At first glance, it sounds needlessly redundant: Patient-centered patient education program. Of course patient education is patient-centered—that’s what it’s all about, right?

Turns out, it’s not so simple.

It has been six years since the Institute of Medicine released its report *Health Literacy: A Prescription to End Confusion*, yet the problem identified persists today: 9 in 10 adults have difficulty understanding health information given to them by their providers.

The implications of this are far reaching. The ability to understand health information affects:

- Rates of hospitalization, length of stay, and readmission
- Patient safety
- Medication reconciliation
- Use of screening and other preventive health services
- Adherence to medication and treatment regimens
- Rates of complications from chronic diseases, such as diabetes and hypertension
- Cost of health care

A 2008 survey by Ralph Keeney, PhD at Duke University’s Fuqua School of Business, puts a deeper spin on the issue. Using actuarial and risk data, Keeney’s research indicated that personal decisions—for example, the decision to smoke, drink, or have unprotected sex—play a role in the cause of death for 55 percent of 15 to 64 year olds. In 1900, Keeney calculated, less than 15 percent of deaths in this age group could be traced back to personal decisions.

If Keeney’s calculations are correct, we have more control over our health than ever before. But if
patients don’t have access to accurate, easy to understand, actionable health information, how can they make the informed decisions that lead to longer, healthier lives?

Multifaceted Issue Requires Multifaceted Response

Health literacy—defined as the ability to “obtain, process, and understand basic health information and services needed to make appropriate health decisions”—involves many factors: reading ability, language, culture, and the communication skills and techniques of both patient and provider.

But there’s more to it than even that. As our healthcare system is set up right now, the intersection between patient and provider is rarely at a time when the patient is relaxed and ready to receive information. When a patient is in the doctor’s office or the hospital, illness, stress, time, and other life concerns press in and make true learning difficult. Plus, the bulk of a patient’s health decisions are made when a clinician—or a patient handout—is nowhere in sight.

Some of this is beyond the control of health plans and healthcare providers. But there is something they can control: what, how, where and when health information is presented to patients.

When the topic of health literacy first hit the scene, the tendency was to think of it in terms of the skills of the person receiving the information. Now the focus is shifting to the organizations and individuals who are delivering that information. In May of this year, the Office of Disease Prevention and Health Promotion at the U.S. Department of Health and Human Services released a detailed National Action Plan to Improve Health Literacy. The first two goals of the plan are firmly directed at the healthcare industry:

- Develop and disseminate health and safety information that is accurate, accessible, and actionable
- Promote changes in the health care system that improve health information, communication, informed decision making, and access to health services

Joint Commission, the Centers for Medicare and Medicaid Services, and other organizations have made effective patient education and communication programs a priority. Patient activation and engagement is one of the five pillars of meaningful use of electronic health records (EHRs), as defined in the final rule released by CMS in mid-July.

Meeting the Needs of Diverse Patient Populations

“The point is not just to get information out there; you have to get it out in a way that is actionable,” says Lane Stiles, Director of Fairview Press, a division of Fairview Health System in Minnesota. And that varies widely from patient to patient.

“Each patient is his or her own unique individual with their unique needs,” says Andrea Segura-Smith, Interim Associate Vice President of Nursing and Chief Nursing Officer at John Muir Medical Center in Walnut Creek, CA. “You can have a repertoire, but how do you individualize it for that patient, how do you bring it together effectively at the bedside?”

The key is to offer patient education by a variety of means so that you have multiple ways to deliver information. Building such a repertoire and using it effectively takes a cross-organizational and even a community effort, but the result can be more effective patient care, higher patient engagement, improved health outcomes, and lower healthcare costs.

Let’s look at the process of developing a patient-centered patient education program:
What
The first step is to determine the content: What information do you want to convey to the patient? What are the best sources of that information? What’s the best way to present it?

If the top criterion for patient education materials is that they are easy to understand, then the first requirement is that materials must adhere to the principles of plain language, such as:

- Active voice
- Specific focus
- Graphics
- Interactive elements, such as questions to engage reader

It sounds simple, but it’s not. “Medical terminology is plain language for clinicians,” Jan Kraus, Manager of the Dr. Joseph F. Smith Medical Library at Aspirus Wausau Hospital, and a leader in the Hospital’s health literacy efforts. “People often think they’re using plain language but they’re actually not.”

This is true both in spoken and in written patient education.

The average patient reads at about an 8th grade level, with a significant portion reading at the 5th or 6th grade level. And all patients, regardless of reading level, prefer clear, easy to understand language, says Doug Seubert, health literacy consultant in Marshfield, WI, and former health information specialist at Marshfield Clinic. Yet most patient education material is written at the 10th grade level or above.

There are a variety of scales that can be used to measure readability. Fairview Press passes each document through all 10 scales to make sure that it meets the criteria of plain language. At Aspirus Health, patient education materials are reviewed with a group of literacy students who meet with clinicians once a month as part of its Health Literacy Ambassador Program. The review not only helps develop clearer materials, it also helps improve the health literacy of these community members.

Why
It’s not just an issue of using clear language. It’s also developing a clear message that matches the goal of both clinician and patient. “We tend to inundate patients with information,” says Stiles. Too much of even a good thing muddies the message and compromises the effectiveness.

Seubert gives this example: For a patient with diabetes who asks about tips on healthy eating, a 1-page handout that focuses specifically on choosing the right foods to maintain glycemic control is more effective than a 40-page book that explains what diabetes is, how it is treated, and when to see your doctor—no matter how clearly the book is written.

To hone in on the most salient points, it’s important to know the purpose. The true goal of much patient education is to change specific behavior—improve medication adherence, quit smoking, lower cholesterol, etc. The more closely the content aligns with the specific goal, the greater the chance of patient activation.

In fact, the more closely tailored the content is to the individual’s needs, the more effective it is in changing behavior. Researchers at the University of Michigan’s Health Media Research Laboratory used a functional MRI to look at the brains of patients who used online patient education materials to help them quit smoking. There were 3 types of materials: generic instructions, motivational (offer of money for success), and personalized messages. He found that when the patient information was tailored to the individual—taking into account actual data from the patient record as well as medical history and demographics—more blood flowed to the prefrontal cortex, the part of the brain that organizes information and makes decisions.
Different patients have different information needs. Stiles finds that organ transplant patients are often highly motivated to read sophisticated materials to understand all aspects of their condition. However, someone coming for a routine colonoscopy every 10 years usually wants clear, simple, and easy-to-understand instructions on how to prepare and what to expect.

In order to get the patient perspective when choosing or designing patient education materials, many hospitals include patients in the process. “The most successful information we have, we worked with the end users in developing or choosing the materials,” says Kraus.

**How**

For various reasons, handouts are the number one way we deliver patient education. They’re quick and easy to distribute, and patients even ask for them sometimes. But they may not be that effective.

Part of this is due to a mismatch between reading ability of the patient and the reading level of the materials. But it also has to do with learning style and patient preference. Many patients remain more comfortable with print, but an increasing number feel just as or more comfortable with audio, video and other media.

The trick is knowing who is whom. You can’t tell just by demographics. Patients of different backgrounds and different ages may have different preferences and comfort levels with print and/or technology. The best way to find out? Ask.

This is especially important with patients who do not speak English or for whom English is not their first language. At John Muir Medical Center, there’s a huddle with a social worker, the charge nurse, the patient and a family member in order to plan a strategy for communicating with the patient. “We ask them what language they want to receive information in and how they want us to communicate with them,” she explains. “Some request an interpreter; some prefer a family member.” The choice is documented in the patient record.

Translation and interpreter services are expensive and not always easily available, so providers sometimes have to get creative on how to maximize resources. Fairview has started to use small, inexpensive video cameras to tape patient education sessions when an interpreter is called in. If a therapist is demonstrating a self-care technique to a patient and the patient consents, staff will tape that presentation and offer it to the patient to take home on a DVD. With the patient’s permission, they may also offer it to others who speak that language and need to learn the same technique.

**Where and When**

The rise in technology not only gives different options for how to distribute information, it also gives providers and health plans more options for where and when to distribute that information.

To maximize effectiveness, patient education materials need to be accessible to patients when it will have the biggest impact. Is that in the exam room or the bedside, at checkout, or at some other point in the healthcare encounter?

“If you just hand out something, it’s not very helpful, even if it’s a great document,” says Jan Kraus. Somehow, the information has to get integrated into the clinical process.

Print on demand solutions—in which materials chosen for a specific patient can be printed as needed—can help. Stiles recommends looking at the workflow in the clinic or hospital to determine the optimal way to use this system. Generally speaking, he says, it is more effective for the clinician to go over materials
with the patient in the exam room rather than to have it printed in the reception area and ready for pick up at checkout.

The move towards EHRs is putting more computers in the exam room, which not only allows clinicians to use print on demand systems more easily, it also gives them the ability to tailor education efforts directly to the patient.

“If you take a few minutes out to talk to the patient and show them things from their medical record—charts and graphs of their vital signs and lab results—this can be a very, very powerful tool for patient activation,” says Seubert. Seeing a trended graph of one’s own cholesterol levels is much more effective than seeing isolated numbers on a lab printout and getting a handout about ways to lower cholesterol.

But when you come right down to it, many health decisions are not made in the doctor’s office or the hospital. They are made in the home or at work. “When they’re home, that’s when patients need information that is clear and understandable as possible,” says Kraus. “They also need to be able to identify when they need to call their health care provider if they have a question.”

For example, the providers can email a link to pertinent information to the patient. The patient can use accessibility options on their computer to click on the text and have it read to them or make the print larger so it’s easier to see. Hyperlinks to animations and glossary terms allow patients to explore to the depth that suits their interest level. (As a not-insignificant side benefit, that email becomes another point of contact with the patient—a reminder that the provider cares enough to ensure the patient has the information he or she needs.)

Technology: Expanding Access or Widening Health Disparities?

The move towards all things digital has some people worried that some patients will be left behind. While studies show between 70 and 90 percent of adults access health information on the web, that means 20 to 30 percent still don’t. And even those who access health information that way may still prefer print at least in some circumstances.

Still, the digital revolution continues and increasingly health information is delivered not via a desktop or even laptop computer, but via cellphone. Yes, there’s an app for a wide range of health functions, from reminders to check glucose levels or apply sunscreen to information about the nutritional content of foods.

Cellphone and especially Smartphone use is actually rising more than computers. According to the Nielson 2010 Media Industry Fact Sheet, there are more than 223 million cellphone users in the United States. The number of mobile Web users is 60.7 million, up 33 percent from 2008. In the 3rd quarter of 2009, 25 percent of mobile devices sold were smartphones. That share is expected to grow to 40 or 50 percent in 2010.

According to Stiles, immigrants are among the early adapters of smartphones. Smartphones do not require as large an initial outlay as a computer, but offer many of the same capabilities, such as email and internet access.

But Stiles reminds us, technology alone can’t do it. “The technology presents opportunities, but it is not a solution in itself. It still requires thoughtfulness and intentionality.”
Healthcare providers are uploading videos and podcasts to their websites, YouTube, FaceBook, and other social media so that patients can have easy access to patient education materials in a wide range of formats.

Fairview allows patients to submit their own videos to share with other patients. Stiles cites a boy with diabetes who made a video about how to use a glucose monitor. “This really helps other patient connect, it’s more relevant to them,” Stiles says.

**Enterprise Solutions**

“It can be a huge and expensive undertaking” to develop or even just to choose and purchase the diversity of materials to meet the wide-ranging needs of patients, says Doug Seubert.

Many hospitals turn to an outside organization to supply patient education materials that meet these plain language principles and offer content in a variety of formats, including print, video, and audio. Most of these companies translate the materials into Spanish and other common foreign languages.

“Having enough different topics, having it be interactive, having it available in enough different languages available all in one package, that’s a very attractive option,” says Seubert.

Even with their own publishing division in house, Fairview chose to go to an outside vendor for much of their patient education materials. Previously, they had purchased or used materials from a variety of sources. That sometimes resulted in conflicting or confusing messages when the sources differed or didn’t align with the Fairview’s own practices. “With one vendor to work with, we had more control over the messaging,” Stiles explains.

Fairview chose an enterprise solution that provides information on a wide range of topics in multiple electronic formats and integrates into the electronic health record system used by Fairview’s staff. The clinician can type in a keyword to find and print out materials for the patient. A note is placed in the patient’s record to document that the patient was given or shown the information.

Stiles says having one vendor “doesn’t solve all communication problems, but it does address myriad problems that come from having multiple vendors or limited means of delivery information. It solves all those problems.”

And that lets Stiles and the Fairview staff focus on the unique needs of their community and on improving the personal connection between clinician and patient—which is indeed where the most important patient education takes place.

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