Casebook on Health Literacy  
*Interdisciplinary GradSem in Literacy Studies, March 2015*

Our discussion of health literacy will focus on documents from a number of government agencies that have defined health literacy as central to improving healthcare delivery in the United States. Please read the excerpts and notes below. You may want to read through the links as well, particularly the ones from AHRQ and the Office of Disease Prevention and Health Promotion. As you read, perhaps keep in mind the following questions: How is health literacy being defined? Who’s responsible? And what are the stakes of these definitions?

To begin, we offer the following quotation as a primer:

“Quite simply, the responsibility is ours as professionals to communicate in plain language. Without clear communication, we cannot expect people to adopt the healthy behaviors and recommendations that we champion. When people receive accurate, easy-to-use information about a health issue, they are better able to take action to protect and promote their health and wellness. That is why health literacy is so critical to our efforts in the U.S. Department of Health and Human Services. It is the currency for everything we do.” – Howard K. Koh, M.D., M.P.H., Assistant Secretary for Health, U.S. Department of Health and Human Services

http://www.health.gov/communication/hlactionplan/pdf/Health_Lit_Action_Plan_Summary.pdf)*

Consider also this case narrative, from Ch. 2 of *Health Literacy: A Prescription to End Confusion* (2004):

“A 29-year-old African-American woman with three days of abdominal pain and fever was brought to a Baltimore emergency department by her family. After a brief evaluation she was told that she would need an exploratory laparotomy. She subsequently became agitated and demanded to have her family take her home. When approached by staff, she yelled ‘I came here in pain and all you want is to do is an exploratory on me! You will not make me a guinea pig!’ She refused to consent to any procedures and later died of appendicitis.”


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In December 2010, the U.S. department of Health and Human Services launched a new health promotion and disease prevention agenda, called
Healthy People 2020. The product of an “unparalleled” stakeholder feedback process, Healthy People 2020 was crafted on input from public health experts, federal, state, and local government officials, over 2,000 organizations, and, “perhaps most importantly,” the public. Its stated objectives include:

- Adolescent Health
- Blood Disorders and Blood Safety
- Dementias, including Alzheimer’s Disease
- Early and Middle Childhood
- Genomics
- Global Health
- Health-Related Quality of Life and Well-Being
- Healthcare-Associated Infections
- Lesbian, Gay, Bisexual and Transgender Health
- Older Adults
- Preparedness
- Sleep Health
- Social Determinants of Health”


As an overarching policy agenda, Healthy People 2020 thus has the rather unenviable task of motivating a huge patchwork of national, state, and local entities to work towards these objectives in a more or less coordinated fashion. While part of Healthy People 2020’s mission, the role of health literacy in achieving these objectives is relatively obscure, at least from the documents presented on its website. This link directs to their health communication and IT website, the site of a collection of info on health literacy.

Notice the links in the bottom right-hand corner (under “Learn More”) to other agencies and their health literacy pages. Four of these are discussed below. While similar, these pages each contain slightly different perspectives on health literacy.

*Agency for Healthcare Research and Quality, “CAHPS Item Set for Addressing Health Literacy”*:

https://cahps.ahrq.gov/surveys-guidance/item-sets/literacy/index.html
The AHRQ aligns itself with the patient-centered care movement. It disseminates survey tools for assessing providers’ health literacy activities. They define health literacy thusly:

“Health literacy is commonly defined as patients’ ability to obtain, process, and understand the basic health information and services they need to make appropriate health decisions. While health literacy depends in part on individuals’ skills, it also depends on the complexity of health information and how it is communicated.”

AHRQ uses patient perspectives to measure health literacy provision. The questionnaire item set designated as “health literacy” encompasses the topics “communication about prescription medicines,” “self-management support,” and “communication generally.” The other item sets—cultural competence, health information technology, and patient-centered medical home—encompass the following topics, none of which are designated as health literacy-related:

- “Access”
- “After hours care”
- “Complementary and alternative medicine”
- “Interpreters”
- “Mental or emotional health”
- “Provider knowledge of specialist care”
- “Shared decisionmaking”
- “Trust”
- “Wait time for urgent care”


Here we encounter more definitional complications.

This site links to a free online training provided by HRSA for healthcare professionals. It identifies health literacy as a goal commensurate with (though not equal to) a.), acknowledging cultural diversity and b.), accommodating low English proficiency. Health literacy is intended to help professionals “bridge knowledge gaps that can prevent patients from adhering to prevention and treatment protocols.” The impact of cultural difference on effective communication is clearly acknowledged, yet conceptualized as distinct from literacy. Literacy from this perspective more nearly involves the skills and information required to ‘fill’ patients with the proper knowledge.

The CDC: http://www.cdc.gov/healthcommunication/
This website, identified on HealthyPeople.gov by the link “CDC Health Literacy” does not explicitly talk about health literacy. Rather, it is a resource center for professionals and organizations wanting to build “communication or social marketing campaigns and programs.” Modules include information on how to select/interface with target audiences and using multiple communication channels. (“Entertainment Education” is evidently an important topic as well.)


Finally, consider the Office of Disease Prevention and Health Promotion’s “Health Literate Care Model.” Integrated with models of “Chronic Care” and a “universal precautions approach,” the model assumes as a fundamental tenet the impossibility of knowing how much the patient knows. The patient’s level of health literacy is also recognized to vary depending on levels of stress, pain, and other immediate contextual factors.

The model makes it clear that community partners providing affordable housing, education, and nutrition services are recognized as integral to creating a “health literate system.” Improved verbal interactions and written communication, as well as more equal, collaborative relationships between practitioners and patients, is the crux of the system. Note the language exhorting practitioners to “engage patients as partners in care and improvement efforts [emphasis mine].”