Health Literacy and HIT: Implications for the New Communication Landscape

Christina Zarcadoolas, PhD
CUNY School of Public Health, Hunter &
Wen-Ying Sylvia Chou, PhD, MPH
Health Communication and Informatics Research Branch, NCI
We have been surrounded by health messages.
When it comes to health information we are…

overfed and undernourished.

Why?
More than half the adults in the US have low health literacy &
Almost half of the population reads @ 8th grade level and lower.
(NALS1993 & NAAL 2003)
What is health literacy?

The wide range of skills, and competencies that people develop over their lifetimes to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life….

(Zarcadoolas, Pleasant & Greer, 2003; 2006)
Literacy

• Over 70% of those 65+ have low literacy skills
• Most health communications materials are written at 10th – 12th grade >
• Web based information is 10th – 17th >
Boldface type indicates chronic disease or condition.
(From DHHS “The Power of Prevention: Steps to a Healthier US Program and Policy Perspective” 2003
http://www.healthierus.gov/steps/summit/prevportfolio/power/index.html#we
Fundamental Literacy

- Reading
- Writing
- Speaking
- Numeracy
An early assumed solution (1980-90’s) – simplify the language

- Easy to read
- Linguistically appropriate
- Culturally relevant
Simplifying does not necessarily lead to improved health literacy

A notice from a health insurer

“Due to the fact that this drug is not on our formulary we are denying your claim for reimbursement.”

Simplified

“We deny (will not pay) your claim. We are denying your claim because this drug is not on our list of approved medications.”
Health literacy demands of previous message:

- The insurance company has the authority to pay or not pay bills – they do not automatically pay for any service or medication, even if the doctor recommends it.
- Insurers use a finite (and often changing) list of allowable medications that they will and will not pay for.
- Not all medicines are the same.
- To greater or lesser degree, consumers must understand that they can:
  - request an appeal,
  - speak to their doctor about an alternative medication and treatment options,
  - think about changing health plans, or even
  - become an advocate for health care reform.
Wardrobe Malfunction

Medication taking -
Is it really a
“reading”/fundamental literacy problem?
Target Guest

AMOXICILLIN 500MG

Take: One capsule by mouth three times daily.

gty: 30
refill: No

Dr. Smith
disp: 02/27/05 REL

Rx: 1234567-0000

(877) 798-2743

TARGET PHARMACY
900 Nicollet Mall
Minneapolis, MN 55401
• 2005 Target debuted its easy-to-read/color coded prescription label

• 2008 - study of 23,745 Target users & 162,368 matched non-Target pharmacy users.

• No statistically significant difference in medication adherence among the two groups.
What does this important health message demand of the consumer/reader?
Clear language is necessary….

But it is **NOT sufficient**.

It will not solve the low health literacy problems in the US.
Understand?

• “Aoccdrnig to a rscheearch at Cmabrigde Uinervtisy, it deosn't mttarer in waht oredr the ltteers in a wrod are, the olny iprmoetnt thng is taht the frist and lsat ltteer be at the rghit pclae. The rset can be a total mses and you can sitll raed it wouthit a porbelm. Tihs is bcuseae the huamn mnid deos not raed ervey lteter by istlef, but the wrod as a wlohe.
Why is 2009 H1N1 virus sometimes called “swine flu”? This virus was originally referred to as “swine flu” because laboratory testing showed that many of the genes in this new virus were very similar to influenza viruses that normally occur in pigs (swine) in North America. But further study has shown that this new virus is very different from what normally circulates in North American pigs. It has two genes from flu viruses that normally circulate in pigs in Europe and Asia and bird (avian) genes and human genes. Scientists call this a "quadruple reassortant" virus.

(www.cdc.gov/h1n1flu/qa.htm)

- Genes
- “new virus”
- Pigs!
4 Domains of Health

- Fundamental literacy
- Science literacy
- Civic literacy
- Cultural literacy

Science Literacy

- Between 5 and 15% of the public qualify as scientifically literate.
- 18% can be considered an attentive science public.
  - fundamental scientific concepts, scientific process
  - **Scientific research**
  - Technology & technical complexity,
  - scientific uncertainty and that rapid change in the accepted science is possible.
Science Literacy in US

• Most know Earth travels around the Sun. √
• But few can successfully define molecule. X
• Most don’t understand the scientific process-hypothesis/testing/evidence. X
• Only 50% know antibiotics don’t kill viruses. X
• More than 50% believe the earliest humans did live at the same time as dinosaurs. X
Civic Literacy

- Judging the source of information
- Making decisions on who to trust
- Media literacy skills
- Knowledge of civic and governmental systems
- Knowledge of power, inequity
- Appreciation that personal behaviors affect larger community
IF SOMEONE WERE SMOKING HERE

SOMEONE COULD GET LUNG CANCER HERE.
Two residents wade through chest-deep water after finding bread and soda from a local grocery store after Hurricane Katrina came through the area in New Orleans, Louisiana. (AFP)
A young man walks through chest deep flood water after looting a grocery store in New Orleans on Tuesday, Aug. 30, 2005. Flood waters continue to rise in New Orleans after Hurricane Katrina did extensive damage when it made landfall on Monday. (AP)
Cultural Literacy

• Ability to recognize, understand and use the collective beliefs, customs, worldview, and social identity

• Bilateral - experts should understand aspects of the culture of the recipient and visa versa.
Percent Distribution of Foreign Born by World Region of Birth: 2000

- Latin America: 51.0%
- Asia: 25.5%
- Europe: 15.3%
- Other Regions: 8.1%
The Sioux San Hospital of Rapid City, South Dakota, is an Indian Health Service (IHS) hospital. (Kibbe Conti, working with Lakota Indians)
The communication technology revolution

Web 2.0
Informatics
eHealth
• 250 million >
users on facebook
worldwide
Who’s Online (PEW 2010)

Demographics of internet users

Below is the percentage of each group who use the internet, according to our December 2010 survey. As an example, 76% of adult women use the internet.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>% who use the internet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total adults</td>
<td>77</td>
</tr>
<tr>
<td>Men</td>
<td>78</td>
</tr>
<tr>
<td>Women</td>
<td>76</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White, Non-Hispanic</td>
<td>80</td>
</tr>
<tr>
<td>Black, Non-Hispanic</td>
<td>69</td>
</tr>
<tr>
<td>Hispanic (English- and Spanish-speaking)</td>
<td>66</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>90</td>
</tr>
<tr>
<td>30-49</td>
<td>84</td>
</tr>
<tr>
<td>50-64</td>
<td>76</td>
</tr>
<tr>
<td>65+</td>
<td>46</td>
</tr>
<tr>
<td><strong>Household income</strong></td>
<td></td>
</tr>
<tr>
<td>Less than $30,000/yr</td>
<td>63</td>
</tr>
<tr>
<td>$30,000-$49,999</td>
<td>79</td>
</tr>
<tr>
<td>$50,000-$74,999</td>
<td>92</td>
</tr>
<tr>
<td>$75,000+</td>
<td>96</td>
</tr>
<tr>
<td><strong>Educational attainment</strong></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>40</td>
</tr>
<tr>
<td>High School</td>
<td>69</td>
</tr>
<tr>
<td>Some College</td>
<td>89</td>
</tr>
<tr>
<td>College +</td>
<td>93</td>
</tr>
<tr>
<td><strong>Community type</strong></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>78</td>
</tr>
<tr>
<td>Suburban</td>
<td>80</td>
</tr>
<tr>
<td>Rural</td>
<td>68</td>
</tr>
</tbody>
</table>
• 69 percent of African Americans and 58 percent of Hispanics now regularly use the Internet, compared with 79 percent of whites.

• Rate of broadband adoption in African American homes has risen to 59 percent from the 46 percent. (Joint Commission for Political and Economic Studies, 2/25/10 National Minority Broadband Adoption: Comparative Trends in Adoption, Acceptance and Use, Joint Center’s website at (www.jointcenter.org)
African-Americans and Hispanics leading the charge in growth of mobile.

• 46 % of non-Hispanic blacks and 51% of English-speaking Hispanics use their phones for internet access, compared with 33 percent of non-Hispanic white Americans. (poll not in Spanish language)

• “This is my laptop”

Web 2.0 Crowd Sourcing

Editing places in Google Maps

3145 Fillmore St
San Francisco, CA 94123
(415) 931-8898

Edit
What's this?
Move marker - Edit details - Remove place
View history - Flag as inappropriate

Are you the owner? Claim your business

« Back
Texting

- 75% of teens have cell phones (up 45%/2004)
- They send 50 - 100 text messages a day
- Nearly three quarters (73%) of online teens and an equal number (72%) of young adults use social network sites.
Their Media Diet

12 Hours

Media Consumption

Source: 2009 Alloy College Explorer

- **Computer**: 5.0 hours
- **Television**: 2.5 hours
- **Mobile Device**: 2.4 hours
- **MP3 Player**: 1.3 hours
- **Gaming Device**: 0.75 hours
Empowering Communities with Direct Access to Health Data

Christina Zarcadoolas, PhD, Wendy Vaughon, MPH
With Sara J. Czaja, PhD,
Maxine L. Rockoff, PhD, Joslyn Levy MPA
NIH R21 1 R21 CA133487-01A2
SBM
April 28, 2011
Overview Current Study

• What are people’s perceptions of portals – utility, value & likelihood to use
• Identify readability & navigability - usability
• Focus on 3 common functions of EMRs:
  – Medication management
  – Lab/test results
  – Health maintenance/prevention
Methods

• Initial task analysis, readability & health literacy load analysis of a wide range of portals (reviewed 30)
• Focus groups with consumers
• Usability testing of 3 portals with $\approx 55$ consumers using “dummy” patient profiles
• Analyze data - develop preliminary best practice guidelines for design
Focus Group Participants’ Experience with IT (N=28)

- 100% had computer experience
  - 66.7% had a home computer

- 93% had experience with the Internet

- 75% (of users) had Internet access at home

- All participants used a cell phone, 57% had a smart phone they used occasionally to frequently
Common Themes Across Groups (a)

- Consumers unanimously very interested in patient accessible EMRs although most didn’t have access to one.
- Age associated with use of social media/technology.
- Physical access to technology not a primary barrier.
- Many participants accessed the internet wirelessly using mobile technology.
  
  “This is my laptop.”

- High interest in lab/test results, but reviewing results, posed unusually high reading and numeracy demands
  - “If I could read it and understand it [I would use it] … I can’t understand it.”
Common Themes Across Groups (c)

Access empowers

● “Information is power.”

● “It all boils down to the same thing … a lot of people don’t take charge of their health because they don’t … remember to take care of themselves and a lot of times they don’t even know at what age they should be checking for what things.”
A few had privacy concerns

“It might just make them [children] more hesitant to disclose things to their doctor if they know that their parents can view this … might just make them not want to say things that they don’t want their parents to know”

Some had security concerns.

“I’m a little leery about putting my information on these internets. I mean, I don’t even do banking on the internet.”
<table>
<thead>
<tr>
<th>Subtasks/Steps</th>
<th>Sensory/Perceptual Demands</th>
<th>Cognitive Demands</th>
<th>Literacy/Readability Demands</th>
<th>Response Execution Demands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access correct med info</td>
<td>Locate/identify medication; locate dosage information</td>
<td>Read labels, discriminate among types of meds; ignore irrelevant info on page; Comprehend dosage info</td>
<td>Comprehension of unfamiliar/difficult words; discriminate name from instructions; read directive language</td>
<td>Ability to scroll on page</td>
</tr>
<tr>
<td>Locate medication instruction info</td>
<td></td>
<td>Ignore irrelevant information and discriminate between dosage &amp; instruction; Discriminate between various meds; Read/understand med instructions; compute &amp; use simple manipulation of numbers</td>
<td>Familiarity with symbols and indexical clues (Rx) Comprehend abbreviations and sentence fragments - “I tablet twice daily” and deleted syntax</td>
<td></td>
</tr>
</tbody>
</table>
# Health Literacy Load Analysis

<table>
<thead>
<tr>
<th>Component</th>
<th>Your Value</th>
<th>Standard Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHOLESTEROL</td>
<td>210</td>
<td>100 - 199 mg/dL</td>
</tr>
<tr>
<td>LDL CHOLESTEROL</td>
<td>141</td>
<td>0 - 99 mg/dL</td>
</tr>
<tr>
<td>HDL CHOLESTEROL</td>
<td>49</td>
<td>40 - 59 mg/dL</td>
</tr>
<tr>
<td>TRIGLYCERIDES</td>
<td>183</td>
<td>≤ 150 mg/dL</td>
</tr>
</tbody>
</table>

## General Information

<table>
<thead>
<tr>
<th>Health Literacy Load</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understand #s symbolic and interpretable</td>
</tr>
<tr>
<td>Comprehension of terms: “Your Value”, Standard Range, mg/dL</td>
</tr>
<tr>
<td>Compute where 210 fits in 100-199</td>
</tr>
<tr>
<td>Science literacy-cholesterol risk, possible further statistical interpretation abilities(probabilities)</td>
</tr>
</tbody>
</table>
Common Health Literacy Barriers Found in EMRs - Readability/Task Analysis

- Complex vocabulary, sentence structure (language)
- Poor design and navigation
- High health literacy load
- High numeracy demands, especially in the presentation of lab/test results
- Prevention and maintenance information was important to participants, but current systems use a wide range of packaged patient education, none ideally controlled for literacy or health literacy.
Current Stage of Study: Usability Testing

- 54, 2 hr. one on one usability sessions
  - includes computer/internet training for all participants, regardless of prior experience
- Review 3 patient portals to perform tasks:
  - Medication management
  - Lab/test results
  - Health maintenance (preventive care)
Snapshot Preliminary Findings “in the field”

• System ‘1’
  – 3/24 located the problem list
  – 12/24 determined if medications could be refilled
  – 12/24 determined if test results were normal or abnormal

• System ‘2’
  – 8/24 located recommendations for cancer screening tests
  – 14/24 found information about side effects for the medication
  – 14/24 found past test results

• System ‘3’
  – 11/24 located the problem list
  – 11/24 found lab/test results
  – 8/24 found past results
Portal Example - linguistic labelling
Problems Encountered

• Mismatch between user’s linguistic search strategies and portal language.

“A lot of the places I clicked on was not what I expected.”
Problems Encountered

- Reading complex language and abbreviations, e.g., “pure hypercholesterolemia”, “LDL”, “PHR”
- Symbols < >
## Portal Example - Symbols

<table>
<thead>
<tr>
<th>Name</th>
<th>Due Date</th>
<th>Status</th>
<th>Last Done</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumococcal Vaccine (Pneumovax)</td>
<td>Completed</td>
<td>09/26/2006</td>
<td></td>
</tr>
<tr>
<td>Bone Densitometry</td>
<td>&gt; 5 years ago</td>
<td>Overdue</td>
<td></td>
</tr>
<tr>
<td>Stool Test For Blood</td>
<td>&gt; 5 years ago</td>
<td>Overdue</td>
<td></td>
</tr>
<tr>
<td>Colorectal Cancer Screening Discussion</td>
<td>&gt; 5 years ago</td>
<td>Overdue</td>
<td>03/24/1992</td>
</tr>
<tr>
<td>Diabetic Eye Exam</td>
<td>01/13/2005</td>
<td>Overdue</td>
<td>01/13/2004</td>
</tr>
<tr>
<td>Diabetic Foot Exam</td>
<td>01/13/2005</td>
<td>Overdue</td>
<td>01/13/2004</td>
</tr>
<tr>
<td>Glycohemoglobin</td>
<td>02/20/2008</td>
<td>Overdue</td>
<td>08/20/2007</td>
</tr>
<tr>
<td>Lipid Screening</td>
<td>07/18/2008</td>
<td>Overdue</td>
<td>07/18/2007</td>
</tr>
<tr>
<td>Influenza Vaccine</td>
<td>10/01/2008</td>
<td></td>
<td>09/26/2006</td>
</tr>
<tr>
<td>Mammogram</td>
<td>02/22/2010</td>
<td></td>
<td>02/22/2008</td>
</tr>
<tr>
<td>Pap Smear</td>
<td>01/02/2011</td>
<td></td>
<td>01/02/2008</td>
</tr>
<tr>
<td>Tetanus And Diphtheria Vaccine</td>
<td>08/17/2017</td>
<td></td>
<td>08/17/2007</td>
</tr>
<tr>
<td>Sigmoidoscopy</td>
<td>08/17/2017</td>
<td></td>
<td>08/17/2007</td>
</tr>
</tbody>
</table>
# Portal Example - Numeracy

**COMPLETE BLOOD COUNT (BLOOD)**

<table>
<thead>
<tr>
<th>DATE</th>
<th>WBC 4.0-11.0 K/uL</th>
<th>RBC 4.6-6.2 m/uL</th>
<th>Hgb 14.0-18.0 g/dL</th>
<th>Hct 40-52 %</th>
<th>MCV 82-98 fl</th>
<th>MCH 27-32 pg</th>
<th>MCHC 31-35 %</th>
<th>RDW 10.5-15.5 %</th>
<th>CHCM</th>
</tr>
</thead>
<tbody>
<tr>
<td>33/17/10 1:54P</td>
<td>23.3*#</td>
<td>2.58*#</td>
<td>9.0*#</td>
<td>25.3*#</td>
<td>98#</td>
<td>34.9*#</td>
<td>35.6*</td>
<td>16.9*</td>
<td></td>
</tr>
<tr>
<td>33/17/10 1:27P</td>
<td>4.0</td>
<td>4.61</td>
<td>12.8*</td>
<td>37.9*</td>
<td>82</td>
<td>27.9</td>
<td>33.9</td>
<td>12.3</td>
<td></td>
</tr>
<tr>
<td>33/17/10 1:26P</td>
<td>10.0#</td>
<td>3.72*</td>
<td>11.6*</td>
<td>34.1*</td>
<td>92#</td>
<td>31.2*</td>
<td>34.0</td>
<td>13.3</td>
<td></td>
</tr>
<tr>
<td>33/17/10 11:25A</td>
<td>3.9*#</td>
<td>4.49*</td>
<td>12.6*</td>
<td>36.9*</td>
<td>82</td>
<td>28.1</td>
<td>34.1</td>
<td>12.4</td>
<td></td>
</tr>
<tr>
<td>33/11/10 9:38A</td>
<td>8.7#</td>
<td>3.89*#</td>
<td>12.1*#</td>
<td>34.0*#</td>
<td>88#</td>
<td>31.2</td>
<td>35.7*</td>
<td>13.6</td>
<td></td>
</tr>
<tr>
<td>33/11/10 9:37A</td>
<td>4.8#</td>
<td>2.71*</td>
<td>9.1*</td>
<td>26.6*</td>
<td>98</td>
<td>33.7*</td>
<td>34.3</td>
<td>16.4*</td>
<td></td>
</tr>
<tr>
<td>33/10/10 9:17A</td>
<td>2.3*</td>
<td>2.56*</td>
<td>8.7*</td>
<td>26.0*</td>
<td>102*</td>
<td>34.2*</td>
<td>33.6</td>
<td>19.8*</td>
<td></td>
</tr>
<tr>
<td>33/10/10 9:17A</td>
<td>11.6*#</td>
<td>5.03#</td>
<td>13.8*#</td>
<td>41.4*#</td>
<td>82#</td>
<td>27.5#</td>
<td>33.3</td>
<td>13.3</td>
<td></td>
</tr>
<tr>
<td>33/10/10 9:16A</td>
<td>10.0#</td>
<td>2.76*</td>
<td>9.2*</td>
<td>27.7*</td>
<td>101*#</td>
<td>33.4*</td>
<td>33.3</td>
<td>16.5*</td>
<td></td>
</tr>
<tr>
<td>33/10/10 9:15A</td>
<td>10.0#</td>
<td>3.09*</td>
<td>9.4*</td>
<td>28.5*</td>
<td>92</td>
<td>30.4</td>
<td>32.9</td>
<td>16.8*</td>
<td></td>
</tr>
</tbody>
</table>
### Patient Portal - Numeracy

**CHOLESTEROL PANEL**

<table>
<thead>
<tr>
<th>Component</th>
<th>Your Value</th>
<th>Standard Range</th>
<th>Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRIGLYCERIDES</td>
<td>183</td>
<td>&lt;150</td>
<td>mg/dL</td>
</tr>
<tr>
<td>HDL</td>
<td>39</td>
<td>40 - 59</td>
<td>mg/dL</td>
</tr>
<tr>
<td>CHOLESTEROL</td>
<td>240</td>
<td>100 - 199</td>
<td>mg/dL</td>
</tr>
<tr>
<td>LDL CHOLESTEROL</td>
<td>164</td>
<td>0 - 99</td>
<td>mg/dL</td>
</tr>
</tbody>
</table>

[View Historical Results]

**General Information**
Patient Portals – Lab Results

LIPID PANEL - Historical Results

The data for the result components that you selected are displayed below. Adjust the date range to display more or less data. Enter the dates in the format of mm/dd/yy or you can use "t" or "T" to specify today's date (t-1 to specify yesterday, etc). Use the Chart, Line Graph and Bar Graph buttons to see different views of the data.

Data Selection

Select data to view:

- 10 most recent values

Graph of lab results over time
### Health Literacy Load Analysis

<table>
<thead>
<tr>
<th>Component</th>
<th>Your Value</th>
<th>Standard Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHOLESTEROL</td>
<td>210</td>
<td>100 - 199 mg/dL</td>
</tr>
<tr>
<td>LDL CHOLESTEROL</td>
<td>141</td>
<td>0 - 99 mg/dL</td>
</tr>
<tr>
<td>HDL CHOLESTEROL</td>
<td>40</td>
<td>40 - 59 mg/dL</td>
</tr>
<tr>
<td>TRIGLYCERIDES</td>
<td>103</td>
<td>&lt;150 mg/dL</td>
</tr>
</tbody>
</table>

### General Information

<table>
<thead>
<tr>
<th>Health Literacy Load</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understand #s symbolic and interpretable</td>
</tr>
<tr>
<td>Comprehension of terms: “Your Value”, Standard Range, mg/dl</td>
</tr>
<tr>
<td>Compute where 210 fits in 100-199</td>
</tr>
<tr>
<td>Science literacy-cholesterol risk, possible further statistical interpretation abilities(probabilities)</td>
</tr>
</tbody>
</table>


1. Know your audience

• ... the audience you have
• ... the audience you want
2. Know your material

- ... the text you have
- ... the text you need to have
3. Collaborate with target audience

Dissemination vs collaboration

• Are your main “outreach” activities informed by audience input?
• Are you getting input from consumers/patient throughout (start/formative/evaluative)?
  – Content
  – How that content needs to be framed to resonate with consumers
  – Who is informing culturally framed messages
Strategies

1. Use health literacy principles to ask and re-ask WHY questions
2. Identify roles of culture and identity
3. Use appropriate social marketing to make messages noticeable
4. Think in the right medium/s
5. Strive for shared decision making & empowerment
4. **Conduct a Health Literacy Load Analysis**

What does the material/message assume/require of the patient

– Fundamental literacy
– Science literacy
– Civic literacy
– Cultural literacy
5. Be Reflexible

- Explore how your messages are holding up - what’s the evidence to support your approach?
- Be prepared to revise.
Health Literacy Initiative - parting words

It is important that there is:

• institutional support
• a multidisciplinary team to address issues...and,
• budget!
Advancing Health Literacy
A Framework for Understanding and Action

By
Christina Zarcadoolas
Andrew Pleasant
David S. Greer

Christina.zarcadoolas@mssm.edu