

Health literacy

Achieving “meaningful use” for patients

By Lane Stiles, MA

The potential benefits of interoperable electronic health records (EHRs), including reduced costs and improved health outcomes, have been widely touted for years. But we will never realize the full benefits of EHRs unless and until we use them to directly engage patients and families to help them manage their health more effectively.

This may seem so obvious as to hardly be worth saying. After all, the second health outcomes priority identified by the Meaningful Use workgroup of the national Health Information Technology Policy Committee is “to engage patients and families in their health care.” Meaningful use, says the committee, “should result in health care that is patient-centered.”

And in “A Prescription for Meeting Minnesota’s 2015 Interoperable Electronic Health Record Mandate,” the Minnesota e-Health Initiative declares that “citizens as users of health care are central to e-health. Improving the quality and safety of care is ultimately about patients.” (Minnesota Department of Health, 2008)

Yet patients are rarely, if ever, at the table when EHR systems are planned and implemented. And providing patients with meaningful access to health information is at best an afterthought.

Why is this the case? Perhaps because patients have to be intentionally invited to

a table where providers are already sitting. Or perhaps because engaging patients seems such a distant and airy goal when compared to the immediate and costly challenge of turning mountains of paper records into digital ones.

But engaging patients is not a goal that can be avoided indefinitely. Stage 1 of meaningful use, as currently defined, requires that patients be provided “with an electronic copy of their health information (including diagnostics test results, problem list, medication lists, allergies) upon request.” Stage 3 requires “patient access to self-management tools.” Depending on the implementation, an EHR may provide several touchpoints for patients: printed discharge instructions and after-visit summaries, embedded patient education, secure messaging, patient portals, personal health records (PHRs), and more.

If we don’t plan for these exchanges of information and interactions with patients, how can we ensure that we are communicating clearly and effectively with them? What do we gain (or, perhaps more importantly, what is risked) if we use EHRs to deliver information to patients without any consideration for how relevant, actionable, or useful it is? What is the cost if we have to reconfigure applications to comply with meaningful use standards down the line?

Meaningful use will occur for patients only when they are literally able to use EHRs

meaningfully. This means that patients must be able to obtain, process, and understand the information transmitted through EHRs to make appropriate health decisions.

If you are familiar with the concept of health literacy, the language I’m using here should strike a chord. The Institute of Medicine, in its influential report “Health Literacy: A Prescription to End Confusion,” defines health literacy in exactly these terms: the degree to which patients are able “to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” The American Medical Association and the Partnership for Clear Health Communication use a similar, though more plain-language, definition: “the ability to read, understand, and act on health care information.”

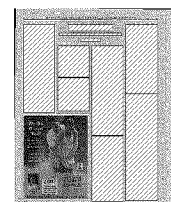
Ultimately, we cannot separate the issue of health literacy from a patient’s meaningful use of EHRs. This is clear in the report of the Meaningful Use workgroup, which explicitly states, “Appropriate health literacy is a critical component of patient engagement and empowerment.”

Health literacy and patient engagement

Why is health literacy critical?

For one thing, health literacy is a more significant indicator of health status than education, race, ethnicity, or socioeconomic status. Low health literacy makes patients significantly less safe, less healthy, and more expensive to care for.

For another, we routinely overestimate the literacy skills



of our patients. According to the two most recent national assessments of adult literacy in America, between 36 percent and 43 percent of literate American adults struggle with the most basic literacy tasks.

This problem becomes even more acute in the electronic environment of the EHR, where patients must draw on many different types of literacies to function effectively. General literacy is the “ability to read, write and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and develop one’s knowledge and potential” (National Literacy Act of 1991). To be health-literate, you must have, in addition to general literacy, a functional knowledge of the culture and concepts of health care. To be health-literate in an electronic environment (what is increasingly referred to as “e-health literacy”), you need even more skills: computer literacy, media literacy, information literacy, and science literacy.

The average American adult reads at the eighth-grade level, yet health care information typically is written at a 10th-grade level or higher. Our health care delivery systems are so complex, in fact, that, according to the 2003 National Assessment of Adult Literacy, only 12 percent of literate Americans are proficient at navigating them. And even those few who are proficient can struggle when under stress, on medication, encountering new information, or experiencing problems with visual or cognitive acuity.

Because health literacy is a systemic issue that can affect

anyone, it doesn’t make sense to think of it solely as a deficit of certain individuals. Health literacy is also the capacity of health care providers and health care systems to communicate clearly, educate about health, and empower patients. Under this broader definition, developed by the Minnesota Health Literacy Partnership, a health-literate individual is one who can access and use health information effectively; a health-literate provider is one who can deliver health information to patients effectively. Communication is a two-way street, requiring an empowered patient and an empowering provider.

Making electronic documents more health-literate

In this context, then, how can we make EHR systems more health-literate and patient-centered? How can we help patients and families become meaningful EHR-users?

The most obvious answer is, involve patients in the planning and testing of the EHR system. Before implementing an EHR:

- Test the content and formatting of any text intended for patients to make sure it is readable and actionable.
- Test the design of patient portals and other electronic touchpoints to make sure screens are usable and navigable.
- Test all printed documents intended for patients to make sure they print out legibly.
- Ask patients to help you evaluate the clinical data that will flow to them through the EHR. Patients and families are not likely to understand or be able to act upon data that is full of technical jargon,

abbreviations, acronyms, and clinical coding. But this is how information is often delivered to them—because this is how it is delivered to clinicians.

In addition to involving patients, it is also a good idea to involve patient educators and health communications specialists in EHR design and implementation. These are the experts on patient-centered communication, yet they are rarely consulted when EHR decisions about patient communications are made. Patient educators and health communications specialists are adept at making communications readable, actionable, usable, navigable, and legible. For example,

HEALTH LITERACY to page 36 they know how to use readability metrics, such as SMOG, Fry, and Flesch-Kincaid, to measure reading level. They know how to revise jargon into plain language. They know how to choose and style fonts and format documents according to current best practices for readability. They know how to “chunk” information, limit messages, and focus a patient’s attention on what the patient needs to know and do to have the best outcome.

Most EHRs permit users to create customized text for discharge instructions, after-visit summaries, and other documents given to patients. Patient educators and health communications specialists can help edit and standardize such scripts for health literacy. They can also work with clinical and IT staff to raise awareness about health literacy and educate them on best practices for patient-centered communication. If

providers were more sensitive to this issue, we might be able to avoid messages like the following, which was sent via secure e-mail through a patient portal when the patient complained of back pain:

Try both aleve 2pills bid with flexeril at hs, if not better see me next week.

Few patients would be able to decipher a message like this, but it typifies the sort of information routinely delivered to patients through EHRs. Here are some additional actual examples of clinical jargon delivered to patients through after-visit summaries:

- *We performed the following: MAM MAMMOGRAM SCRN BIL DIGITAL, PANEL BASIC METABOLIC (BMP), TSH, CBC WITH PLATELET*
- *Diagnoses: Routine Medical Exam [v70.0B] – Primary; HTN (Hypertension) [401.9AE]; Fatigue [780.79B]; Osteoporosis [733.00C]; Anxiety [300.00E]; SCREENING MAMMOGRAM [V76.12B]*
- *CARDIAC REHAB PLAN OF CARE: Increase Exercise Tolerance: Endurance and Strength; Tobacco Cessation: Ongoing Education and Counseling; Nutrition Consult: Low Fat/ Low Cholesterol, Low Sodium and Lipids; Cardiac Rehab Education: Diagnosis, Home Exercise, Home Management, Medication, Risk Factor and Stress Management; Length of program is based on achievement of outcomes up to 36 sessions or 3 months, maybe determined by insurance guidelines.*

These cryptic messages,

obscured by inscrutable abbreviations, clinical codes, and all-capital letters, are clearly intended for providers, not patients. Why give patients information that can only confuse and frustrate them, especially when research tells us how much they value and respond to clear and usable information about their diagnoses and treatments?

As care (and payer) models increasingly embrace such concepts as shared decision-making, participatory medicine, and patient-centered medical home and as “meaningful use” codifies standards for patient engagement and empowerment, it is crucial that providers and their EHR systems become more health-literate. Research shows that everyone benefits from clear health communication, not just those with low health literacy. As the Institute of Medicine has declared: Health literacy is “fundamental to quality care.”

If you are interested in learning more about health literacy, see the resources listed in the sidebar on page 23. ❏

Lane Stiles, MA, is director of Fairview Press, a division of Fairview Health Services.

*Meaningful use will occur
for patients only when they are literally
able to use EHRs meaningfully.*

Health literacy resources

- The Department of Health and Human Services offers a basic primer, "Quick Guide to Health Literacy" (www.health.gov/communication/literacy/quickguide/).
- The AMA Foundation has created a highly effective video and manual for physicians titled "Health Literacy and Patient Safety: Helping Patients Understand" (www.ama-assn.org/ama/pub/about-ama/ama-foundation/our-programs/public-health/health-literacy-program/health-literacy-kit.shtml)
- For information on editing written materials, see "How to Create and Assess Print Materials," by Rima Rudd of Harvard School of Public Health (www.hsph.harvard.edu/healthliteracy/materials.html).
- The Agency for Healthcare Research and Quality has created a very effective resource for e-health literacy titled "Accessible Health Information Technology (IT) for Populations with Limited Literacy: A Guide for Developers and Purchasers of Health IT" (http://healthit.aHRQ.gov/portal/server.pt/gateway/PTARGS_0_1248_803031_0_0_18/LiteracyGuide.pdf).
- The Minnesota Health Literacy Partnership (<http://healthlit.themlc.org>) is a collaboration of Minnesota health care organizations and consumer groups working to improve the health of Minnesotans through clear communication. The Partnership offers free training modules for providers on its website.