The Importance of a National Data Set for Health Literacy

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Institute of Medicine: Workshop on Measures of Health Literacy, February 26, 2009
IOM had it right on Health Literacy

“Health Literacy is where the expectations, preferences and skills of individuals seeking health information meet the expectations, preferences and skill of individuals providing information. Health literacy arises from a convergence of education, health services, and social and cultural factors, and brings together research and practice from diverse fields.”
Healthy People

- Multi-decade national agenda for disease prevention and health promotion
- Individual objectives provides a foundation for multiple initiatives and activities, including data collection
- Objectives provide focal point and continuity for a decade
Healthy People 2010

Chapter 11: Health Communication

• Access to the Internet
• Improvement of health literacy
• Research and evaluation of health communication programs
• Disclosure of information to assess the quality of health web sites
• Centers of Excellence
• Healthcare providers’ communication skills
Healthy People Objective on Health Literacy

Objective 11-2. Increase the health literacy of the population.

*Data source: 2003 National Assessment of Adult Literacy*

Note: When the objective was released in 2000, it did not have data for a baseline or targets. These are expected for all objectives. No data=no objective for 2020?
Some Results of Having Objective and NAAL Data

- NIH/AHRQ/CDC Health Literacy Program Announcement
- Surgeon General’s Workshop on Improving Health Literacy
- Town Halls on Improving Health Literacy
- National Action Plan on Improving Health Literacy
- Professional societies’ focus on improving health literacy, e.g. ADA, AAP, ACP, AMA
Healthy People Defines the End Game

• According to Healthy People 2010, individuals are “health literate” when they possess the skills to understand information and services and use them to make appropriate decisions about health.

• Alarmingly, the NAAL shows almost 90% of the population doesn’t possess these skills.

• Without the objective and the NAAL (or other), we lose the ability to track these skills over time.
## What do We Want to Measure: Range of Action for Behavior Change

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual effects</td>
<td>individuals improve knowledge and attitudes</td>
</tr>
<tr>
<td>Social diffusion</td>
<td>change in public norms</td>
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<tr>
<td>Institutional diffusion</td>
<td>change in elite opinion, influencing policy, influencing individuals</td>
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Data… It Depends on your Perspective

• Cosmic Zoom – we keep getting stuck pulling focus

• Einstein had it right: “No problem can be solved from the same level of consciousness that created it.” and “Concern for man and his fate must always form the chief interest of all technical endeavors. Never forget this in the midst of your diagrams and equations.” — Einstein

• Missing the handoff, losing the gold
  “Americans flub handoffs in relays, lose shot at gold” by The Associated Press Thursday August 21, 2008, 9:23 AM
Health Literacy: There’s a lot to Measure

• Pervades all health issues
  – prevention, diagnosis, intervention, cure—chronic or acute disease

• Pervades social issues
  – disparities, cultural difference, language difference, access issue

Economic strain both on individuals and systems, lost human capital... lost time and money
Additional Considerations for Health Literacy Measurement

- Capacity of individuals who are Limited English proficient
- Capacity of systems to respond to individuals who are Limited English Proficient
- Currently no national data on individuals or systems with Limited English Proficiency other than numbers of persons who speak other languages – major gap!
  - According to current Federal data, there are at least 329 languages spoken or signed in the United States
  - In some cities, less than 60 percent of the population has English as a first language
Doctors’ orders can get lost in translation for immigrants…”

Wall Street Journal 1/9/2003  Barry Newman Page one

- “…But as more people who don’t speak English scatter to places such as Utica, practitioners in the provinces have come to rely on family members, often children, to mediate millions of patient visits.”
- Pills hadn’t worked:
- “Find out whether I should take the pills for a month or a week,” she told Ruvim. He tried to ask the doctor, “Does she has to drink the tablets a week for a month—?”
- Dr. Palumbo stopped him. Instructions, he said, would be provided in writing. His nurse soon appeared with a detailed prescription for medication to be taken once a day. Ruvim attempted to read it out loud, but he struggled again.”
As his patient and her young interpreter left, Dr. Palumbo said, “The kid was pretty bright. He seemed to understand quite well. But, I’d be curious. I guess I don’t really know if she really got the story.”

The 2000 census counted 20 million people who speak poor English, 10 million who speak none. The White House Office of Management and Budget, in a 2002 report estimated the number of patient encounters across language barriers each year at 66 million…
Children Represent even Higher Percentages of Diversity

- Twenty-nine percent of the U.S. population and one in three children is a member of an ethnic or racial minority group.
- By 2025, almost 40 percent of Americans and about half of all U.S. children will be minorities.

AHRQ reported data, Flores et al.
Recent Analysis of Health and Health Disparities Research

Shaniece Charlemagne
Sabra F. Woolley, Ph.D.
National Cancer Institute
Distribution of NIH and AHRQ Grants by Special Interest Area(s)

- Cancer, 20%
- Oral Health, 10%
- Maternal-Child Health, 10%
- HIV, 3%
- Other, 34%
- Screening, 7%
- Tobacco/Smoking, 2%
- Computers/Internet, 3%
- Hypertension, 3%
- Diabetes, 2%
- Stroke, 2%
- Asthma, 2%
- Disability, 2%
Summary

• Interconnected health literacy and health disparities research funded through NIH and AHRQ grants are intended to involve health literacy as a key outcome, health literacy as a key explanatory variable for other outcomes, and prevention/intervention strategies that focus on health literacy.

• More than half of the grants funded by NIH and AHRQ primarily study the adult population. Race/ethnicity, gender, and special populations are more likely not to be specified within the abstract of grants funded. Of the grant abstracts that do specify population to be studied, African Americans, females, and low literacy populations were the primary targets.
Summary continued

• The NIH and AHRQ funded research projects are more likely to be supported through R01 and R03 funding mechanisms. Within the NIH and AHRQ, the National Cancer Institute since 2006 has provided the most funding to grants that address health literacy and health disparities than the other institutes and centers.

• Approximately 20% of the funded grants proposed to utilize CBPR/CBR methods. However, only six percent of the abstracts identified a measurement methodology. In addition, special interest areas that have been primarily funded are Cancer and Other interest areas (i.e. Risk behaviors, mental health, risk factors, child health and injury prevention, science education, etc).
Conclusion

Results of our content analysis indicates that grants funded by NIH and AHRQ present various themes, patterns, and funding opportunities. The different capacities in which NIH and AHRQ affords researchers to address health literacy issues will ultimately reduce health disparities among various populations.
Implications/Recommendations

There is a need for researchers to specify within the funded grant abstracts the population studied (i.e. race/ethnicity, gender, etc), measurement methodology studied, and research methodology utilized.
Some data in quadrants

- Patient-physician communication
- Drug labeling
- Medical instructions and medical compliance
- Health information publications and other resources
- Informed consent
- Responding to medical and insurance forms
- Giving patient history
- Public health training
- Assessments for allied professional programs, such as social work and speech-language pathology
For Reciprocity... We Need a Corollary to What We Know about Individuals

• Individuals are considered to be “health literate” when they possess the skills to understand how to provide information, access and services to ensure they are so effective for the user that the user can make appropriate decisions about health—and do it!

• **However,** these skills and strategies are
  – Absent in ?% of the materials, services and systems
  – Desired by both groups because they often lead to
    • longer life
    • improved quality of life
    • reduction of both chronic disease and health disparities
    • cost savings
Some Additional Literacy Links

- Disease prevention and health promotion
- Occupational health and safety
- Lost or excluded individuals
- Social justice/human rights
- Informed consent

(Raich et. al. HP2010)
Both the Practiced Upon and the Practitioner / Reciprocity

- Not just providing “critical” information, creating knowledge and decision-making skill.
- Not just providing short cut strategies, but creating knowledge toward innovation
No Data—No Problem

No Problem—No Answer
Criteria for Objectives

- Prevention-oriented
- Action-driving
- Based on sound scientific evidence
- Important and understandable to a broad audience
- Measurable at the national level
Influences:
Body of Knowledge, Body of Belief, Body of Behavior

- Community influence
- Literacy, numeracy
- Environmental access or challenge
- Communication ability or disability
- Language difference or disorder
- Family influence
Family

- Defined in realistic terms
- Proximity
- Influence
- Supportiveness
Environmental Influence

- Time required
- Time of day
- Number of days, weeks, months
- Dollars
- Distance
- Open or closed systems
- Easy access or insurmountable challenge
Just For Example...

Latino, African American, and American Indian children are more likely than white and Asian children to never have visited a dentist.

Pourat N, Haves and Have-Nots: A Look at Children’s Use of Dental Care in California, 2005, Oakland: California HealthCare Foundation, 2008 [source California Health Interview Survey]
Local Environments Affect Health

- UCLA Center for Health Policy Research demonstrated the food environment affects both diabetes and obesity.

- “Health status differences related to environment would not be visible or understood without good data”  E. Richard Brown, Ph.D., UCLA
More Challenges…

[Patients recall and comprehend as little as 50% of what they are told by their physicians?]

- How much of what we know that we have learned by listening? 85% (Shorp)
- Amount of the time we are distracted, preoccupied or forgetful? 75% (Hunsaker)
- How much we usually recall immediately after we listen to someone talk? 50%
- We listen at 125-250 words per minute, but think at 1000-3000 words per minute. (High Gain, Inc.)

From International Listening Association
Literacy Is Not a Constant

- Older adults who may have had fine reading, writing, and thinking skills in younger days may have difficulty as they age with reading and understanding information.
  - 66% of people aged 65 and older have poor literacy skills
  - 25% of immigrants have poor literacy
- Vision problems, poverty, learning disabilities, immigration and minority status, and poor education also can contribute to low literacy. [communication difference or disorder]
A Multi-Dimensional Approach to Assess the Rural-Urban Nature of an Area

1. **Population density** (residents per square mile)
   - What areas (counties, census tracts, census blocks, and so forth) should serve as reference?

2. **Land use** (percentage devoted to agricultural/single-family homes/commercially operated buildings)
   - Which serve as the reference point?

3. **Distance between an individual dwelling unit and the nearest residential neighbor**

4. **Travel time from an individual dwelling unit to the nearest urban or commercial center**
   - How should such centers be defined?

Need to Focus on Rural Population Issues

In 1990, the rural American population constituted 24.8% of the total population, living on 97% of the nation’s land (Luloff and Swanson, 1990; Rickets, Johnson-Webb, and Randolph, 1999) based on census bureau criteria.

Program Announcement

Goal is to increase scientific understanding of the nature of health literacy and its relationship to healthy behaviors, illness prevention and treatment, chronic disease management, health disparities, risk assessment of environmental factors, and health outcomes including mental and oral health.

NIH, CDC, AHRQ
Newer Factors Not Quantified

- In reference to "Back to Sleep" … but a broader application “The new behavior is easy and low cost, and the consequence of the behavior is highly valued.” Bob Hornik, 2002, p.15

- Stickiness Factor/ Tipping Point/ Malcom Gladwell

- Paradox of Choice  Barry Schwartz
To Keep the Field Moving Forward...

- Recommendations about data need to be considered in the big picture
  - Need for national data to support a Healthy People objective
- Need for population and systems-based data
- Sustainability of results and true scope of results
- Government “in cooperation with” the private sector for sustainability
- Without data... No policy... Lost human capital and productivity, lost time, lost dollars, weaker generations
NAAL Data Collection

- Field test in expected in 2015
- Main data collection expected in 2016

From the U.S. Department of Education, February 2009
Thanks are in order to:

- IOM for holding this meeting
- The public who have participated in all the surveys to date
- Department of Education for the health literacy components of the NAAL and for tracking adult literacy in America
- Department of Health and Human Services for support of Healthy People, interagency working group on Health Literacy and the efforts of the office of the Surgeon General
- CDC and Dr. Cynthia Baur
- AHRQ
- NIH colleagues who developed, championed, and funded research on health literacy
In Conclusion

- Find the place in the cosmic zoom that will help the most populations
- Find the data that will move understanding, action and policy (stickiness and tipping points)
- Improve the quality and length of life for all Americans through improved health early diagnosis and intervention – and where possible – cure
- Avoid wasteful use of resources that are inaccessible or unusable
- Make sure we have a sustainable, national data set
- Make sure we don't miss the handoff!