

Health Literacy and HIT: Implications for the New Communication Landscape

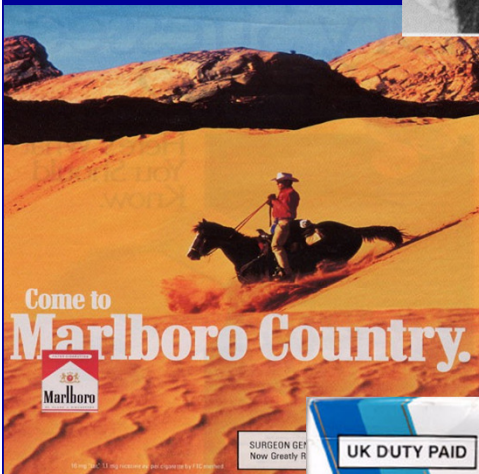
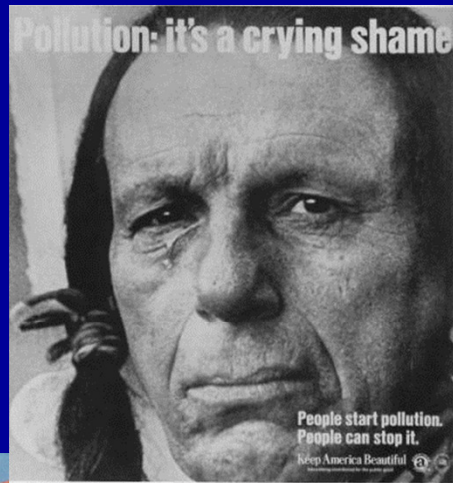
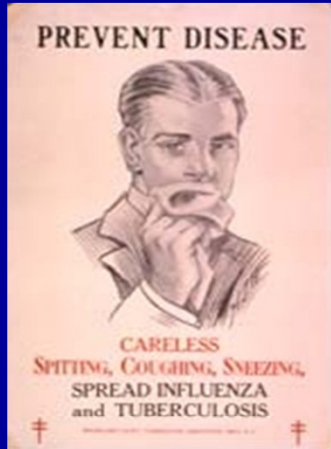
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CUNY School of Public Health, Hunter &

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Health Communication and Informatics Research Branch, NCI

We have been surrounded by health messages



"WHEN I HAVE AN ASTHMA ATTACK I FEEL LIKE A FISH WITH NO WATER."

-JESSE, AGE 5

ATTACK ASTHMA. ACT NOW.
1-866-NO-ATTACKS
 WWW.NOATTACKS.ORG

How many cigarettes does it take to cause a heart attack?

Answer: ONE

You start damaging your artery walls the day you start smoking. Your next puff on a cigarette could trigger a heart attack.

CALL FOR FREE Nicotine Patches

Call the Quitline
1-866-NY-QUITS
 (1-866-697-8487)

Every cigarette is doing you damage.
www.doingyoudamage.com
 Sponsored by: The Western New York Tobacco Free Program

Ad Council

TAKE A SMALL STEP TO GET HEALTHY. Get started at www.smallstep.gov

UK DUTY PAID

Smoking clogs the arteries and causes heart attacks and strokes

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)

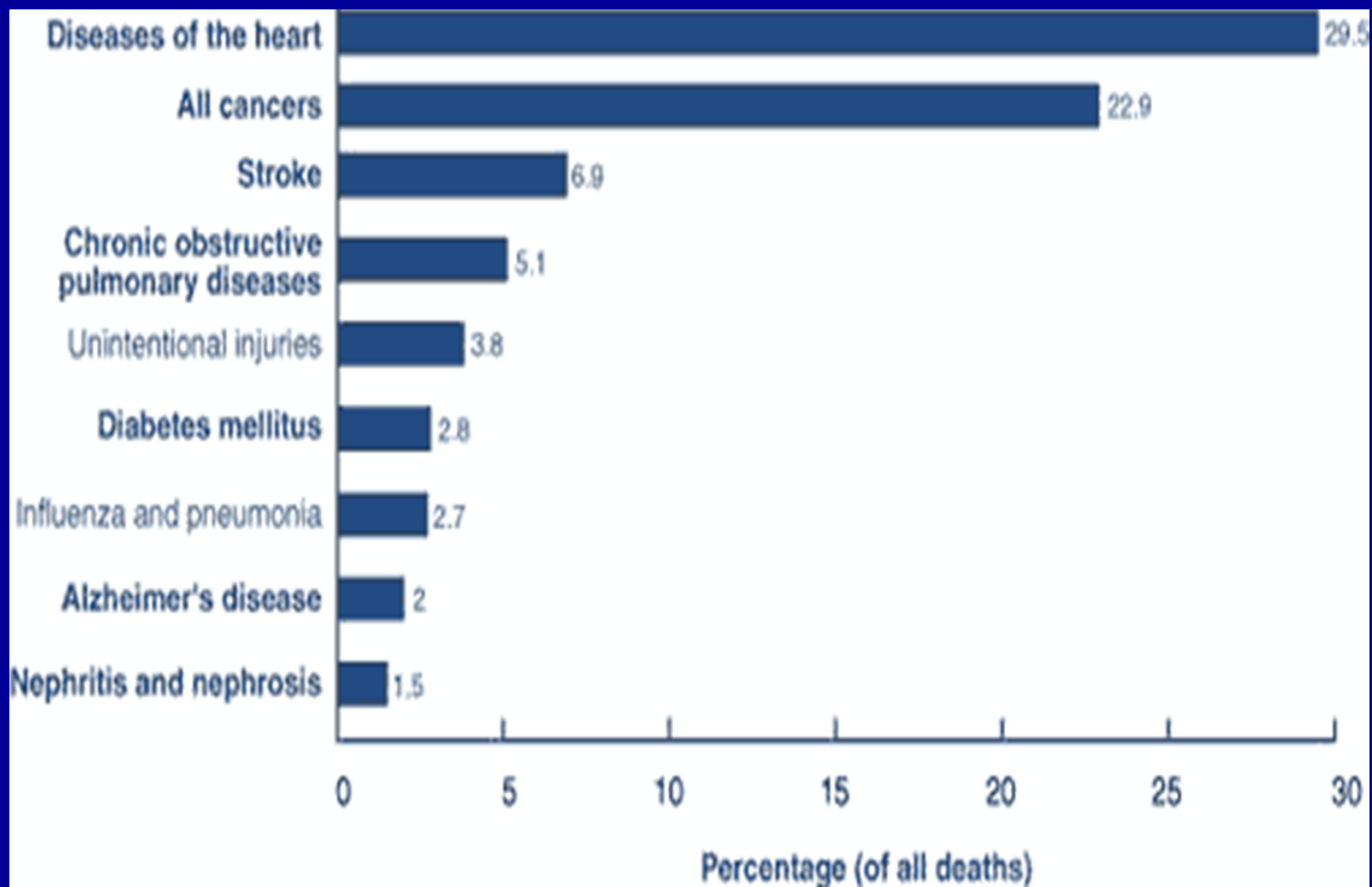
What is health literacy?

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.

Source: National Center for Health Statistics, *Mortality Report*. Hyattsville, MD: U.S. Department of Health and Human Services, 2002.

(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.

F



The Pharmacy America Trusts

200 WILMOT RD
DEERFIELD, IL 60015

PH (800)555-5555

A

DR D. INTERCOM

B

NO 0060023-08291

DATE 05/14/02

D

JOHN SMITH
123 MAIN STREET ANYTOWN, US 11111

C

TAKE ONE CAPSULE BY
MOUTH THREE TIMES DAILY
FOR 10 DAYS UNTIL ALL
TAKEN

K

E

AMOXICILLIN 500MG CAPSULES

I

G

QTY 30 MFG TEVA
NO REFILLS - DR. AUTHORIZATION REQUIRED

USE BEFORE 05/14/03
SLF/SLF

J

Rx ONLY

H



Wardrobe Malfunction

Medication taking -

Is it really a
“reading”/fundamental literacy
problem?

Target Guest

AMOXICILLIN 500MG

Take: One capsule by mouth
three times daily.

qty: 30

refills: No

Dr. Smith

disp: 02/27/05 REL

mfr: GENEVA

NDC: 00781-2613-05

(877) 798-2743

Rx: 1234567-0000

TARGET PHARMACY

900 Nicollet Mall
Minneapolis, MN 55401

PATIENT INFO CARD



- 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?



TAKE CHARGE OF YOUR CARE.

EVERYBODY KNOWS:

TO KILL A VIRUS YOU TAKE ANTIBIOTICS.

WRONG.

IMPROPER USE OF ANTIBIOTICS CREATES AND SPREADS HIGHLY RESISTANT STRAINS OF BACTERIA.

- ▶ If your doctor says you have a cold or the flu, never request an antibiotic.
- ▶ When prescribed an antibiotic, take it well it is gone — even if you feel better.
- ▶ Always take an antibiotic exactly as the doctor orders.

At United Health Foundation, we believe that the more you know, the healthier you will be. Which is why we partnered with the CENTERS FOR DISEASE CONTROL AND PREVENTION to bring you these important health tips. We encourage you to get more involved in your care, to seek out information and to always make sure the information you use comes from a reliable, science-based source. To find out more on this and other important topics, visit UHF.org.

United Health Foundation™

GET IT SMART

Clear language is
necessary....

But it is **NOT sufficient.**

**It will not solve the low health
literacy problems in the US**

Understand?

- “According to a research at Cambridge University, it doesn't matter in what order the letters in a word are, the only important thing is that the first and last letter be at the right place. The rest can be a total mess and you can still read it without a problem. This is because the human mind does not read every letter by itself, but the word as a whole.



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.

- Genes
- "new virus"
- Pigs!

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

4 Domains of Health

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

(Zarcadoolas, Pleasant & Greer, *Advancing Health Literacy: A Framework for Understanding and Action*, 2006)

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.

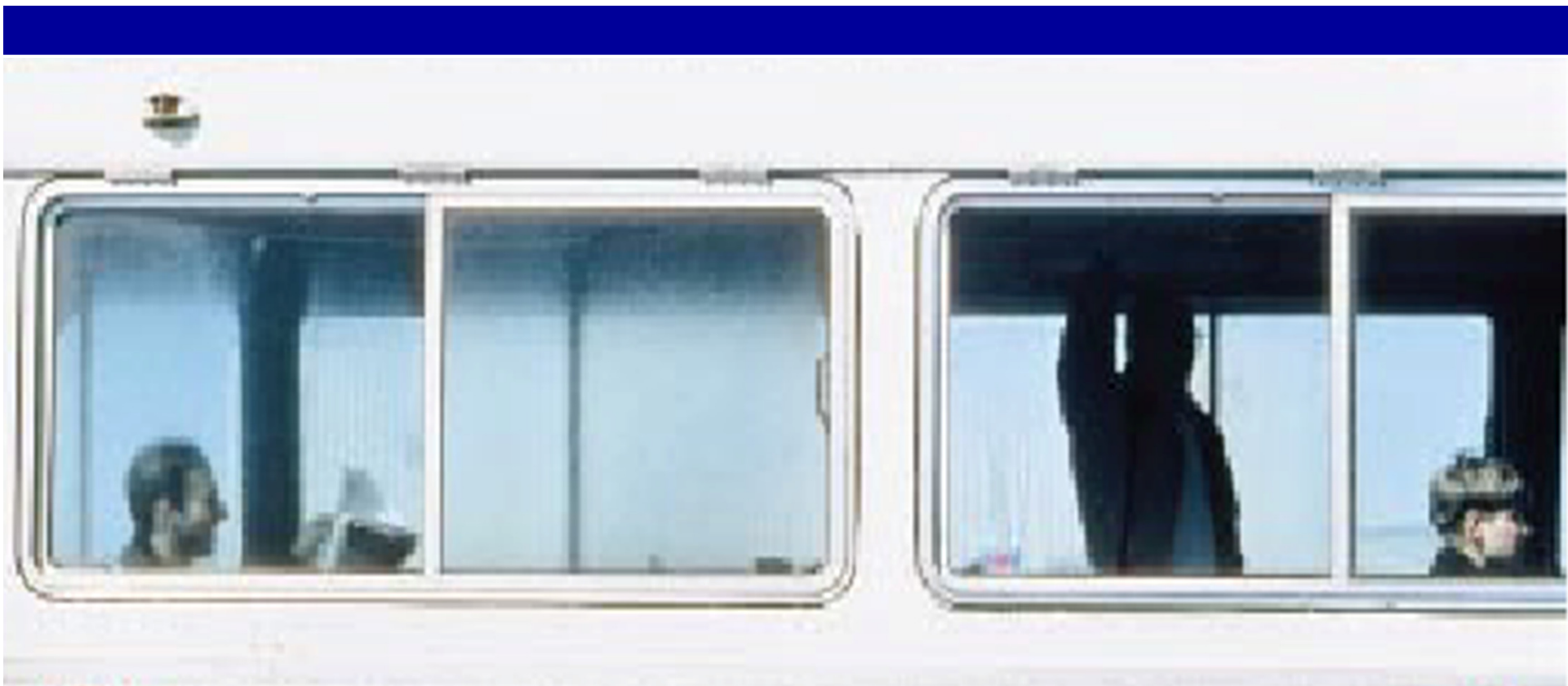


Science Literacy in US

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

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.**





AFP/Getty
3:47 AM

Two residents waded 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/Getty)

[Email Photo](#) [Print Photo](#)

RECOMMEND THIS PHOTO [Recommend It](#)

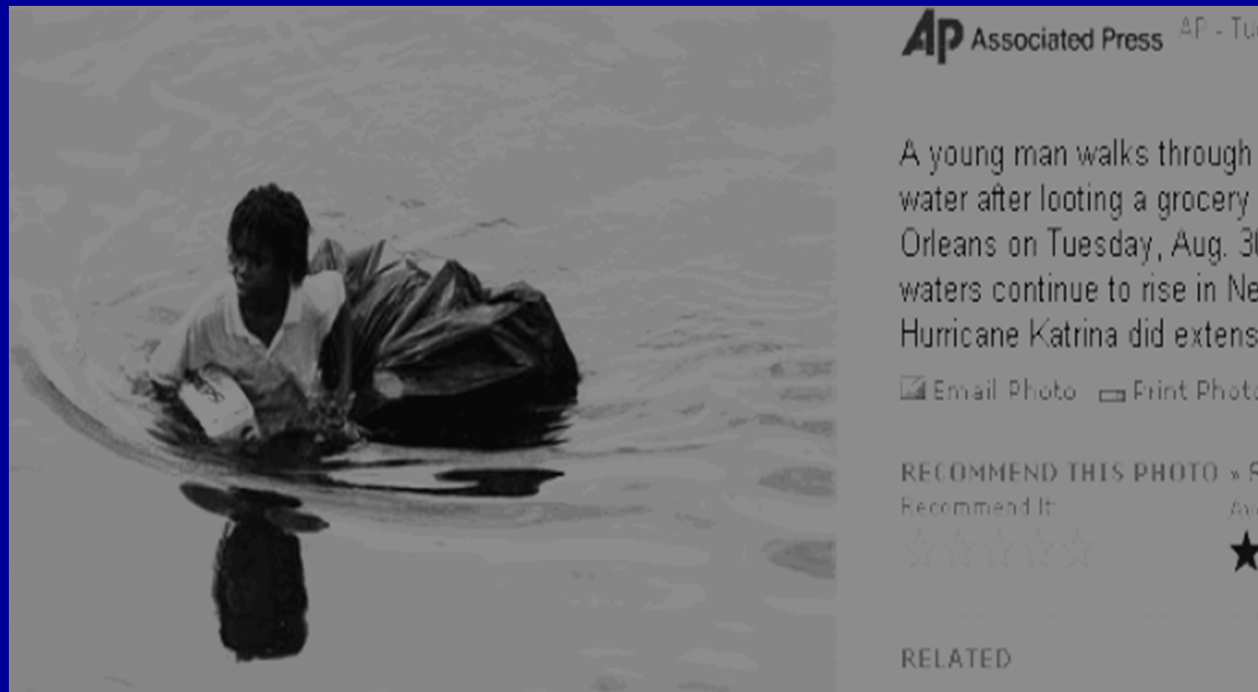


RELATED

- Katrina's Effects, at a Glance
- Hurricanes & Tropical Storms

[photo caption reads]

Two residents waded 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)



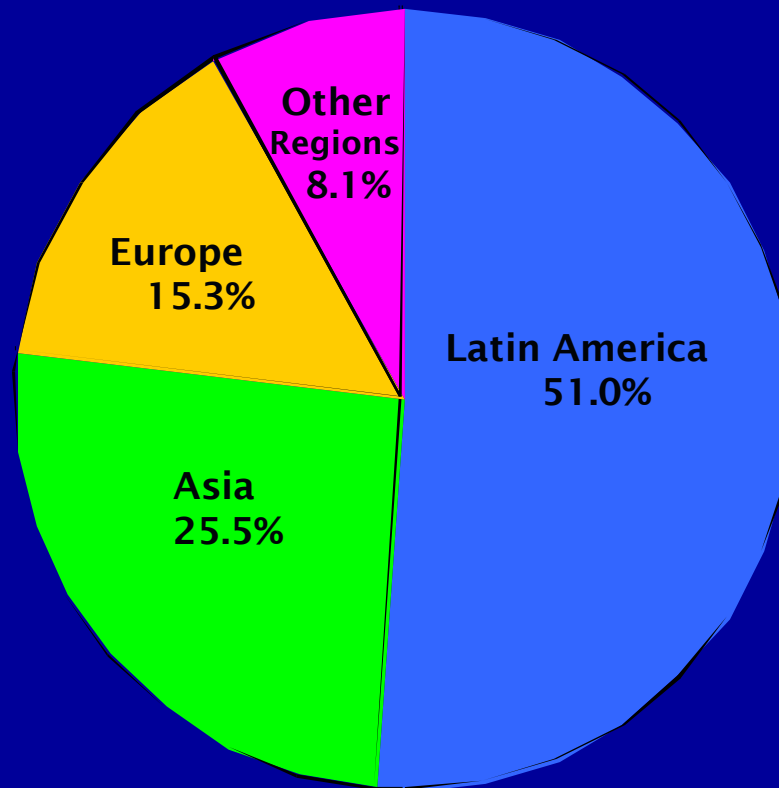
[photo caption reads]

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, world-view, 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



Modern Times

1950s to Today

Today we don't always eat in balance.

For the first time we no longer honor the four lessons of the Medicine Wheel.

1. Our drinks became sweetened and/or contained alcohol.
2. Our meats became fatty and had less protein.
3. We lacked good access to fruits and vegetables and consumed less.
4. We ate grains and starchy vegetables in large quantities, often fried.

At the same time the health of our Nation suffered.



- The Sioux San Hospital of Rapid City, South Dakota, is an Indian Health Service (IHS) hospital. (Kibbe Conti, working with Lakota Indians

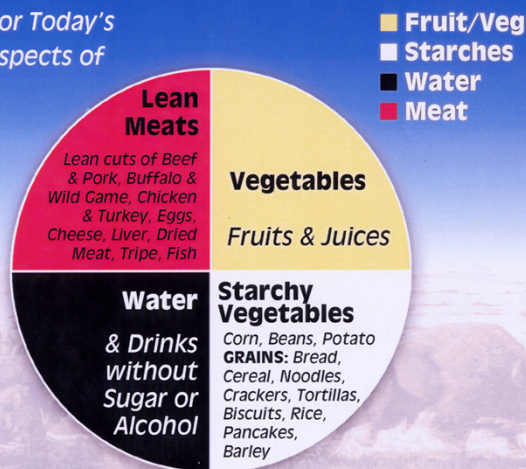
Four Winds Nutrition Guide

BUILDING A HEALTHIER PLATE FOR TODAY

A Balanced Plate of Food for Today's Lakota includes the Four Aspects of Our Ancestral Diet:

1. Water
2. Lean Meat / Protein
3. Fruit or Vegetable
4. Starch / Grain

In a balanced meal, no food group dominates the plate.



The communication technology revolution

Web 2.0

Informatics

eHealth

- 250 million > users on facebook worldwide

facebook

Facebook helps you connect and share with the people in your life.



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.

	% who use the internet
Total adults	77
Men	78
Women	76
Race/ethnicity	
White, Non-Hispanic	80
Black, Non-Hispanic	69
Hispanic (English- and Spanish-speaking)	66
Age	
18-29	90
30-49	84
50-64	76
65+	46
Household income	
Less than \$30,000/yr	63
\$30,000-\$49,999	79
\$50,000-\$74,999	92
\$75,000+	96
Educational attainment	
Less than High School	40
High School	69
Some College	89
College +	93
Community type	
Urban	78
Suburban	80
Rural	68

the modes of their daily lives

Broad Band Use (2010)

- **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”

<http://www.pewinternet.org/Reports/2010/Mobile-Access-2010.aspx>



<http://techcrunch.com/2008/07/11/nielsen-iphone-in-fourth-place-among-smartphones-first-in-customer-satisfaction-not-for-long/>

Web 2.0 Crowd Sourcing

Editing places in Google Maps

☆☆☆☆☆ 7 reviews - [more info](#) »

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



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0:00 / 0:42

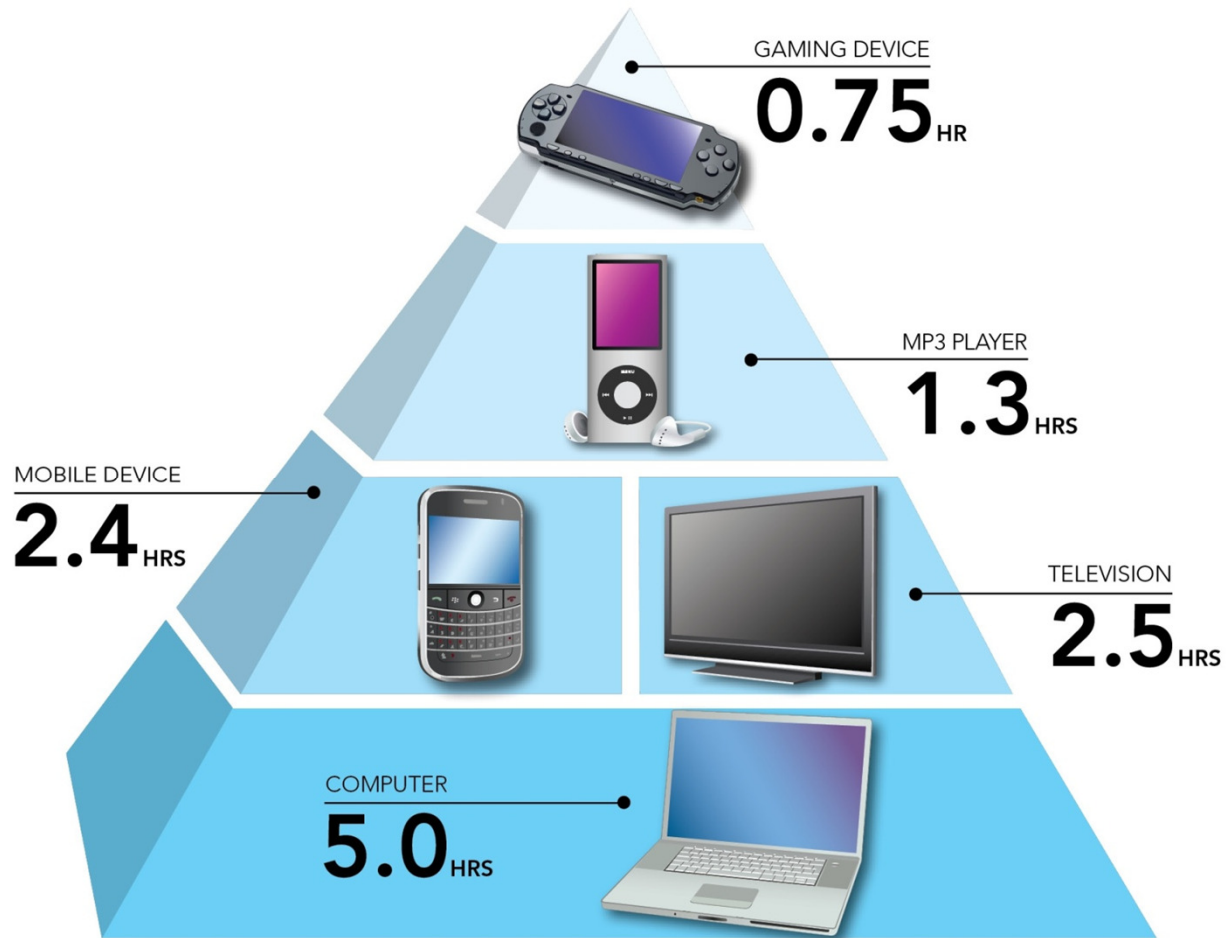
Texting



- 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
Media



Source: 2009 Alloy College Explorer

Empowering Communities with Direct Access to Health Data



Christina Zarcadoolas, PhD, Wendy Vaughn, 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 ≈ 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.”*

Few Privacy/Security Concerns

- 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.”

R_x LIPITOR 10 MG OR TABS
 ⓘ About This Medication
Instructions: 1 tablet by mouth nightly
 Prescribed by ADAM SZERENCZY, D.O. on 12/28/2009
[Request a renewal](#)

R_x ASPIRIN 81 MG OR TBEC
 ⓘ About This Medication
Instructions: 1 tablet by mouth daily
 Prescribed by ADAM SZERENCZY, D.O. on 12/28/2009
[Request a renewal](#)

R_x METFORMIN HCL 500 MG OR TABS
 ⓘ About This Medication
Instructions: 1 tablet twice daily
 Prescribed by ADAM SZERENCZY, D.O. on 12/28/2009
[Request a renewal](#)

Subtasks/steps	Sensory/Perceptual Demands	Cognitive Demands	Literacy/Readability Demands	Response Execution Demands
Access correct med info	Locate /identify medication; locate dosage information	Read labels , discriminate among types of meds; Ignore irrelevant info on page; Comprehend dosage info	Comprehension of unfamiliar/difficult words; discriminate name from instructions; read directive language	Ability to scroll on page
	Locate medication instruction information	Ignore irrelevant information and discriminate between dosage & instruction; Discriminate between various meds; Read/ understand med instructions; compute & use simple manipulation of numbers	Familiarity with symbols and indexical clues (Rx) Comprehend abbreviations and sentence fragments - “1 tablet twice daily” and deleted syntax	

Health Literacy Load Analysis

Component Results		
Component	Your Value	Standard Range
CHOLESTEROL	210	100 - 199 mg/dL
LDL CHOLESTEROL	141	0 - 99 mg/dL
HDL CHOLESTEROL	43	40 - 59 mg/dL
TRIGLYCERIDES	163	- <150 mg/dL

General Information

			Health Literacy Load	
			Understand #s symbolic and interpretable	
			Comprehension of terms: "Your Value", Standard Range, mg/dl	
			Compute where 210 fits in 100-199	
			Science literacy-cholesterol risk, possible further statistical interpretation abilities(probabilities)	

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

Welcome, A Ztest Home Log Out

My Medical Record

- Health Summary
- Test Results
- Medications
- Allergies
- Immunizations
- Preventive Care
- Medical History
- Current Health Issues
- Health Trends
- Letters

Message Center


Refills/Referrals

Appointments

Administrative

Preferences


Directory



Medications

Click on **About This Medication** to see additional information regarding a medication.

If you have no refills left for a prescription, you may want to [request a renewal](#).

 **HELP**

R_x AMBIEN 10 MG OR TABS

[About This Medication](#)

Instructions: 1 Tablet At Bedtime As Needed

Prescribed by [Yuming Wang](#) on 03/28/08

[Request a renewal](#)

R_x PROGRAF 0.5 MG OR CAPS

[About This Medication](#)

Instructions: 6 Capsules Twice Daily

Prescribed by [Frank Czeklinski](#) on 03/17/08

[Request a renewal](#)

R_x TYLENOL/CODEINE #2 TABS 300-15 MG OR

[About This Medication](#)

Instructions: 1 Or 2 Tablets Every 4 To 6 Hours As Needed

Prescribed by [Frank Czeklinski](#) on 03/17/08

[Request a renewal](#)

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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

Name	Due Date	Status	Last Done
Pneumococcal Vaccine (Pneumovax)		Completed	09/26/2006
Bone Densitometry	> 5 years ago	Overdue	
Stool Test For Blood	> 5 years ago	Overdue	
Colorectal Cancer Screening Discussion	> 5 years ago	Overdue	03/24/1992
Diabetic Eye Exam	01/13/2005	Overdue	01/13/2004
Diabetic Foot Exam	01/13/2005	Overdue	01/13/2004
Glycohemoglobin	02/20/2008	Overdue	08/20/2007
Lipid Screening	07/18/2008		07/18/2007
Advance Directive Discussion	07/20/2008		07/20/2007
Influenza Vaccine	10/01/2008		09/26/2006
Mammogram	02/22/2010		02/22/2008
Pap Smear	01/02/2011		01/02/2008
Tetanus And Diphtheria Vaccine	08/17/2017		08/17/2007
Sigmoidoscopy	08/17/2017		08/17/2007

Portal Example - Numeracy

COMPLETE BLOOD COUNT (BLOOD)


DATE	WBC 4.0-11.0 K/uL	RBC 4.6-6.2 m/uL	Hgb 14.0-18.0 g/dL	Hct 40-52 %	MCV 82-98 fL	MCH 27-32 pg	MCHC 31-35 %	RDW 10.5-15.5 %	CHCM
03/17/10 1:54P	23.3*#	2.58*#	9.0*#	25.3*#	98#	34.9*#	35.6*	16.9*	
03/17/10 1:27P	4.0	4.61	12.8*	37.9*	82	27.9	33.9	12.3	
03/17/10 1:26P	10.0#	3.72*	11.6*	34.1*	92#	31.2#	34.0	13.3	
03/17/10 11:25A	3.9*#	4.49*	12.6*	36.9*	82	28.1	34.1	12.4	
03/11/10 9:38A	8.7#	3.89*#	12.1*#	34.0*#	88#	31.2	35.7*	13.6	
03/11/10 9:37A	4.8#	2.71*	9.1*	26.6*	98	33.7*	34.3	16.4*	
03/10/10 9:17A	2.3*	2.56*	8.7*	26.0*	102*	34.2*	33.6	19.8*	
03/10/10 9:17A	11.6*#	5.03#	13.8*#	41.4#	82#	27.5#	33.3	13.3	
03/10/10 9:16A	10.0#	2.76*	9.2*	27.7*	101*#	33.4*	33.3	16.5*	
03/10/10 9:15A	10.0#	3.09*	9.4*	28.5*	92	30.4	32.9	16.8*	

Patient Portal - Numeracy



CHOLESTEROL PANEL



 [About This Test](#)

Component Results

Component	Your Value	Standard Range	Units
TRIGLYCERIDES	183	<150	mg/dL
HDL	39	40 - 59	mg/dL
CHOLESTEROL	240	100 - 199	mg/dL
LDL CHOLESTEROL	164	0 - 99	mg/dL

[View Historical Results](#)

General Information

Patient Portals – Lab Results

- ▶ Proxy
- ▶ My Health Tools
- ▼ My Tests
 - Test Results
 - Test Results Summary
 - Tests Ordered
- ▶ Message Center
- ▶ Ask Medical Advice
- ▶ Appointments
- ▶ Prescriptions
- ▶ My Health Record
- ▶ My Personal Information
- ▶ Customer Service
- ▶ My Health Resources

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.

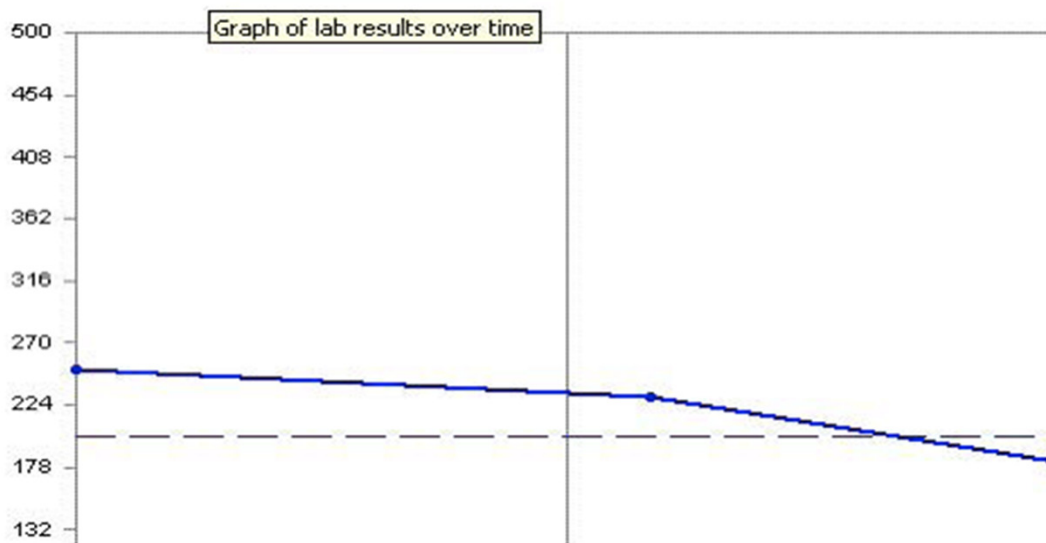
Data Selection

Select data to view:

- 10 most recent values
 Values from 12/4/2007 to 3/3/2008

Apply

Graph



Health Literacy Load Analysis

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			Science literacy-cholesterol risk, possible further statistical interpretation abilities(probabilities)	

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



Photo by Caroline

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

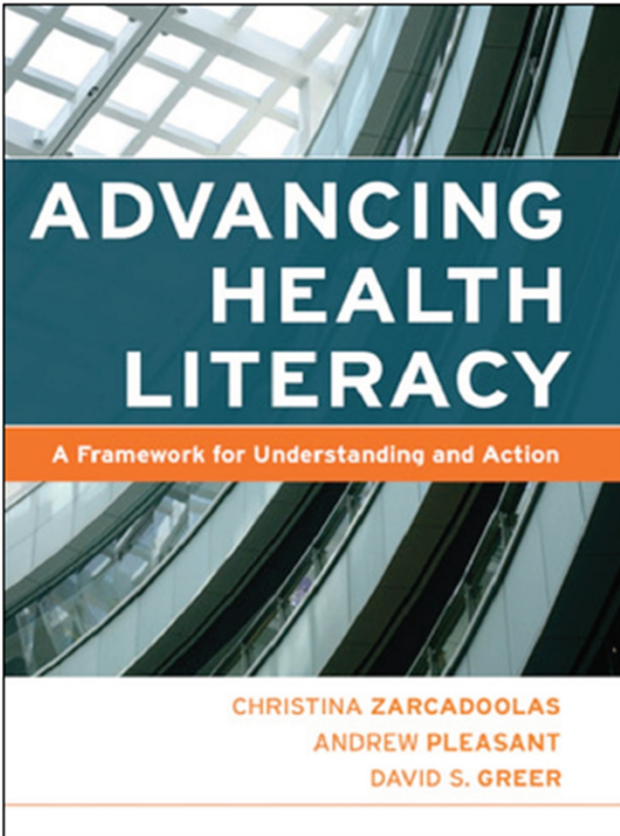
- Explore how your messages are holding up - what's the evidence to support your approach?
- Be prepared to revise.

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
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