



*Translating Research into Practice*

## Consumer Health Literacy: Preparing for Changing Roles, Rights, and Responsibilities in Health and Health Care

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“Health consumers face a number of challenges as they seek health information, including the complexity of the health systems, the rising burden of chronic disease, the need to engage as partners in their care, and the proliferation of consumer information available from numerous and diverse sources. Individuals are asked to assume new roles in seeking information, advocating for their rights and privacy, understanding responsibilities, measuring and monitoring their own health and that of their community, and making decision about insurance and options for care. Underlying these complex demands are the varying and sometimes inadequate levels of first, consumer knowledge and, second, skills for using and applying a wide range of health information.”  
Institute of Medicine, 2004<sup>1</sup>

At least 14% of Wisconsin’s adults read at the very lowest levels.<sup>2</sup> Nationally, the average American reads at the 8<sup>th</sup> to 9<sup>th</sup> grade level, and more than 90 million (47%) United States adults cannot accurately handle information from newspapers, advertisements, or forms. This problem is felt acutely in health care, where nearly 50% of all adults may have problems understanding prescriptions, appointment slips, informed consent documents, insurance forms, and health education materials.

Limited health literacy is associated with more severe disease and more costly care. Higher costs result from more medication and treatment errors, more hospitalizations, longer hospital stays, more provider visits, and failure to obtain appropriate services. Studies suggest that scores of billions are lost nationally each year due to low literacy skills.

Newly released landmark studies from the Institute of Medicine and the Agency for Healthcare Research and Quality<sup>3</sup> detail how limits in health literacy affect health and the health care system. Health profes-

sionals and systems are called upon to increase their awareness of their patients’ competencies and to provide more meaningful interaction.

The Institute of Medicine (IOM) defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Clearly, those most challenged include persons with low educational levels, linguistic or cultural barriers, who are elderly or low socio-economic status.

Most individuals will encounter health literacy barriers at some point. High educational attainment may not be sufficient to negotiate medical and technical language and meanings.

Yet all people, even those with advanced reading skills, are challenged to keep up with their new responsibilities within the health care arena, and thus are at risk for low health care literacy. This owes to the inherent and growing complexity of, for example, legal informed consent, disease management guidelines, and quality information.

Also, consumers may operate at one level of “literacy” or the ability to process information when making decisions in advance, through a deliberate and carefully considered process. But “literacy” may be compro-

mised for a consumer who is in the immediate role of patient, making decisions in the face of acute or urgent health needs, such as hospitalization, emergency surgery, or serious disease diagnosis.

Further, many patients do not want to engage in self-management, collaborative care, or shared decision-making. Patients may be intimidated by the complexity of medical choices or have anxiety about making the right choice. While patients typically express high preferences for information about their illness and its treatment, preferences for participating in treatment decisions are mixed.

Engaging consumers in purchasing decisions based on quality can be even more vexing. Most report cards require multiple performance dimensions. And consumers have to factor in plan type, benefits and coverage levels, provider panel, geographic locations, and costs.

The emergence of “consumer driven” or “consumer directed” health plans, flexible spending accounts, medical savings accounts, and “health reimbursement accounts” has further elevated the importance of health literacy. As well, the federal Medicare prescription drug benefit and other provisions of the Medicare Modernization Act promise to foster confusion among even highly educated enrollees.

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## Potential Programs and Policies

Various sectors – consumers, health professionals, provider entities, purchasers, employers, State government -- have roles in promoting health literacy. Each of these entities will at various points themselves be either an audience or responsible for implementation or monitoring.

### A. Strategies to Support Consumers as “CoProducers of Care”<sup>4</sup>

Evidence indicates that collaborative care results in improved outcomes, including increased functioning, reduced pain, and reduced health care costs. But patients, in order to exert more control in their interactions with providers, require a greater sense of self-efficacy and confidence in their knowledge and ability to perform self-care<sup>5</sup> management tasks. Providers, as well, need to coach patients to be more involved.

- Create simplified, more comprehensible education materials.
- Train providers to communicate more effectively.
- Redesign the health care encounter and systems to support effective communication.
- Incorporate nurses, pharmacists, and ancillary providers into the health care team to provide more points of contact for patient education.
- Elevate the role of health educators in materials design and in training of providers.
- Reform payment and reimbursement practices on the part of purchasers and payers.

### B. Strategies to Support Consumers as “Evaluators of Care”<sup>4</sup>

The “evaluator of care” role refers to the trend toward including the patient’s perspective in the measurement of the performance of health care. Here, consumers are a source of information for determining the quality of care and assessing outcomes. This trend however, needs to go the next step, asking consumers to evaluate the experiences of care and the degree to which they were supported in their coproducer role in the care process.

### C. Strategies to Support Consumers “Informed Choice” Role<sup>4</sup>

Employers, purchaser and providers, in order to educate and motivate consumers to use quality information, should work in partnership toward the following:

- Increase awareness of and perceived advantage to using quality data
- Reduce complexity, with expanded use of non-print and interactive technologies.

- Design reports that are relevant to consumers’ felt needs.
- Establish independent credibility of reported data through an external unbiased entity.
- Achieve consistency of measures across reports.
- Assure comparability of data elements across plan types (HMOs, PPOs, indemnity).
- Promote strategic timing and pertinence if reporting year-round.

### D. Public & Private Sector Standards: Regulation, Enforcement and Monitoring

➤ **Articulate what Constitutes the “Standard of Care” and “Informed Consent”** The IOM reports that the readability levels of informed consent documents exceed the average reading levels of the majority of U.S. adults. This has important ethical and legal implications. Specifically, a signature on a consent form is not adequate evidence that informed consent has been obtained. In determining liability, a court may also consider whether information was conveyed to the patient by a means that was likely to enable patient comprehension.

#### ➤ **Leverage the State Government Role as Purchaser and Regulator**

In 2002, the Council of State Governments published *The State Officials Guide to Health Literacy*.<sup>6</sup> Wisconsin’s Medicaid program has much experience in simplifying enrollment materials and procedures, in helping persons with low health literacy to navigate the managed care program, and building assurance into their contract with providers. Such standards are certainly applicable beyond Medicaid. State government may further health literacy through other programs, in its role as purchaser of health services as well as a regulator of the insurance industry.

#### ➤ **Adopt Public and Private Reporting and Monitoring**

State and private efforts might look to national standards that are being adopted to measure and evaluate health literacy accommodations among providers and health plans. The IOM has called on public and private accreditation bodies, including Medicare, NCQA, JCAHO, to clearly incorporate health literacy into their accreditation standards.

### E. Beyond the Health Care System

Significant opportunities exist outside of the

health care system to address the underlying challenges in health literacy – indeed, to consumers’ ability to attain their rights and fulfill their responsibilities in health and health care.

### ➤ **Implement National Health Education Standards in K-12 Education**

In 1995, the Joint Committee on National Health Standards published the *National Health Education Standards* with the subtitle *Achieving Health Literacy*. These detail the knowledge and skills students should attain by the end of grades 4, 8, and 11.

#### ➤ **Find teachable opportunities to enhance adult literacy**

Promising programs have inserted health literacy curricula into voc-tech, GED, and other adult-education related venues. Adult learners demonstrate interest in this content and readiness to both absorb the information and transmit it to their communities.

#### ➤ **Build Partnerships and Outreach through Community Venues**

Organizations with ties particularly to minority and low-income communities can help consumers maneuver through the health care system and can be important allies in establishing trust. Faith communities, advocacy organizations, ethnic media, and even traditional healers can help design and disseminate messages about health and health care quality.

A report from the 2003 Wisconsin Economic Summit<sup>7</sup> called on the University of Wisconsin System to spearhead a statewide health literacy campaign. The committee noted that UW Extension has a well-placed network of campuses and offices throughout Wisconsin that could work in partnership with state agencies toward this shared mission.

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**Note:** David Kindig served as the chairman of the IOM committee on Health Literacy.

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