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

National Center for Education Statistics, U.S. Department of Education
2003 National Assessment of Adult Literacy

- Proficient: 13%
- Below Basic: 14%
- Basic: 29%
- Intermediate: 44%
Figure 12. Percentage of adults in each prose literacy level, by age: 1992 and 2003

<table>
<thead>
<tr>
<th>Age and year</th>
<th>1992</th>
<th>2003</th>
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<tbody>
<tr>
<td>16–18</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>19–24</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>25–39</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>40–49</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td>50–64</td>
<td>16</td>
<td>13*</td>
</tr>
<tr>
<td>65+</td>
<td>33</td>
<td>23*</td>
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</table>

<table>
<thead>
<tr>
<th>Percent Below Basic</th>
<th>Percent Basic and above</th>
</tr>
</thead>
<tbody>
<tr>
<td>70</td>
<td>10</td>
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<tr>
<td>10</td>
<td>70</td>
</tr>
<tr>
<td>0</td>
<td>80</td>
</tr>
</tbody>
</table>

Legend:
- Below Basic
- Basic
- Intermediate
- Proficient
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
SPECIAL REPORT

DROP OUT 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.
Video

It’s hard to be a patient
### 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

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.

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

Mean MDI Score 0 - 4

- ≤ 3rd: 0.7
- 4th-6th: 1.2
- 7th-8th: 1.5
- ≥9th: 1.7

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

John Smith        Dr. Red

Take two tablets by mouth twice daily.

Humibid LA       600MG
1 refill
Rates of Correct Understanding vs. Demonstration “Take Two Tablets by Mouth Twice Daily”

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

(Medication should be taken with plenty of water) 59%

(4th grade.)
Unfamiliar Multi-step Instructions Rarely Understood

8%

(12\textsuperscript{th}-13\textsuperscript{th} 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)

- 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)

Superfluous markings
(not listed in dosing directions)

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

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Video

It’s easy to make a mistake
Improve Skills and Reduce Complexity

Skills/Ability

Health Literacy

Demands/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

Doak, Doak, Root. 1996.
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
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
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?
Figure 1
Study 1. Mean Comprehension by Presentation Format and Numeracy

Low Numerate

Unordered, all info: 1.8
Ordered, all info: 2.4
Quality and Cost only: 2.5

High Numerate

Unordered, all info: 2.7
Ordered, all info: 2.8
Quality and Cost only: 3.0
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

Comprehension Index (out of 4)

Low Numerate
- Higher is better, No symbols: 2.6
- Higher is better, Symbols: 2.5

High Numerate
- Lower is better, No symbols: 2.0
- Lower is better, Symbols: 1.8
- Higher is better, No symbols: 3.6
- Higher is better, Symbols: 3.2
- Lower is better, No symbols: 3.3
- Lower is better, Symbols: 3.1
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