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SPECIAL POPULATION SERIES

Health Literacy for Health Center Patients and Staff

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Challenges related to health literacy confront us all day long. In order to assist patients in their journey to reach high levels of health, it is imperative that we be informed as to communicate with all patients.

Because this problem is so ubiquitous, it cannot be confined easily to a "special population" status. Yet, some categories of patients are at far greater risk for poor understanding. Further, health literacy cannot be viewed in isolation from comprehensive patient self-management. It is one important aspect in responding to patient needs under the umbrella of patient-centered care.

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Topics in this bulletin describes:

- The nature of the health literacy challenge Risk factors for low health literacy Barriers to understanding Simple ways to improve understanding Resource Links

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## THE NATURE OF THE HEALTH LITERACY CHALLENGE

### Patient Priorities as a Driver of Care

Health literacy is a term often heard in medical settings. It is used to reference a variety of issues but, in fact, it has a specific, multifaceted definition. Understanding this definition is important in order to accomplish strong two-way communication in health care settings. Applying health literacy concepts in a patient-centered setting is equally critical.

**Health literacy tools only become effective if health centers wrap health topics and communication techniques around patient priorities and goals.**

The dance or “negotiation” that brings patient concerns and provider expertise to the same table involves careful listening and clear, two-way communication. If health center staff place the patient in his/her rightful position, which is the driver’s seat, and staff serve as navigator in the passenger seat, health outcomes are improved! Health literacy is a key component of this.

The Institute of Medicine’s 2004 report *Health Literacy: A Prescription to End Confusion* defines health literacy as:

*The degree to which individuals have the capacity to obtain, process, and understand basic information and services needed to make appropriate decisions regarding their health. It lists: writing, listening, speaking, arithmetic, and conceptual knowledge as crucial components of health literacy.*

It is common to be in settings where a “different” language is being spoken, such as in physics, chemistry, or linear algebra and where the meaning is totally lost. When getting help to access the internet, the Information Technologist may insist on explaining the workings of the motherboard. There is no understanding and almost no interest in the “expert” driven explanation. Add stress and fear to this equation and any real understanding goes out the door. As the IOM report describes,

*Even well educated people with strong reading and writing skills may have trouble comprehending a medical form or doctor’s instructions regarding a drug or procedure.*

## Navigating the Health Care System

A second dimension of health literacy is the ability to navigate the health care system to achieve appropriate care. Even individuals involved in the medical field can find the complexities of the health care system daunting when advocating for the needs of a loved one. Health system navigation has yet to have an explicit set of skills to surmount barriers. Persistence and assertiveness are effective in finding the resources, experts, tests, and material. The idea of a health advocate is growing in popularity with for-profit and not-for-profit entities springing up as system navigators...for a fee.

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## Awareness of Cultural Differences

Culture and language clearly plays a role in understanding. Real communication occurs “from a convergence of education, health services, and social and cultural factors, and brings together research and practice from diverse fields.” An awareness of cultural issues is important to cross communication barriers. Health literacy concerns become more acute when different languages and cultural practices are involved. Further, there is much data to support lower levels of overall literacy in non-native English speakers. The combination of cultural context, language barriers, and low levels of literacy means two-way understanding is far less likely. Some of the skills listed below such as “teach back” and reflective listening are essential to ensure a shared understanding. Topics of high priority to the true “expert”, the patient, offered in a culturally sensitive manner will be those likely to be retained and result in health improvements.

Given the broad challenges described by understanding basic health information, navigation of an ever-changing, complex health care system, and cultural differences, it is vital that we fill our health literacy tool bag.

### ONE MAN'S STORY

Glenn, a 58 year old railroad manager living in rural Montana, came to his local health center with his diabetes raging out of control. It was Glenn's understanding that he should eat a banana “whenever his blood sugars were off”, both high and low. The medical staff immediately began focusing on his health issue. The clinic's case manager assisted Glenn in navigating the complex social security disability system and discovered that he did not know how to read. She alerted his providers and they began to provide information to him orally and through the use of charts. Only after repeated failures to manage his diabetes did the clinic staff realize that his lack of understanding of the complexity of his condition involved much more than the ability to read.

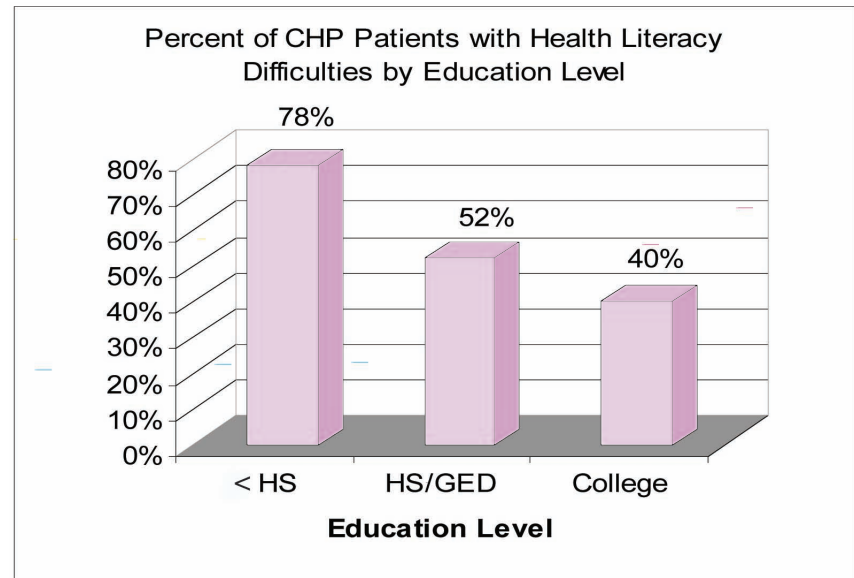
Glenn's health center was able to tap into several resources to help both him and his providers. The in-house literacy program matched Glenn with a tutor. Not only was she able to help him improve his reading skills, she was also able to ascertain what strategies would best address his learning style. The tutor worked with the medical staff to educate them on practices to enhance understanding. And the icing on the cake – Glenn's tutor was also a diabetic! Her first hand knowledge of the fears, frustrations, and medical interventions was a life link for Glenn.

Now, eight years later, Glenn has graduated from insulin injections to taking oral medications. His high blood pressure is under control; he has slimmed down to being closer to his ideal weight; he has quit smoking; he is taking medications for depression; and a whole world has been opened to him through reading. Glenn has taken control of his life! He reads food labels and knows what diet is best for him. He monitors his A1C. He understands symptoms and warning signs and is proactive in his health. Beyond that, through his reading he has reexamined his beliefs on skin color (his tutor exposed him to Rosa Parks), discovered the world outside, and experienced a greater sense of wellbeing, not only controlled diabetes.

## RISK FACTORS FOR LOW HEALTH LITERACY

According to the National Academy of Science publication *Many Americans Lack Health Literacy* by Lisa Pickoff-White, only 12 percent of American adults could easily navigate the healthcare system, although a new assessment from the National Center for Education Statistics shows that more than half of the 19,000 study participants understood basic health instructions such as reading medication labels for dosage.

While all patients are at risk for health literacy challenges, especially in the face of frightening diagnoses, some population groups are more predisposed to communication barriers. According to the *Health Literacy of America's Adults* study released in 2006 by the National Assessment of Adult Literacy (NAAL) lower educational attainment, older age (especially over 65), and non-native English speakers are predisposed to low health literacy. Even so, the same survey describes compromised health literacy levels in all populations. A full 36% of the population is at a basic or below basic level of health literacy. According to the survey, 59% of the adults age



65 or older fell into the basic or below basic literacy level.

One health center found, using the Newest Vital Sign (see the Resources section of this Bulletin), that 54% of its clients were likely to experience health literacy obstacles. In the same health center, 78% of those without a high school diploma (see the bar graph) had literacy difficulties. For those health center patients older than 56 years, 65% had health literacy difficulties.

In terms of seeking health information, “adults with Below Basic or Basic health literacy were less likely than adults with higher health literacy to get information about health issues from written sources (newspapers, magazines, books, brochures, or the Internet)

and more likely than adults with higher health literacy to get a lot of information about health issues from radio and television.” (NAAL, 2006)

## BARRIERS TO ACCESS AND UNDERSTANDING

As in any communication, the ability to access, understand, and act upon healthcare information is a two way street. Both the medical provider and the patient bring skills, background information, fears and inadequacies, and strengths and weaknesses to the table. The following are common barriers to access and understanding that both sides might experience.

## Barriers to Health Literacy of Staff

- ◆ Lack of awareness of what each patient understands, misconceives, and the extent of his/her background knowledge as a result of staff familiarity and use of specialized medical language and understanding of complicated medical conditions;
- ◆ Time constraints to train staff on health literacy issues due to requirements to serve certain numbers of patients per day;
- ◆ Scarcity of educational tools such as low-literacy printed materials and visuals;
- ◆ Lack of understanding of specific cultural nuances;
- ◆ Language other than English as the native language;
- ◆ Medical education and communication training that assumes information only flows from the health organization staff to the patient. (Unidirectional)

## Barriers to Health Literacy of Patients

- ◆ Lack of understanding of specialized medical terminology;
- ◆ Limited ability to read and understand written information;
- ◆ High levels of emotion and apprehension when sick or when a loved one is ill;
- ◆ Difficulty taking in large amounts of information at once;
- ◆ Fear of looking stupid;
- ◆ Language other than English as the native language;
- ◆ Limited understanding of math;
- ◆ Mismatch of learning styles and delivery methods.

And this is just a partial list! When seeing how many components are at play, one can easily see the endless possibilities for misunderstanding. It is important to remember that the potential for health literacy issues

to arise is present in **every single patient-provider encounter** – no matter how well educated, what income bracket, or the age or racial group of the patient or provider. In fact, a study of medical residents was conducted to see if they could predict which patients would experience health literacy difficulties (Bass et al, 2002). The residents identified 10% of their patients, but the actual figure was more than one third. Most physicians who attempt to measure the literacy level of their patients make the mistake of asking for the highest grade or level of education that they completed. It has been shown that the final grade completed often is higher than the actual level of literacy.

Health center leaders must invest in staff training to alter the typical dialogue and remove these barriers. This doesn't mean longer visits. It does mean repeated staff training such that the health care team is able to adopt different ways of communicating with patients. Health care providers

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are challenged by change just as any individual. A meta-analysis described in the Journal of Health Care for the Underserved revealed provider and staff “non-compliance”. It often takes an administrative directive combined with training time and investment on the part of the administration for change to happen. But patient-centered care has big pay offs, both in terms of staff satisfaction because partnering feels far better than futile lecturing, and in patient satisfaction.

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## WAYS TO IMPROVE SERVICE DELIVERY

It is imperative that the health care team attends to the patient’s needs and goals first and foremost. Health centers across the country are in the business of improving health and wellbeing and have opportunities to work with populations that experience language and educational challenges. By combining an understanding of culture and a commitment to true communication, health centers can make great strides in improving outcomes. A set of skills and approaches is critical.

The primary goal behind clear communication and health literacy is informed decision making and improved health. Unless patient priorities are front and center in all visits, there is little hope of behavior change and the subsequent positive health outcome. Health literacy belongs in this context, revolving around patient desires and informational needs. The provider team is “invited”, by virtue of the patient seeking care, to sit in the passenger area, to share a medical perspective and health concerns, but not to drive the car or unilaterally plot the route. Such usurping of patient power undermines patient success and improved wellbeing.

### Moving from Old to New

For a health center to change its approach from the five minute, ineffective one-way provider team lecture to a patient-centered conversation using sound health literacy practices, **organizational commitment is absolutely required.** Unless health literacy and patient-centered care rises to the very top of the list of priorities, no organizational changes are possible. This is

completely analogous to patient priorities. Unless health goals, *their* health goals, are at the top of their list, no change is likely. For health literacy to rise to the top, the organizational leaders must believe that health outcomes can and do improve when the patient-expert is moved to the center of all care. Additionally, leaders must have time, resources, and a cadre of internal leaders to move toward the vision of respectful care.

Where does health literacy and patient-centered communication fall on your list? On a scale of one to ten, is it a seven or greater? If not, put it on the shelf for now in order to address your higher priorities. If you rank health literacy at a seven or greater, the following tools will help you make the change. Remember, these are behavior changes and like patients, they do not happen overnight. The health center must be committed to the change, must make time for education, must purchase a few basic tools, and must monitor its progress so that change occurs and is sustained.

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## Tools for Improved Communication – More than White Space and Short Sentences

### Written Materials

Although providing appropriate reading material is one very important aspect of enhancing health literacy, it should be stressed that written material is only one avenue for increasing understanding and self empowerment.

- ◆ Davis et al. (1998) found that the use of a colorful, easy-to read brochure with a 5<sup>th</sup> grade readability level in addition to a personal recommendation was no more effective than that of a recommendation alone. Their results suggest that simply giving patients a low-literate, culturally appropriate brochure was *not* effective in improving mammography utilization.

**Listening to patient needs, sharing the appropriate level of information around mutually agreed upon priorities, and gentle follow up (as available) will encourage greater levels of understanding and behavior change.**

- ◆ A study conducted by Schwartz, Woloshin, Black, and Welch (1997) indicated that even college educated individuals have difficulty understanding and utilizing medical information. Plimpton and Root (1994) found that materials that were easier to read had a much stronger effect on higher literate than on lower literate patients.

**Written patient educational materials are most assessable when written no higher than a 7<sup>th</sup> grade reading level.**

- ◆ Attention needs to be paid to how appealing text is. A page that is full of text, uses small font, gives no breaks for the eye (white space), and has few graphics does not “invite” the reader into the text.

**Font size of at least 12, 1 ½ line spacing, using bullets and appropriate graphics will be more welcoming to the reader.**

- ◆ Avoid heavy use of medical terminology.

**Use plain English and the active tense for verbs, and write as if you are speaking to a real person.**

*Avoid asking  
“Do you  
understand?”  
or other yes/no  
questions.*

### Face to Face

- ◆ Follow the leader!

**Ask your patient, “What do you hope to accomplish today?”  
Use open-ended questions, reflective listening, and summarize  
key points frequently. “So, it sounds like your main concerns  
are.... What did I miss or get wrong?”**

- ◆ Avoid medical jargon and acronyms when possible.

**Use common, everyday language.**

- ◆ Limit information to what patients really need to know. Detailed pathophysiology can be overwhelming!

**Focus on 3 key messages, provided information in small pieces.  
Repeat to enhance recall.**

- ◆ Slow down your pace of speech.

**Allow for moments of silence to allow new information to be  
digested and for questions to be formulated.**

- ◆ Explain concepts using analogies.

**Analogies should be visual so it can be seen in your mind’s eye,  
familiar to the patient, and clear and short. “An aneurysm is  
like the bulge you can get in a garden hose. The bigger the  
bulge, the weaker the wall and the more likely it will burst.”**

- ◆ Avoid asking “Do you understand?” or other yes/no questions.

**Ask patients to “teach back”. “Can you help me go through  
what we covered regarding your diabetes?” Or, another team  
member can “wrap up” the visit and ask what was discussed.  
“What did Dr. Smith discuss with you? Sometimes we use  
really strange words in clinics, do you have any questions about  
what was said? What questions do you have?”**

- ◆ Two sets of ears are better than one.

**Encourage patients to bring a family member or friend to all  
visits.**



*Offer patients a clipboard with paper so that they can take notes.*

- ◆ Because patients tend to feel inhibited in these settings, offer patients a clipboard with paper so that they can take notes.

**Keep clip boards and/or scratch paper in a prominent location in all exam rooms. If the patient does not take notes, take some for him/her while you talk and offer your notes to them when they leave. Draw pictures and diagrams that may accompany the patient when he/she leaves.**

- ◆ Use non-written modalities to share information (audio, video).

**Consider taping visits and/or instructions. Navigate the computer together.**

- ◆ Assess your patient's stage of change. Use importance scales or other rating systems from the self-management/motivational interviewing world. Neither organizational leaders nor patients are motivated to change low priority areas. We are setting the patient and ourselves up for disappointment. Our goal is to find, mutually, areas that are of high priority.

**“On a scale of one to ten, how much of a priority is weight loss for you?” If it is not a seven or greater, it will not happen. Ask the follow up question, “Wow. Sounds like this is very important to you. Again, on a scale of one to ten, how confident are you of achieving your goal?” If the patient is below a “seven”, work with them on barrier removal or lowering, or suggest smaller steps that allow for early successes and let self-assurance grow. Then take on the next, slightly bigger challenge.**

## RESOURCE LINKS

### Health Literacy

- ◆ **“Newest Vital Sign”** – a tool developed by Pfizer, Inc. to assess general literacy and numeracy skills as applied to health information that can be administered in about three minutes and is available in both English and Spanish at <http://128.121.233.134/default.aspx>
- ◆ **Clear Language Group** – targets adults with limited topic understanding, information overload, and/or limited English proficiency or reading skills. The Group is a national consortium of health literacy, plain language, and cross cultural communication specialists at [www.clearlanguagegroup.com](http://www.clearlanguagegroup.com)
- ◆ **“Pfizer Clear Health Communication Principles” Handbook** – an 86 page handbook for creating patient education material at <http://www.pfizerhealthliteracy.org/pdf/PfizerPrinciples.pdf>
- ◆ **Pfizer Clear Health Communication Initiative** – great resource including a “prevalence calculator” that estimates level of limited health literacy in patient population served at <http://www.clearhealthcommunication.org/>
- ◆ **“Plain language and clear writing principles”** – suggests that good writing is clear thinking on paper. The document contains specific information relevant to readers; keeps to plain-language principles; and is logically arranged and easy to follow at [www.plainlanguage.gov](http://www.plainlanguage.gov)
- ◆ **The Commonwealth Fund’s** website includes a description of how to work with limited English proficiency clients at [http://www.cmwf.org/publications/publications\\_show.htm?doc\\_id=444660&#doc444660](http://www.cmwf.org/publications/publications_show.htm?doc_id=444660&#doc444660)
- ◆ **Harvard School of Public Health, Health Literacy Studies** – examine literacy-related barriers to a variety of health services and care and work with researchers in adult education to identify skills needed to access programs and services, manage chronic diseases, and participate in disease prevention activities. Very helpful chart on creation of materials at [www.hsph.harvard.edu/healthliteracy/](http://www.hsph.harvard.edu/healthliteracy/)
- ◆ **The Institute of Medicine Health Literacy Resources** – is an extensive list of health literacy resources and studies at <http://www.iom.edu/CMS/3793/31487/34403.aspx>
- ◆ **The National Assessment of Adult Literacy** – A wealth of data and information on literacy and health literacy at <http://nces.ed.gov/naal/>
- ◆ **The Health Literacy of America’s Adults** – Results from the 2006 NAAL at <http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2006483> .
- ◆ **Unified Health Communication 101: Addressing Health Literacy, Cultural Competency, and Limited English Proficiency** – a free on-line learning resource for providers at <http://www.hrsa.gov/healthliteracy/training.htm>.
- ◆ **U.S. Department of Health and Human Service’s Office of Disease Prevention and Health Promotion Communication Activities** – identifies resources to promote health literacy at [www.health.gov/communication/literacy/default.htm](http://www.health.gov/communication/literacy/default.htm)

## Patient Centered Care/Self Management

- ◆ The **Commonwealth Fund's** *What's New in Patient-Centered Care* highlights one of the six domains of quality [www.ihl.org/IHI/Topics/PatientCenteredCare/PatientCenteredCareGeneral/](http://www.ihl.org/IHI/Topics/PatientCenteredCare/PatientCenteredCareGeneral/)
- ◆ **Expanding Patient-Centered Care to Empower Patients and Assist Providers** – a series of tools developed by the Agency for Healthcare Research and Quality (AHRQ) to help patients and their health care providers make better decisions at [www.ahrq.gov/qual/ptcareria.htm](http://www.ahrq.gov/qual/ptcareria.htm)
- ◆ **Stanford University School of Medicine** Chronic Disease Self-management Program at <http://patienteducation.stanford.edu/programs/cdsmp.html>
- ◆ **The Institute of Healthcare Improvement** Patient Self-management Resources [www.ihl.org/IHI/Topics/HIVAIDS/HIVDiseaseGeneral/Changes/IndividualChanges/Tap+community+resources.htm](http://www.ihl.org/IHI/Topics/HIVAIDS/HIVDiseaseGeneral/Changes/IndividualChanges/Tap+community+resources.htm)
- ◆ **The Institute of Optimizing Health Outcomes** program to improve the capacity of patients and care givers to take an active role in managing their health condition. [www.optimizinghealth.org/index.php/site/resources/patient\\_self\\_management](http://www.optimizinghealth.org/index.php/site/resources/patient_self_management)
- ◆ **The Institute of Healthcare Improvement** information on Advancing Patient-Centered Care, at <http://www.ihl.org/IHI/Topics/PatientCenteredCare/>



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