



Health Literacy:

*The Pathway to Patient Engagement
and Cost-Effective Care*



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OVERVIEW

The Policy Goals: Technology-Enabled Patient Engagement

The goal of the advanced information infrastructure envisioned in the Recovery Actⁱ is to transform health care in this country from a fragmented system that treats people after they become sick to a coordinated cost-effective system that helps keep people healthy. This goal cannot be met unless patients become partners with their providers and take an active role in choosing health care options and implementing treatment plans. Indeed, “engaging patients and families in their health care”ⁱⁱ is listed as a priority outcome for the Recovery Act’s \$25.8 billionⁱⁱⁱ investment in health information technology (health IT).

This paper explores the necessary foundation for successful patient engagement.

The Challenges: Communication and Technology

The Recovery Act creates a complex set of health IT requirements and activities. The technological challenges are significant; the communication challenges, more so. If health IT is to have a sustained impact on improving quality and reducing the cost of care, patients need accessible, easily understandable information (such as personal health data and educational materials) to assist them in making decisions about access to care, treatment and costs.

Without forethought and planning to be sure that most consumers can use the technology and *understand* the information available to them, the new infrastructure might have an unintended consequence: it might create a system that does not work for many consumers — especially the most vulnerable patient populations.

Providers face communication challenges as well. Due to the heightened expectations for meaningful patient consent and technical engagement, providers are burdened with the need for sophisticated customer service, easy-to-read collateral materials, easy-to-use websites and available technical support. Few providers are prepared to shoulder this burden — or capable of it.

The Solution: Consumer Support

To establish efficient and successful communication with consumers and promote meaningful use of health IT, providers need resources designed with a focus on health literacy, and consumers need easy-to-read information and easy-to-use technology. Integrating health literacy *best practices*,^{iv} user-friendly technology options and multimedia communication channels early on will yield more successful and cost-effective patient-engagement solutions.^v

BACKGROUND

The most capable and caring of clinicians cannot unilaterally improve a patient's health, foster healthier lifestyles and reduce the risk of chronic illness; patients must be true partners in their care for these things to happen. The patient is the critical component for determining quality of care and health outcomes. Take, for example, medication instructions.^{vi} Only the patient (together with a caregiver, if one is present) can ensure that medicine is taken properly and that any problems such as adverse reactions, affordability or confusing instructions are shared with the provider.

Implicit in the Recovery Act is the need for clear communication with the patients themselves. Patients have varied levels of education and literacy, different cultural needs and understanding, disparate technological skills and access to technology, and varying familiarity with the health care system and its unique vocabulary and culture. Data from the National Adult Literacy Survey suggests that close to 50% of all adults have problems understanding many aspects of health care, including prescriptions, appointment slips, and health education materials.^{vii}

The Recovery Act investment in health IT was based on the understanding that a modernized infrastructure is a prerequisite for improving quality and reducing the cost of health care. The law creates incentives for providers to adopt electronic health records (EHRs) and also promotes or establishes state-level health information exchanges (HIEs), which will make health information available to providers and consumers when and where they need it. The call for meaningful use recognizes that the new technology must support a patient-centered system designed to reduce health disparities and ensure access to the benefits of health IT for *all* patients. Consequently, technical and customer service support should help enable multiple communication channels that can reach all patients.

Privacy and Consent

The Recovery Act raises new concerns about the protection of health information and includes new safeguards to assure that patient information is kept private. Policy recommendations strongly support the patient's right to give or deny consent for medical records to be shared in an exchange. This consent will be the novice consumer's introduction to EHRs and to his or her expanded privacy rights vis-à-vis automated health information. Properly introducing the consumer to the concept of consent is a critical first step toward meaningful use of EHRs and HIEs.

Health Literacy in an Increasingly Automated Health System

Health literacy is the ability to find, read and use health-related information to make decisions about one's own health care. A person's health literacy is determined by his or her education, experience, culture, language skills and civic engagement. The person's ancillary knowledge of science, technology, politics and many other subjects also informs his or her ability to know about and understand health issues.

To reach people at most levels of health literacy, it is necessary to communicate clearly, in plain language, in the first language of the reader, using well-organized content that follows the reader's logic. The communication media should be visually compelling as well, to draw the reader or web user in to the material with an implicit promise that he or she will be able to navigate, read and understand it and apply it to his or her own circumstances.



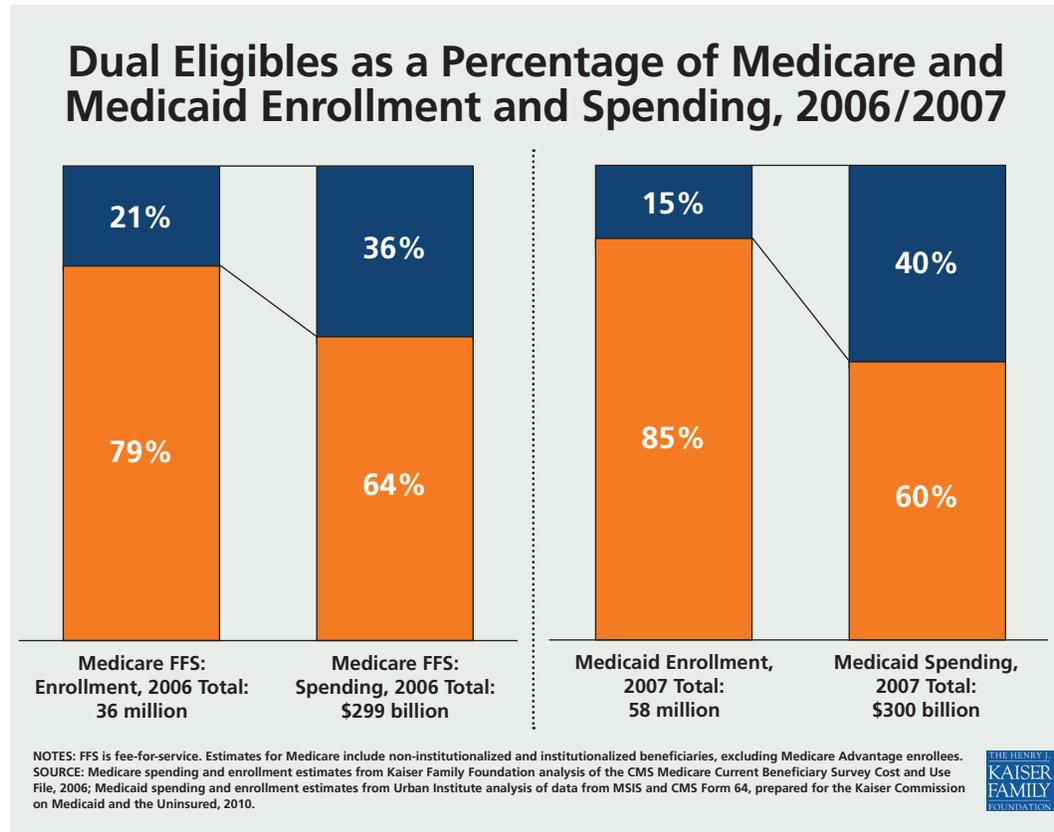
When given the instructions "Take two tablets by mouth twice daily," fewer than 35% percent of patients with limited literacy skills could correctly interpret the number of pills they should take in one day.^{viii}

Good health literacy — skills and knowledge that lead people to information that they can use — is founded on plain language strategies and clear, uncluttered, visually encouraging design. Deviations from those principles are likely to result in barriers to readability and usability, inappropriate health care and wasted time and money.

Plain language strategies, while not new, are typically absent from use in health materials, which are often formatted poorly and written using vocabulary that is not familiar to the target audience. The linguistic and cultural diversity, disparate abilities and economic disparity of the U.S. population require translation and appropriate access strategies to engage consumers in their health care.

Longer is sometimes clearer: "Take two pills every morning and two more pills every evening."

The need to address the challenges of health literacy and technology access is perhaps most evident among patients who are dually eligible for Medicare and Medicaid, a population that drives a disproportionate share of spending (see the chart below).^{ix} These “dual eligibles” have a different demographic profile than other Medicare beneficiaries: they have a greater number of permanent disabilities, more poverty and less education, and they represent a larger share of racial and ethnic minority groups (42% vs. 17%). They are in poorer health: more than 60% have cognitive impairments and more than half have three or more chronic illnesses.^x To reach the goal of improving care and reducing costs with this population, we must bridge the health literacy divide.



To explore the many challenges facing health care consumers, we have created patient-engagement scenarios for the composite, fictitious consumer described below.

Rosa Gonzales

Who she is

Rosa is a 72-year-old Hispanic woman who was educated through grade five in her country of origin. She is a naturalized citizen of the U.S. When she came to this country at age 16, she went right to work and did not continue her education. Her English is not good, but she did fine in her job as a hotel maid because her supervisor and many of the other maids spoke Spanish.

Now retired and a grandmother, she has health insurance through Medicaid and Medicare and cares for her three grandchildren while her adult children work. She is the one who takes the children for regular checkups and shots and to the doctor when they are sick. She accepts what she perceives as the authority and superiority of the providers (both the grandchildren's and her own) completely; she seldom asks questions or confirms instructions, not wanting to reveal her limited English or challenge what providers have said.

Her medical problems

Rosa's chief medical problems are diabetes, high blood pressure and other symptoms of cardiovascular disease. She sees an internist, a cardiologist and an endocrinologist and periodically presents at the local emergency room. Her eyesight is poor, even with corrective lenses. Her adult children help her navigate the health care system, and she does what they tell her to do, often without fully understanding why.

Her technology skills

There's a computer in Rosa's home, but she doesn't use it. (Her children and grandchildren use it.) Rosa uses a cell phone; it is her only telephone.

Patient-engagement challenges

The combination of Rosa's life circumstances and health status pose a broad number of challenges that will make patient engagement for her and her grandchildren complicated.

Consumer engagement during early health IT implementation

Below are four scenarios that illustrate the potential effects of certain barriers to patient engagement that could undermine successful meaningful use. The asterisks (*) point to the likely outcomes if the barriers are not addressed. *The four scenarios are not mutually exclusive.* A fifth scenario illustrates how an improved outcome could occur when the consumer's health literacy limitations are anticipated.

SCENARIO 1: Rosa faces readability barriers

In 2011 only Rosa's hospital and cardiologist are seeking the meaningful use incentive. Both reach out with education materials and an HIE consent form, but these materials are written at too high a reading level, and the Spanish translation is not adapted to Rosa's literacy level. In addition, the print is very small and hard for Rosa to see.

- * Rosa likely waits or does not allow her information to be shared through the HIE because of uncertainty and fear of what it will mean to her care, her insurance or how she is perceived by her doctors.

SCENARIO 2: *Rosa faces technology barriers*

Rosa has given consent to the hospital to share electronic information, and she attempts to find her records after a recent visit to the emergency room. However, her home computer is not appropriately configured. She and her children try to call the hospital for assistance. They are transferred to the EHR help desk and the hospital's administration office, neither of which can identify the problem or provide assistance.

- * Rosa does not receive sufficient technical support, and she stops trying.

SCENARIO 3: *Rosa faces coordination, consistency and patient-engagement barriers*

Rosa has given consent to both specialists and to the hospital. However, her internist has not yet fully adopted an EHR and still lags in meaningful use because of the more flexible Medicaid incentive time frames. Rosa's providers vary in their levels of consumer technical and translation support. The information Rosa finds on the EHR seems to recommend conflicting health practices: her endocrinologist suggested an increase in exercise, while her cardiologist indicated exercise was not recommended, because of a form of neuropathy that affects her heart rate.

- * Rosa is confused, but she is hesitant to discuss her inability to read and understand the site's content with her specialists. Her internist is not receiving information in a timely manner to help coordinate her care.

SCENARIO 4: *Rosa faces literacy barriers that cause her to make mistakes*

The pediatrician for Rosa's grandchildren has been given HIE consent and uses eRx to prescribe antibiotics for strep throat. No one has adequately explained the treatment plan to Rosa in Spanish. When a second grandchild becomes ill with a sore throat and the child for whom the prescription was intended begins to feel better, Rosa stops giving the drug to the grandchild with strep and gives it instead to the other grandchild.

- * Rosa finds out that she should not have stopped the prescription or shifted it to another child only when she takes both children back to the pediatrician because neither child has fully recovered.

These first four scenarios all failed to anticipate health literacy needs or establish a centralized option for consent and technical support. The following scenario describes a coordinated health literacy-enabled alternative.

SCENARIO 5: *Rosa gains some familiarity with EHRs*

Rosa's introduction to EHRs and consent forms was relatively smooth because she learned about them at a community-based organization, a trusted source of support and information in her life.

The state HIE has engaged the local Hispanic health advocacy organization to help new patients use automated health record information. This partnership brings with it the following customer-centered features:

- The HIE has a website with standardized (and customizable) interfaces that this and other community organizations can use to access educational materials and to assist patients in determining whether they want to allow their health information to be shared.
 - The advocacy organization serves as a health information guide and can provide information verbally or provide easy-to-read print materials in a consumer-friendly format.
 - Rather than consent being negotiated with each of the four providers, consent decisions can be made for all of Rosa's providers through the website. Providers can refer patients to the HIE site or to the community organization partners to streamline the initial consent decisions and management.
 - The website also provides technical support for patients accessing information from an EHR, a consumer portal that can send messages to cell phones, and guidance about assistive devices that can be used in support of EHR access and information about the 24-hour technical and language (interpreter) help line and three-way calling services that can be used with providers' offices (for languages and relay services).
- * Rosa is able to understand the consent process and HIE, make an informed decision and rely on this multichannel, multimedia infrastructure to engage with the health care system and better understand information about her and her grandchildren's health care.

SUMMARY

If patients like Rosa (dual eligibles who represent Medicare and Medicaid's sickest, poorest and often most costly beneficiaries) are left behind because patient engagement fails for them, then the health IT investments of the Recovery Act might fail.

We could delay addressing these needs until stage 2 of meaningful use, but that would risk creating a two-tiered care-delivery system and wasting resource investments.

Early investment in health literacy strategies and single access points can help identify streamlined approaches that give all patients the same potential benefits if they choose to allow their EHR information to be shared and engage with their providers in planning their health care.

Consumer Education, Health Literacy and Community Engagement from the Start

Taking the following steps as we seek to engage patients in their care could determine the success or failure of the Recovery Act health IT investments:

- Develop basic education content, tools and interfaces for consumers, HIEs, regional extension centers, providers, EHR vendors and community organizations.
- Develop content using plain language and allowing for community feedback during development.
- Establish multimedia distribution channels (including cell phones) for providing information.
- Design web interfaces that are intuitive and user-friendly and conduct both health literacy and accessibility reviews.
- Design consumer-friendly consent forms written in plain language, formatted to enhance readability and translated into threshold languages.
- Perform usability testing of web and print materials, choosing test participants who represent the spectrum of the general population and who include readers of varying literacy levels and physical and mental abilities.
- Educate community-based organizations about EHRs, and ask them to provide learning opportunities and support for their members, in the first language of the member.

But Is It Affordable?

Taking these steps to make the initial communications about health IT, HIE and consent accessible for all consumers will require resources and financial investment. Fortunately, the Recovery Act and health reform have set aside funding, and the funding resources for state Medicaid EHR incentive programs, HIEs and regional extension centers anticipate education and outreach campaigns. Ideally, state Medicaid agencies, in partnership with the Medicare program and the Office of the National Coordinator for Health Information Technology, will leverage their combined funding to address some of the critical health literacy needs of the dually eligible.

Even if these funds are limited, the cost of *not* making this investment should compel action. “Poor health literacy can have profound financial consequences. In 2001, low functional literacy resulted in an estimated \$32 to \$58 billion in additional health care costs.”^{xi} Current demographics trends will likely make these costs grow.

As we work toward the important goals of quality improvement and cost-effective care, we should begin with investing in health literacy when building models for patient engagement and meaningful use. Those models, if well done, will lay the foundation for all consumers and, in particular, for the most vulnerable consumers, who have the most to gain if we succeed.

Endnotes:

- ⁱ The American Recovery and Reinvestment Act of 2009, or ARRA, including the Health Information Technology for Economic and Clinical Health Act, or HITECH.
- ⁱⁱ As first established by the Health IT Policy Committee “engage patients and families in their health care” is one of five policy priorities for health outcomes in the framework for meaningful use of EHRs. Medicare and Medicaid Programs; Electronic Health Record Incentive Program; Final Rule Federal Register / Vol. 75, No. 144 / Wednesday, July 28, 2010, p. 44372,
- ⁱⁱⁱ Funding amount listed on the United States Department of Health and Human Services Recovery Act Website Programs page on November 29, 2010, <http://www.hhs.gov/recovery/programs/index.html#Health>.
- ^{iv} Williams, D. “A review of plain English writing tips for U.S. government documents.” MA thesis, George Mason University, 1999,
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Cutts, M. “Unspeakable acts revisited.” *Information design journal* 9, no. 1:39–43, 1998.
- ^v “Clear, candid, accurate, culturally and linguistically competent provider-patient communication is essential for the prevention, diagnosis, treatment, and management of

health concerns.” Chapter 11 Health Communication Objective 11-6.

http://www.healthypeople.gov/document/HTML/Volume1/11HealthCom.htm#_ednref23

- vi Literacy and misunderstanding prescription drug labels. Terry C. Davis, PhD; Michael S. Wolf, PhD, MPH; Pat F. Bass III, MD; Jason A. Thompson, BA; Hugh H. Tilson, MD, DrPH; Marolee Neuberger, MS; and Ruth M. Parker, MD, Literacy and Misunderstanding Prescription Drug Labels, *Annals of Internal Medicine*, December 2006 Volume 145 Number 12, pp. 887–894.
<http://www.annals.org/content/145/12/887.full.pdf>
- vii Center for Health Care Strategies Fact Sheet 3, Impact of Low Health Literacy Skills on Annual Health Care Expenditures.
http://www.chcs.org/publications3960/publications_show.htm?doc_id=291711
- viii Davis, et al., pp. 887–894.
- ix Medicare spending and enrollment estimates from Kaiser Family Foundation analysis of the CMS Medicare Current Beneficiary Survey Cost and Use File, 2006; Medicaid spending and enrollment estimates from Urban Institute analysis of data from MSIS and CMS Form 64, prepared for the Kaiser Commission on Medicaid and the Uninsured, 2010.
<http://facts.kff.org/chart.aspx?cb=58&sctn=166&ch=1767>
- x Kaiser Family Foundation analysis of the CMS Medicare Current Beneficiary Survey Cost and Use File, Comparison of Dual Eligibles and Other Medicare Beneficiaries, 2006.
<http://facts.kff.org/chart.aspx?cb=58&sctn=166&ch=1765>
- xi Center for Health Care Strategies Fact Sheet 3, Impact of low Health Literacy Skills on Annual Health Care Expenditures.
http://www.chcs.org/publications3960/publications_show.htm?doc_id=291711