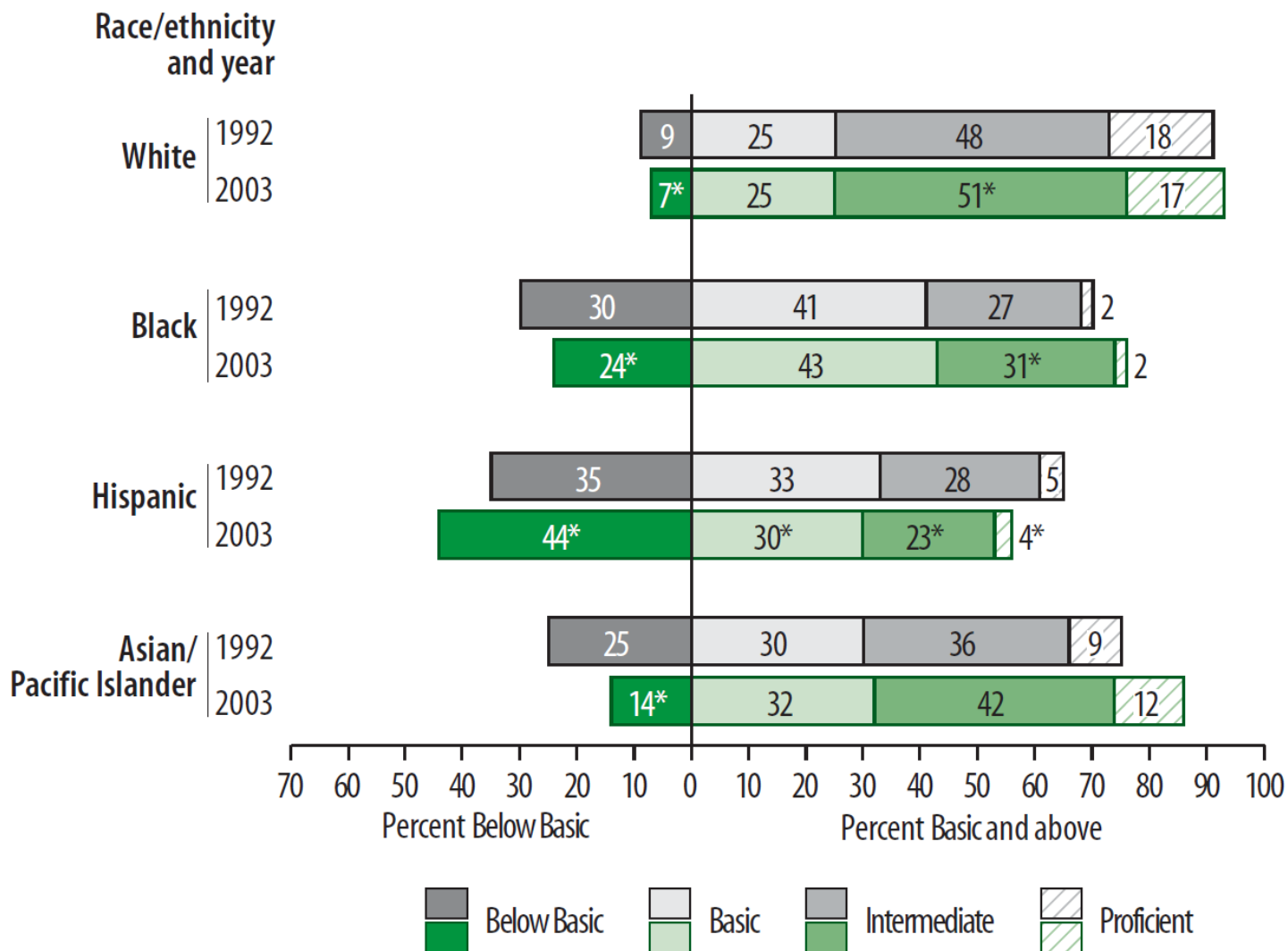


Table 7. Average prose, document, and quantitative literacy scores of adults, by educational attainment: 1992 and 2003

Literacy scale and educational attainment	1992	2003
Prose		
Still in high school	268	262
Less than/some high school	216	207*
GED/high school equivalency	265	260
High school graduate	268	262*
Vocational/trade/business school	278	268*
Some college	292	287*
Associate's/2-year degree	306	298*
College graduate	325	314*
Graduate studies/degree	340	327*

Nutrition Facts

Serving Size $\frac{1}{2}$ cup
Servings per container 4

Amount per serving

Calories 250 Fat Cal 120

%DV

Total Fat 13g 20%

Sat Fat 9g 40%

Cholesterol 28mg 12%

Sodium 55mg 2%

Total Carbohydrate 30g 12%

Dietary Fiber 2g

Sugars 23g

Protein 4g 8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

READ TO SUBJECT:

This information is on the back of a container of a pint of ice cream.

1. If you eat the entire container, how many calories will you eat?

Answer: 1,000 is the only correct answer

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?

Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl?"

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

Answer: 33 is the only correct answer

4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?

Answer: 10% is the only correct answer

READ TO SUBJECT:

Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?

Answer: No

6. (Ask only if the patient responds "no" to question 5): Why not?

Answer: Because it has peanut oil.

Sample TOFHLA

Reading Comprehension

Your doctor has sent you to have a _____ X-ray.

- a. stomach
- b. diabetes
- c. stitches
- d. germs

You must have an _____ stomach when you come in for ____.

- a. asthma
- b. empty
- c. incest
- d. anemia

- a. is
- b. am
- c. if
- d. it

REALM

Prevention & Patient
Education Project
Terry Davis, PhD
P.O. box 33932
Box 598
Shreveport, LA 71130-3932

fat
flu
pill
dose
eye
stress
smear
nerves
germs
meals
disease
cancer
caffeine
attack
kidney
hormones
herpes
seizure
bowel
asthma
rectal
incest

fatigue
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infection
exercise
behavior
prescription
notify
gallbladder
calories
depression
miscarriage
pregnancy
arthritis
nutrition
menopause
appendix
abnormal
syphilis
hemorrhoids
nausea
directed

allergic
menstrual
testicle
colitis
emergency
medication
occupation
sexually
alcoholism
irritation
constipation
gonorrhea
inflammatory
diabetes
hepatitis
antibiotics
diagnosis
potassium
anemia
obesity
osteoporosis
impetigo

Is Health Literacy an Exposure or Outcome?

- Studies to date use it as an exposure variable
 - Assumed relatively stable
 - Interventions are not targeted to improve scores on these instruments
- No published longitudinal studies of improvement or decline in these measures
- How would you design a study to improve scores? (enroll in literacy programs)



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

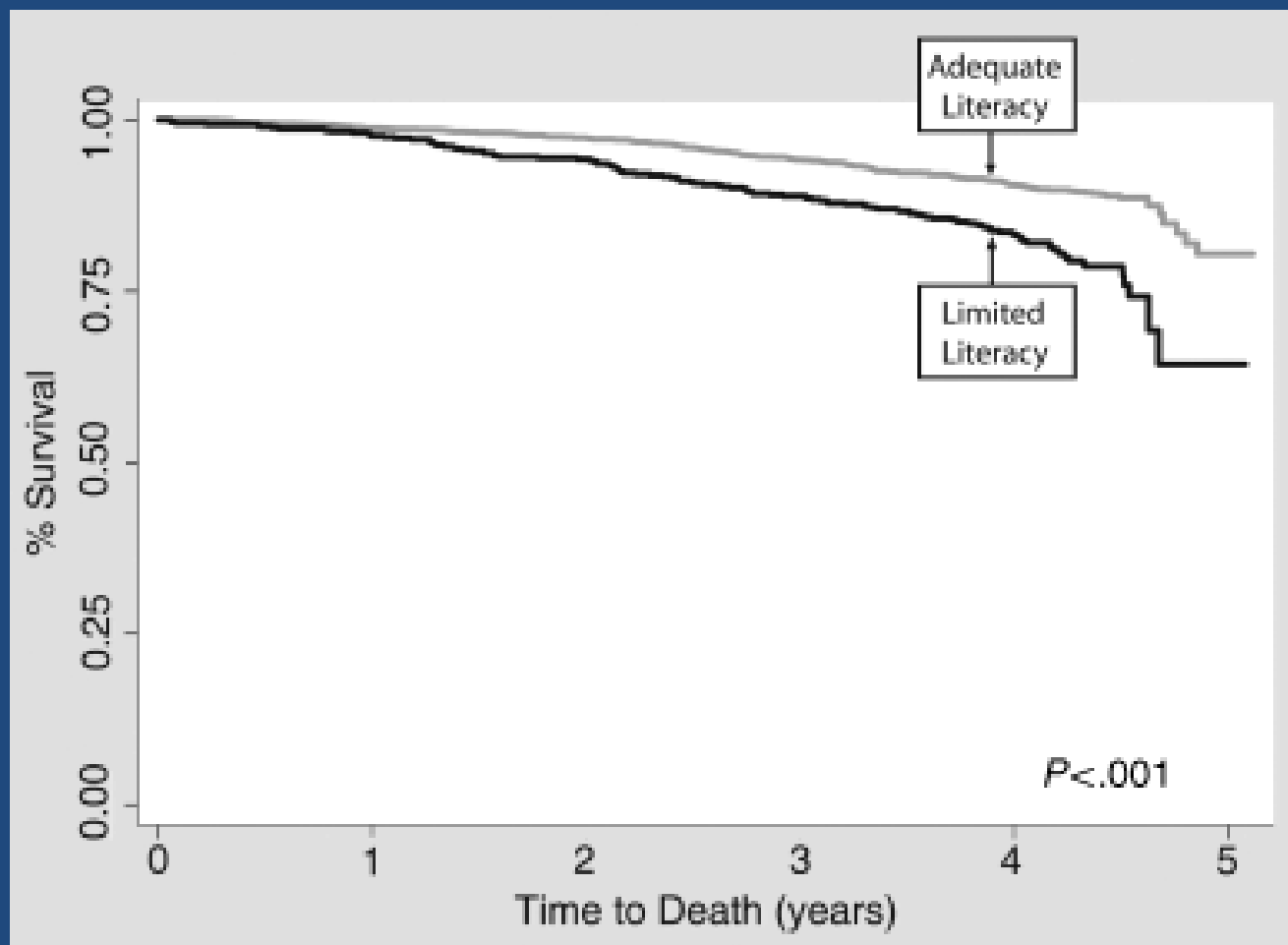
Behaviors Only

- 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

Literacy and Mortality



Adult Hospitalization

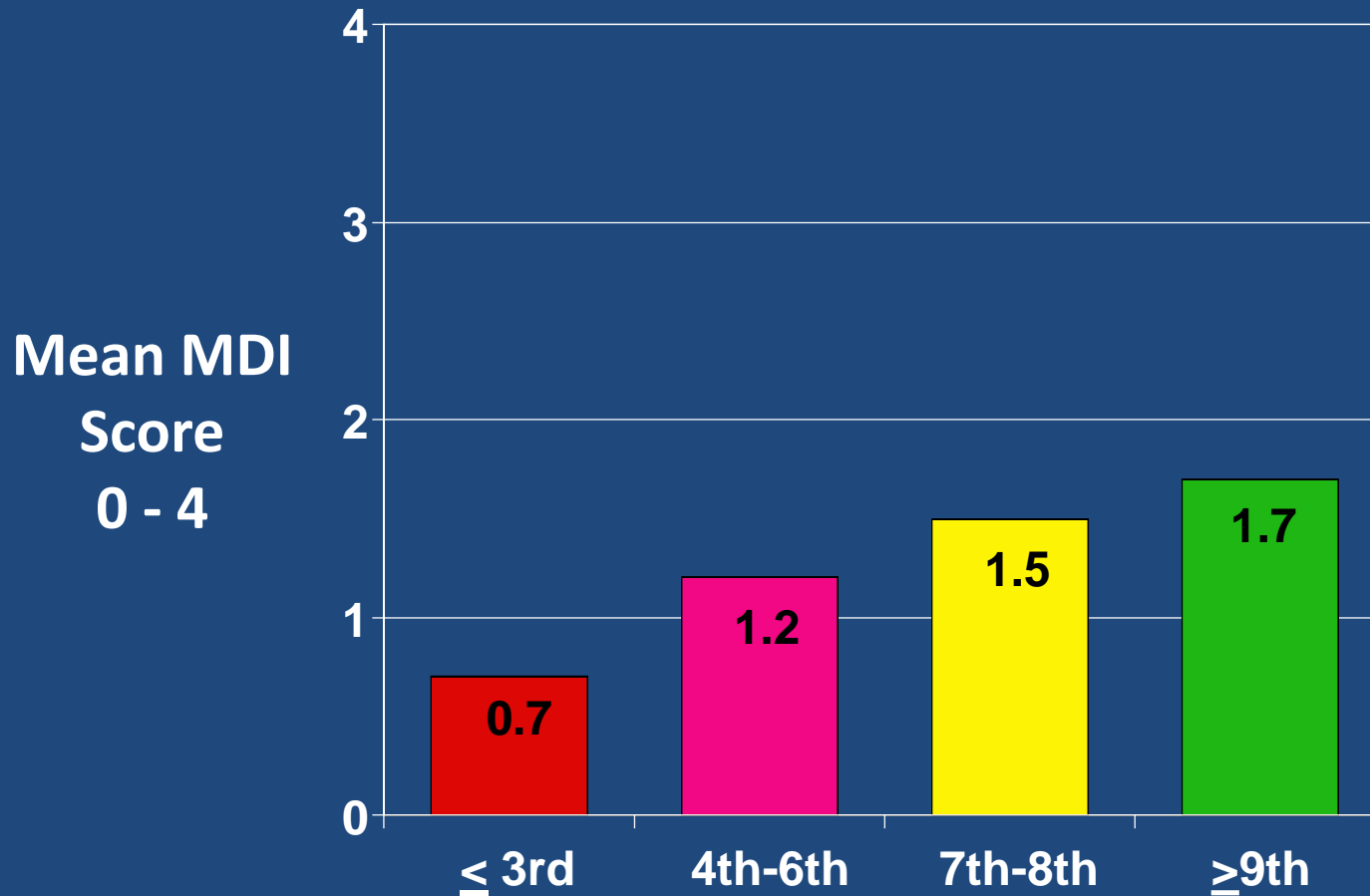
- People with low literacy have 30-70% increased risk of hospitalization
- RR = 1.29 (1.07-1.55) Medicare Managed Care
- RR = 1.69 (1.13-2.53) Urban Public Hospital

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

Cognitive Ability in the Hospital

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

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

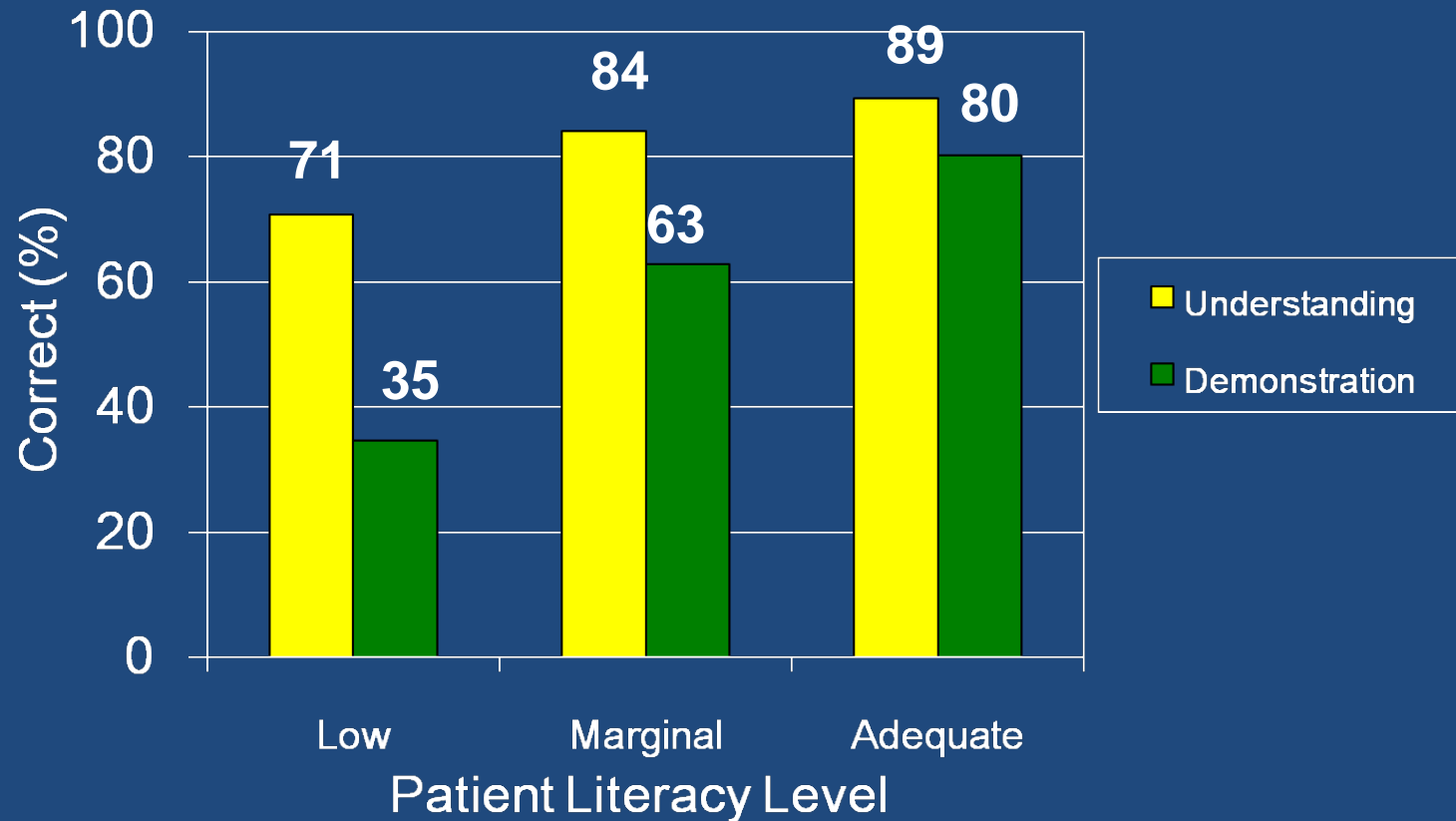


Williams et al. *Chest* 1998, **114**(4):1008-1015.

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



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



Can Patients Comprehend Rx Drug Warning Labels?



Simple Familiar Wording Understood by Most Patients



84%

(1st grade.)

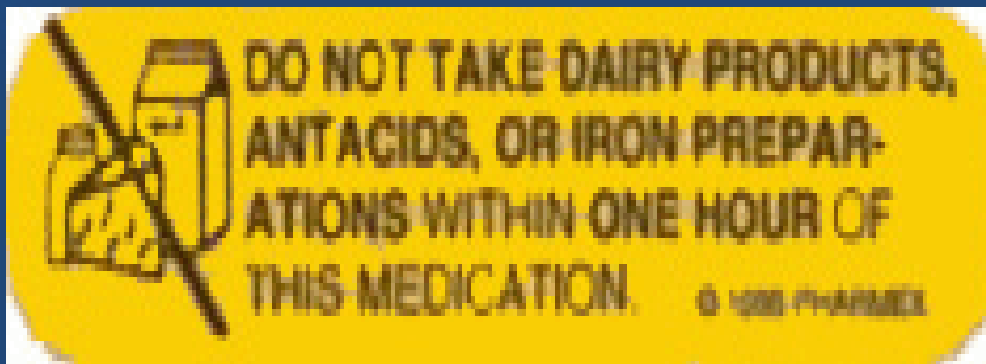
More Complex Message Limited Comprehension



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

A Dosing directions from packaging

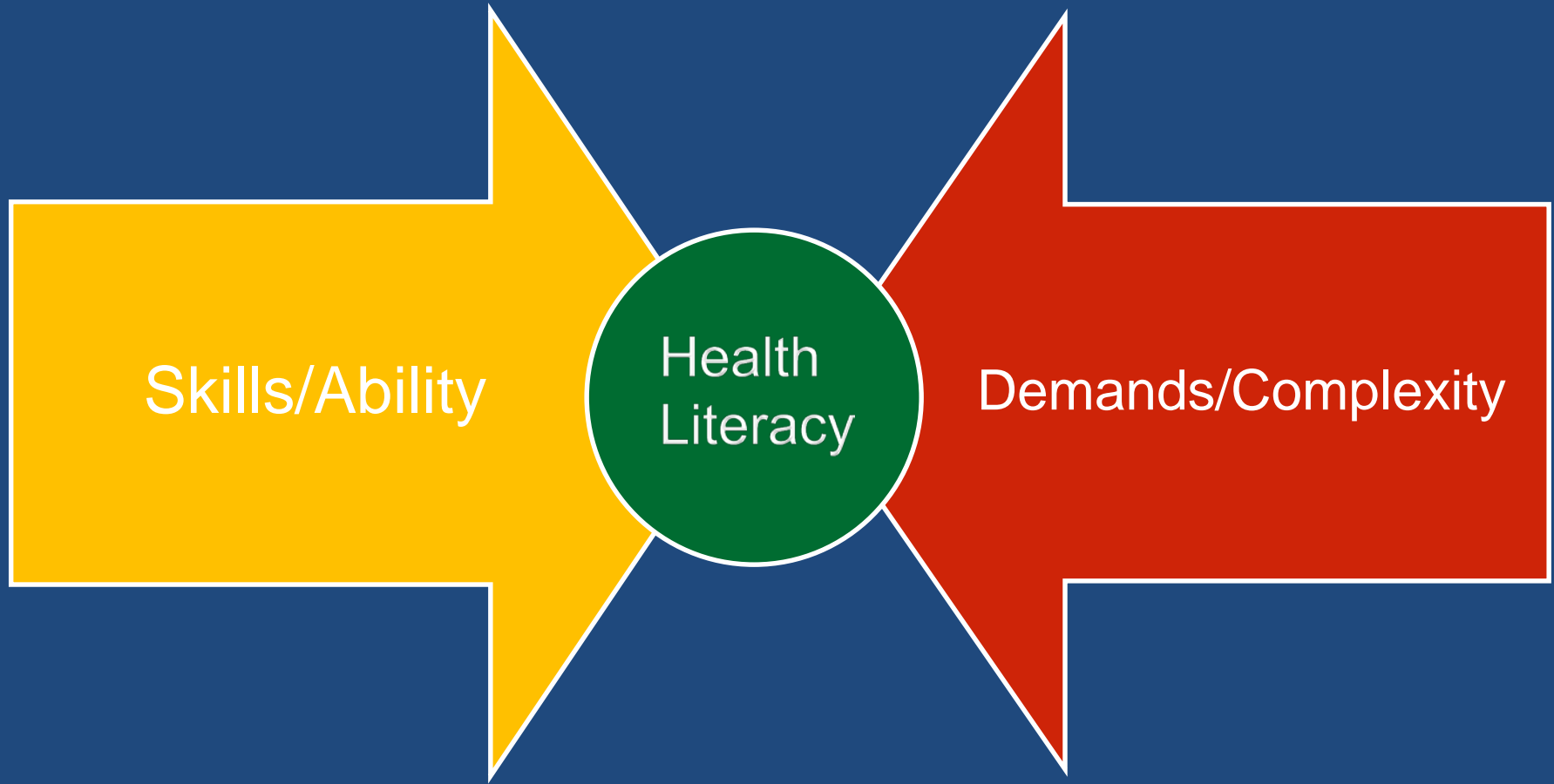
Missing markings
(absent from measuring device)

dose
2 tablespoons (30 mL) every 4 hours
1 tablespoon (15 mL) every 4 hours
do not use unless directed by a doctor
do not use

B Measuring device (one view)



Improve Skills and Reduce Complexity



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

Current PCORI facing Patient Materials

- The different ways of treating early-stage prostate cancer (active surveillance, radiotherapy, or surgery) affect men differently. Men who have surgery or radiotherapy have more sexual, urinary, and bowel problems in the first year compared with men who were treated with active surveillance. After 2 to 3 years, most symptoms improve, but there may still be differences.
- Reading level: 12.7

Strategy 2

Teach-back Method



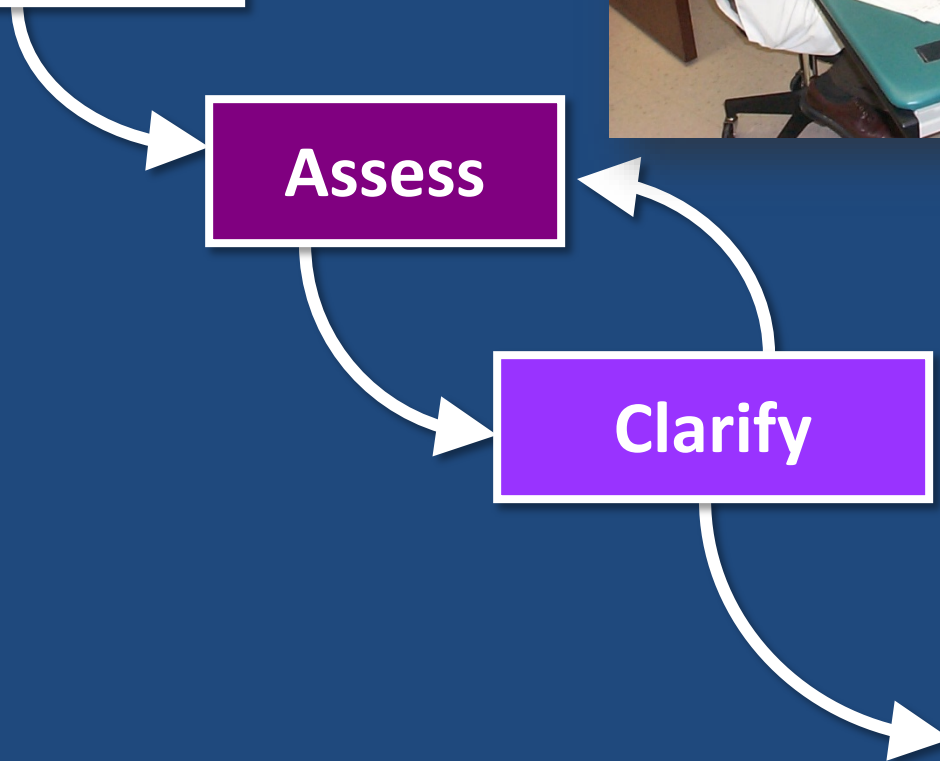


Explain

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
Rated quality of hospital food (higher is better)	4.1	1.1	2.0
% of time guidelines for heart attack care are followed	82%	92%	87%
% of time guidelines for pneumonia care are followed	60%	89%	78%
No. of registered nurses per 100 patients	18	38	29
Has computer system to prevent medication errors	No	Limited	Limited
	Yes	Yes	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?

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

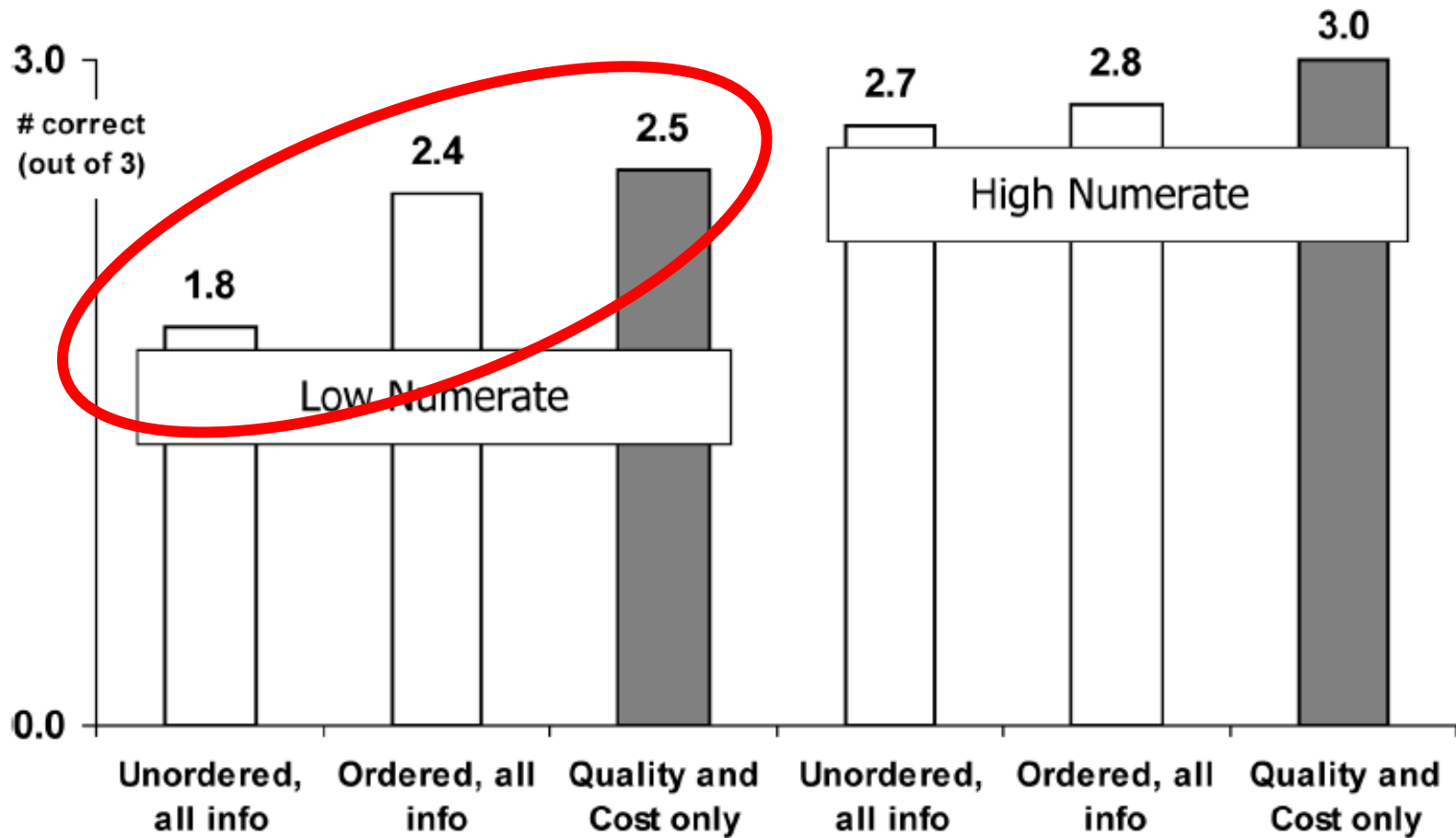











Table 5
Study 3: Patient-to-Nurse Ratio Is Presented as “Higher Is Better”
with Easier-to-Evaluate Symbols

	No. of Registered Nurses per 100 Patients	Your Out-of-Pocket Cost
Hospital A	38 	\$\$\$
Hospital B	36 	\$\$\$\$
Hospital C	32 	\$\$\$\$

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?

Hospital L	23 	\$\$\$\$
Hospital M	26 	\$
Hospital N	24 	\$\$\$
Hospital O	17 	\$\$




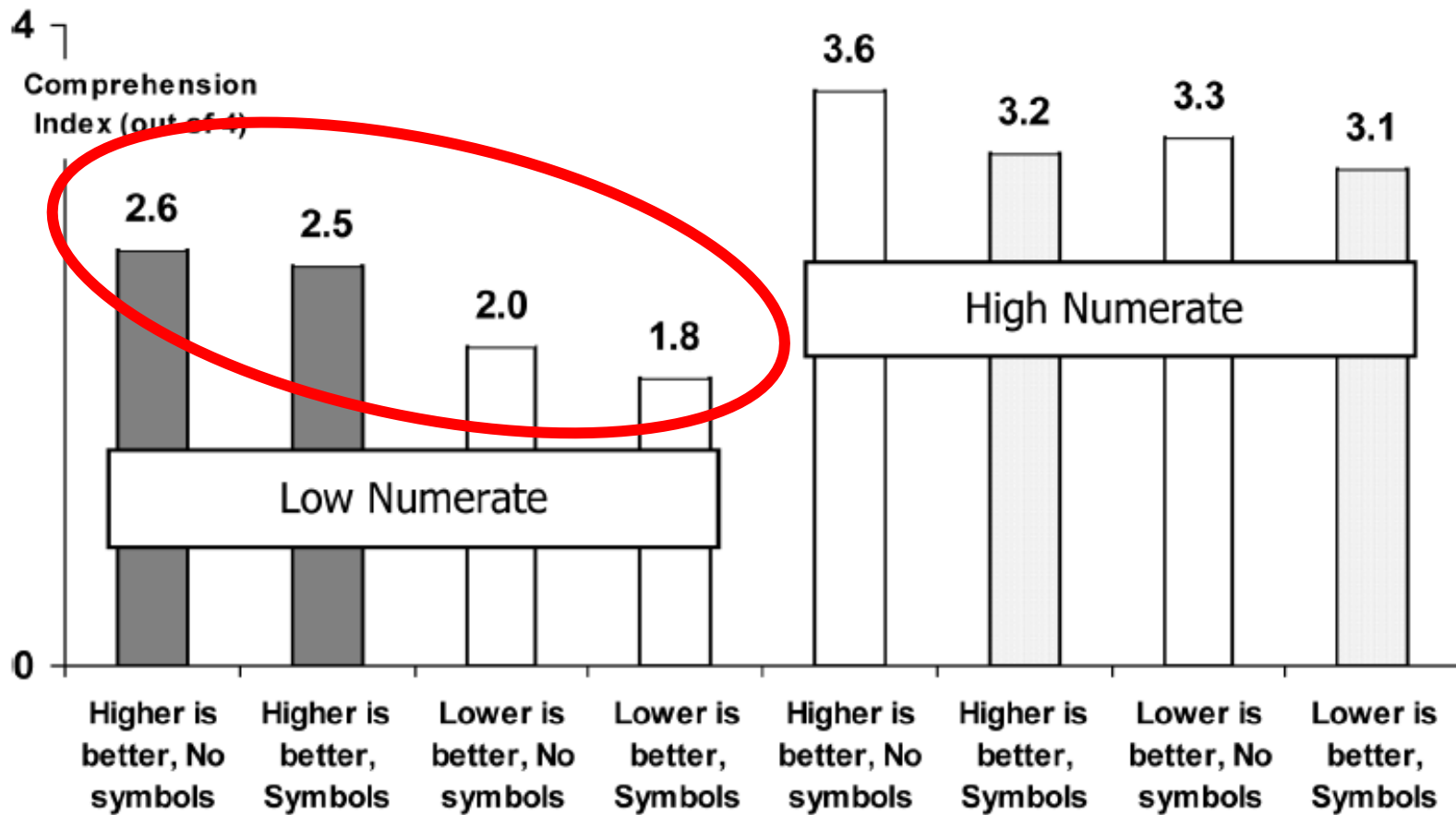
Note:  = more registered nurses per 100 patients;  = average number of registered nurses per 100 patients;  = fewer registered nurses per 100 patients.

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



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