

Integrating Health Literacy Best Practices in Biomonitoring Results Communication

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How well do adults read and write?



Definitions

“Using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential.”

-National Assessment of Adult Literacy, 2003

Health Literacy:

“The degree to which individuals have the capacity to obtain, process, understand, and act on basic health information and services needed to make appropriate health decisions.”

-Healthy People 2010

U.S. Reading Levels Compared to Health Information Readability

- **90 million U.S. adults** have trouble understanding and acting on health information
- The average American reads at the **7th-8th grade level** (20% < 5th grade level)
- Most adults read **3-5 grades lower** than the highest grade of school completed
- Most health information is written at the **10-12th grade level**

Most would not understand these texts

From a research consent form: “A comparison of the effectiveness of educational media in combination with a counseling method on smoking habits is being examined.”

From a patient information sheet: “Therefore, patients should be monitored for extraocular CMV infections and retinitis in the opposite eye, if only one infected eye is being treated.”

How well do patients understand how to take their medicine or prepare for a medical procedure?



Health
Literacy

DO NOT DRINK ALCOHOLIC BEVERAGES & MAINTAINANCE THERAPY
May cause drowsiness and dizziness. Alcohol may intensify the effect. Use care when operating a car or dangerous machinery. Do not take with Grapefruit Juice.

Rx: 404989
TAKE ONE TABLET DAY FOR 10 DAYS
PENICILLIN VK 500mg
No Refills, authorization required.
RPh: COURSEY, THOMAS
Date Filled: 11-20-2002

prescription to

Simple Message: Understood by 84% of people



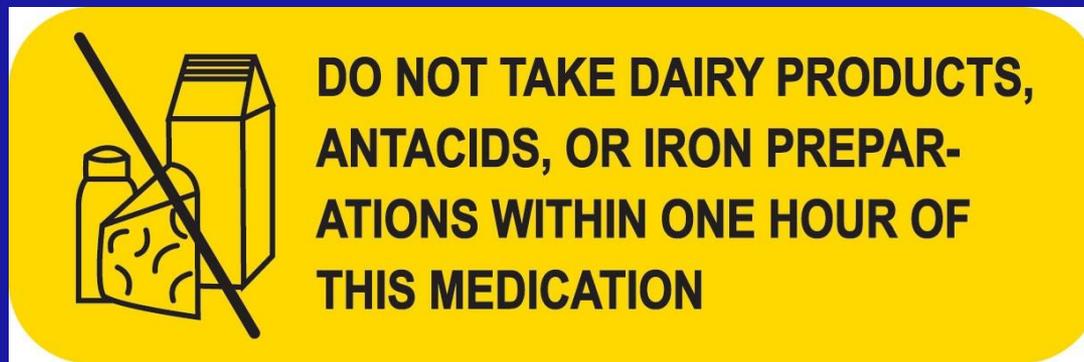
(1st grade)

More complex message: Understood by 59% of people



(10th-12th grade)

Very complex message: Understood by 8% of people



(12th-13th grade)

Beyond Health Literacy Measurements: Research and Participatory Design

1. **Define** communication objectives and audiences.
2. **Assess** audiences' knowledge, attitudes, behaviors.
3. Set up a **participatory design** process with audiences.
4. **Iteratively develop and test** communication.
5. Engage audiences & stakeholders to **plan delivery**.
6. **Evaluate** impact and revise.
7. **Adapt** for other language and cultural groups.

Best Practices in Health Communication

- Find out what people want and need to know, what they understand, how they want the information, and how it can be made relevant to their cultures and situations
- Aim for 6th-7th grade reading level or lower
- Focus on 2-3 main messages, group similar information together, break up complex topics
- Use shorter words & sentences, larger fonts, simple pictures (avoid complex charts)

Relating Best Practices to Biomonitoring

- 55% of U.S. adults lack the knowledge and skills required to use numbers in printed materials (National Assessment of Adult Literacy, 2003)
- Graphs are abstract, require matching different kinds of information, and are not perceived as real (poorly understood by people with limited literacy skills)
- Better to use analogies, pictures; tie to information patient already knows

Ways to Frame Risk Information

- Be clear about timeframes (Is the risk now? In 5 years? Over a lifetime?)
- Specify which risk you are talking about
- Usually better to frame risk in positive and absolute terms (“you are twice as likely to” vs. 1 out of 4 people will”)
- Preface uncertain risk information by acknowledging that scientists continue to study and learn, and provide patients/families with reputable sources to learn more

Cohort Study of Young Girls' Nutrition, Environment, and Transitions (CYGNET)

- Project of the Bay Area Breast Cancer and the Environment Research Center (1 of 4 funded by NIEHS and NCI; Bob Hiatt, UCSF, Director)
- Larry Kushi, PI (Division of Research, Kaiser (co-PIs from UCSF, UCB, CDPH, U. of Michigan, Roswell Park Cancer Institute)
- Community outreach translation core (COTC) being led by Zero Breast Cancer (Janice Barlow, Executive Director)

CYGNET Study Goals, Population

- Goal: to better understand the role of environmental, genetic and other factors in the onset of female puberty as a susceptible exposure period relating to later risks of breast cancer
- 440 girls recruited when they were 6-8 years old from Kaiser clinics in Oakland, San Francisco, San Rafael
- Testing for more than 80 chemicals/congeners found in personal care and household products, the diet, or persistent in the environment (esp. endocrine disruptors)
- CYGNET team decided for ethical reasons to report results to study participants and parents

Challenges in Reporting Results

- Young girls are a vulnerable population, since their development is not complete and they may be affected by early exposures or other environmental risk factors
- Little knowledge of “safe” levels for most chemicals tested (effects on puberty just now being studied)
- Limited means for reducing personal exposure
- Challenges in selecting a reference value for comparison
- Very large number of chemical test results to report

Challenges in Reporting Results

- Anxiety that may be caused by information with uncertain implications
- Misinterpreting results to signify increased risks
- Underestimating potential risks
- Failing to act to reduce known risks

CYGNET Results Communication Process

- HRA conducting 4 focus groups with parents of girls in study (3 in English, 1 in Spanish)
- Primary goal: learn parents' preferences for content and format of reporting their daughters' individual study results
- Additional goals: understand parents' knowledge about the study goals and anticipated outcomes, expectations about what they will learn, and general understanding, fears, and misconceptions about their daughters' risks from environmental exposures

Work Completed/Next Steps

- Reviewed literature (biomonitoring and risk communication); conducted readability assessments of several report-back materials used in other studies, and selected 3 to test in focus groups
- Focus groups will be held in August; recorded, transcribed and analyzed by late September; results reported to CYGNET investigators by end of October
- Possible next phases: (1) design, test and refine new reporting tool based on FG results; (2) evaluate CYGNET's results communication experience (proposal submitted to NIH by Julia Brody, Silent Spring Institute)

Related Work

- *Perspectives* issue with Rachel Morello-Frosch
- Maternal-Infant Environmental Exposure Project (MIEEP), LOI under review by The California Wellness Foundation
 - Collaborators at CDPH, UCSF, and UCB are designing a pilot study to measure and compare levels of >100 chemicals in 50 pregnant women (through blood and urine) and their newborn infants (through umbilical cord blood, representing in utero exposures) at UCSF and SFGH

MIEEP Study Details

- CDC will analyze samples for up to 10 chemical classes (possibly more than 100 different chemicals); CDPH lab will analyze samples for metals, phthalates, and organophosphates
- Participants to complete questionnaires to assess how they may be exposed (e.g., work, diet, consumer products) for a subset of chemicals
- Develop and test an approach to providing participants with their individual results and guidance about the implications of those results

Thank You

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