What is Health Literacy and How Do We Measure It?

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Objectives of the NIH R-01

- To create a publicly available health literacy instrument that can be used:
  - For population-based surveillance
  - To measure an individual’s health literacy in intervention and research studies
Existing Instruments to Measure Health Literacy

- TOHFLA, REALM, WRAT, Ask-Me-3
  - Largely measure reading ability
  - Other limitations
- National Assessment of Adult Literacy (NAAL)
  - Some advantages
  - Not publicly available
Specific Project Tasks

1) Develop conceptual framework for the instrument
2) Develop health literacy items
3) Cognitively test items
4) Pilot test items in a survey
5) Conduct psychometric analyses of pilot data
What is Health Literacy?

- Health literacy is not simply a function of basic literacy skills, but is “dependent on individual and system factors, including communication skills of lay persons and professionals, lay and professional knowledge of health topics, culture, the demands of the healthcare and public health systems, and the demands of the situation/context”. (Healthy People 2010)

- Health literacy varies by context and setting and is not necessarily related to years of education or general reading ability (National Networks of Libraries of Medicine)

- “Even well educated people with strong reading and writing skills may have trouble comprehending a medical form or doctor's instructions regarding a drug or procedure”. (IOM, 2004)
Our Working Definition of 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” (Ratzan and Parker (2000), in IOM (2004) and Healthy People 2010, DHHS (2005))

- “The degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make *informed* health decisions.”
Conceptual Framework for Individual Health Literacy

**HEALTH LITERACY SKILLS**
- Print Literacy (reading, writing)
- Numeracy Skills
- Communication (listening, speaking, negotiating)
- Information Seeking (navigation)

**UNDERSTANDING OF STIMULUS**

**CAPABILITIES**
- Vision
- Hearing
- Verbal ability
- Memory
- Cognitive/Reasoning/Processing

**MODERATORS**
- Motivation
- Self-efficacy
- Perception of outcome/behavior
- Attitude toward outcome or behavior
- Coping strategies
- Social support
- Emotions
- Behavioral intention
- Trust in information/source/stimulus
- Decision making skills
- Fatalism

**STIMULUS CONSIDERATIONS**
- Health literacy demand: complexity and difficulty of stimulus; one vs. many stimuli
- Channel: print, mass media
- Message: health promoting vs. disease preventing; fear appeals; narrative vs. non-narrative
- Messenger: relationship of messenger to recipient, credibility of/trust in messenger/source; communication skills of messenger

**DEMOGRAPHICS**
- Age
- Race/Ethnicity
- Gender

**RESOURCES**
- Occupation
- Employment
- Income
- Social support
- Culture
- Language
- Education
- Literacy

**HEALTH RELATED STIMULUS**

**PRIOR KNOWLEDGE**
- Vocabulary
- Conceptual knowledge of health/health care

**INFORMED DECISION MAKING**

**HEALTH-RELATED OUTCOMES**
Skills-based Approach to Measuring Health Literacy: Key Assumptions

- Measure people’s ability to use different types of health information to make informed decisions
- Include skills needed across the life course (in periods of health and illness)
- Issues range from disease prevention to treatment and self-management
- U.S. health care system-based
- Skill needs may change corresponding to advances in health-related materials and technology development
Health Literacy Domains

- Print
  - Prose
  - Document
- Numeracy
- Communication – listening, speaking, negotiating
- Information Seeking - navigation
Hierarchical Process

- First...identify the skill/task
- Then...select the stimuli
- Then...choose the mode of administration
Criteria for Selection of Skills

1) Understanding health related concepts and terms (in writing and verbally)

2) Interpreting tables, charts, symbols, maps/other visuals

3) Making inferences based on available data

4) Applying information to new situations

5) Arithmetic manipulations
Criteria for Selection of Stimuli

1) Sufficiently related to the health of the public
2) Widely applicable, balanced content
3) Accessible to many subgroups (gender-neutral, culturally sensitive)
4) Clinically important and not controversial
5) Appropriate length of content
6) Mixture of public and private sector materials
7) Likely to stand the test of time
8) Variety of formats/channels
9) Wide range of difficulty
10) Has face validity
Criteria for Survey Items

1) No prior knowledge required
2) Has one correct response option and realistic distracters
3) Uses plain language techniques
4) Questions are independent of each other
5) Include a range of difficulty
6) Cognitively tests well
Interactive Tool: Are You at Risk for a Heart Attack?

- This interactive tool measures your chance of having a heart attack in the next 10 years. The tool uses the values you enter to calculate your risk score.

Note: The calculation is based on information from the Framingham Heart Study. During the past 50 years, the Framingham Heart Study has studied the progression of heart disease and its risk factors.

Attribution: Interactive tool by Healthwise, Incorporated. This information was adapted from the U.S. National Cholesterol Education Program’s "Risk Assessment Tool."
John is 39 years old and smokes. His blood pressure is 130/90 and he’s on blood pressure medicine. His HDL cholesterol is 50 and his total cholesterol is 230. What is his estimated 10 year risk of a heart attack?

a) 20%

b) 12% (correct response)

c) 10%

d) 2%
Heart Disease Risk Calculator (continued)

Attribution: Interactive tool by Healthwise, Incorporated. This information was adapted from the U.S. National Cholesterol Education Program's "Risk Assessment Tool."
Heart Disease Risk Calculator (continued)

Fill in your values and then click to calculate.

Systolic blood pressure: Select your value

Are you taking blood pressure medication?  
- Yes
- No

Click to continue

Attribution: Interactive tool by Healthwise, Incorporated. This information was adapted from the U.S. National Cholesterol Education Program's "Risk Assessment Tool."
Heart Disease Risk Calculator (continued)

Attribution: Interactive tool by Healthwise, Incorporated. This information was adapted from the U.S. National Cholesterol Education Program’s "Risk Assessment Tool."
Heart Disease Risk Calculator (continued)

![Interactive tool by Healthwise, Incorporated. This information was adapted from the U.S. National Cholesterol Education Program's "Risk Assessment Tool."](image)

### Your estimated 10-year risk of heart attack

<table>
<thead>
<tr>
<th>Male</th>
<th>Smoker? Yes</th>
<th>Age: 35-39</th>
<th>Systolic BP: 130-139</th>
</tr>
</thead>
<tbody>
<tr>
<td>BP med? Yes</td>
<td>HDL cholesterol: 50-59 mg/dL (1.28-1.53 mmol/L)</td>
<td>Total cholesterol: 200-239 mg/dL (5.18-6.21 mmol/L)</td>
<td></td>
</tr>
</tbody>
</table>

That means 12 people in 100 with these risk factors will have a heart attack in the next 10 years.

Click to recalculate
Five Steps to Safer Health Care

1. Ask questions if you have doubts or concerns.
Ask questions until you understand the answer. Choose a doctor you feel comfortable talking to. Take a telephone list with you to help you ask questions and understand the answers.

2. Keep and bring a list of ALL the medicines you take.
Check your doctor and determine a list of all the medicines that you take, including over-the-counter, non-prescription, and herbal remedies. Verify that your list is accurate and up-to-date, and bring a copy with you to every doctor visit. Ask if there are any interactions or side effects to watch for. If you are very sick, take the list to the clinic or emergency room with you.

3. Get the results of any test or procedure.
Ask when and how you will get the results of tests or procedures. Each result may affect your health in a different way. If you do not get them when expected, ask why or how long it will take. Call your doctor and ask for results. Ask what the results mean for you.

4. Talk to your doctor about which hospital is best for your health needs.
Ask your doctor where he is trained and what hospitals he prefers. If you become very sick in hospital, please share this information with your doctor. Ask if there is a hospital in the area you are comfortable with. You may also wish to discuss other options, such as home care, community clinics, or urgent care centers, with your doctor.

5. Make sure you understand what will happen if you need surgery.
Make sure you understand what will happen if you need surgery. Ask your doctor what will happen during the procedure. Ask for a copy of the preoperative checklist and discuss any concerns you may have. Ask your doctor what he expects you to do before and after surgery. Ask about the recovery process and any possible side effects. Be sure to understand all the risks and benefits of the procedure. If you have any questions, ask your doctor before surgery.

Attribution: Flyer sponsored by the Agency for Healthcare Research & Quality (AHRQ), DHHS.
John picked up his usual prescription from the pharmacy, but the pills were half their usual size. What should he do?

a) Take two pills instead of one to get the same dosage  
b) Cut the pills in half because they are twice as strong as the larger ones  
c) Take a pill every other day instead of every day  
d) Ask the pharmacist what to do (correct response)
Maintaining a Healthy Weight

- **Maintaining weight**
  - Energy In = Energy Out
  - Your weight will stay the same when the calories you eat and drink equal the calories you burn.

- **Losing weight**
  - Energy In < Energy Out
  - You will lose weight when the calories you eat and drink are less than the calories you burn.

- **Gaining weight**
  - Energy In > Energy Out
  - You will gain weight when the calories you eat and drink are greater than the calories you burn.

*Attribution: Image sponsored by MyPyramid.gov, United States Department of Agriculture (USDA).*
What is one way for a person to maintain weight?

a) Make sure the amount of energy they take in is greater than the energy they use

b) Make sure the amount of energy they take in equals the energy they use (correct response)

c) Make sure the amount of energy they take in is less than the energy they use.
Signs of a Stroke

Let me tell you what happened. My father has high blood pressure. Last week we went fishing.

He dropped his gear. He said he felt weak on one side.

He did not talk clearly.

He said his sight blurred, and he felt dizzy.

He felt okay in a few minutes. Still, I did not wait. I called 911 for help. I knew what was happening to Dad are the warning signs of a stroke.

I learned the signs of a stroke and saved my father’s life. You can save lives, too. Remember, some people have all of these signs, but some people have only a few of them. If you or someone else have even a few of these signs, get help fast!

The signs of a stroke are:

- feeling weak or numb on one side
- blurry vision, or no vision, usually in one eye
- unable to talk clearly
- dizziness or falling
- severe headache

My father is alive today because I know the signs of a stroke. You can save lives, too, if you learn these signs.

Attribution: Flyer sponsored by the American Heart Association.
EASY: Which of the following is NOT a sign of a stroke?
   a) Difficulty breathing (correct response)
   b) Blurred vision
   c) Bad headache
   d) Numbness on one side.

MEDIUM: Which of the following is a true statement?
   a) Someone who is having a stroke will have all of the signs
   b) Someone who is having a stroke may have only two or three signs (correct response)
   c) Everyone who has a stroke dies if they are not treated right away
The California Fires

“THE CALIFORNIA FIRES: HEALTH PROBLEMS; Effects of Wildfire Smoke Vary, Experts Say
By DAVID TULLER

The inhalation of tiny smoke particles from wildfires, while unpleasant, is unlikely to cause long-term damage to healthy people unless it occurs over a prolonged period, doctors and environmental health specialists said.

But the experts also warned that young children, the elderly and anyone with chronic pulmonary or cardiovascular conditions could be at risk for complications, and those people were particularly advised to stay indoors and run their air-conditioners while the fires in Southern California continued to rage.

The primary danger, experts say, arises from particles from vegetation and other burned matter that can lodge deep in the lungs and, in some cases, lead to severe shortness of breath, asthma attacks, bronchitis and other pulmonary ailments.

The most damaging particles are invisible to the eye and can evade the body's normal protective mechanisms, like tiny hairs in the nostrils and cells within the lungs designed to expel or destroy alien substances.

"If you can see the particles, they’re not going to hurt you, unless they land in your eye," said Dr. William Hughson, a professor of medicine at the University of California at San Diego and director of its Center for Occupational and Environmental Medicine. The particles to be concerned about, Dr. Hughson said, are smaller than three microns in size, or three-thousandths of a millimeter.

Which type of burned matter is most likely to hurt a person’s lungs?

a) Bigger pieces
b) Smaller pieces (correct response)
c) It depends on the type of material
Bill is at the beach and taking this medicine, he should:

a) Continue his outdoor activities without any changes
b) Not take his medicine for now
c) Take the medicine before going outdoors in the morning
d) Sit in the shade if he is going to be outdoors (correct response)
This 1 minute PSA ad shows and describes “at risk” groups that should be immunized every year (based on health condition, age and exposure to those at risk).

Attribution: Video sponsored by the American Lung Association, and posted on YouTube.com.
Faces of Influenza: Questions

- **EASY:** Which of these groups of people should be immunized against influenza?
  a) Everyone
  b) Anyone 50 years of age and older (correct response)
  c) Anyone under 50 years of age
  d) College students

- **MEDIUM:** How often should a person be immunized for influenza?
  a) When they first get diagnosed with a chronic medical condition
  b) When they have a baby
  c) Every year (correct response)
  d) When they get a cold
Mode of Data Collection

- Web-based has the advantage of being able to address all the domains of health literacy including listening skills and information seeking and accommodates interactive multi-media
  - Audio
  - Video
  - Navigation
Addressing Reliability and Validity

- Reliability
  - Internal consistency
  - Test-retest reliability
- Content validity
  - Expert panel review
  - Content coverage
- Construct validity
  - Factor analyses
  - Group comparisons
- Criterion validity
  - Relationship with other health literacy measures
Questions for the Field

- Survey mode issues
  - Skills that can be measured/items that can be asked
  - Stimuli that can be presented

- How will emerging technologies allow us to improve our measurement of health literacy, especially oral literacy?

- What are advantages and disadvantages of using real world stimuli vs. stimuli developed for assessments?

- On which national surveys would health literacy items and scales best fit?

- How do we deal with the need for stimuli to be updated and/or changed over time?
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