Executive Summary

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

Better Health Through Informed Policy
“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, Health Literacy: A Prescription to End Confusion

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

Issue Summary

At least 14% of Wisconsin’s adults read at the very lowest levels. Nationally, the average American reads at the 8th to 9th 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 and emergency department visits, longer hospital stays, more provider visits, and failure to obtain appropriate services. Billions of dollars are lost nationally each year due to low literacy skills that make it difficult for patients to comprehend and utilize instructions that pertain to their health.

Health literacy is receiving increased attention as a critical component for managing personal health and navigating the health care system. This Executive Summary discusses the challenges of health literacy and potential policy and program initiatives in the corporate and public sector. Newly released landmark studies from the Institute of Medicine and the Agency for Healthcare Research and Quality detail the pervasiveness of functional illiteracy, along with how limits in health literacy affect health and the health care system. Health professionals and systems are called upon to increase their awareness of their patients’ competencies and to provide more meaningful interaction.

The Institute of Medicine (IOM) in 2004 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, or low socio-economic status.

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, informed consent documents, disease management guidelines, and information on the quality of care provided by doctors and hospitals. It also relates to the multitude of psychosocial, ethical, and situational factors that may surround health care decisions.
That is, the consumer 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 compromised for a consumer who is in the immediate role of patient, having to make 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. The amount of information in most HMO report cards is beyond what humans can effectively process and use. They require comparison of multiple plans on 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 enormous complexity of the federal Medicare prescription drug benefit and other provisions of the Medicare Modernization Act promise to foster confusion among even highly educated enrollees.

Nonetheless, consumers have a critical role to play in improving quality of care and health outcomes. Employers and purchasers, expecting to motivate providers to improve quality (and, perhaps lower cost), are promoting consumer use of comparative performance information in their health care decisions.

Beyond such “informed choice,” consumers are increasingly engaged in what has been termed “co-producers” and “evaluators” of care — roles that have the potential to improve the quality of their care and of the system as a whole. The co-producer role refers to patients helping to “produce” health by acting as effective partners with providers. The evaluator role refers to consumers providing data on provider and system performance and participating in defining the parameters of quality. Consumers thus have a significant role in selecting, managing, and evaluating their care and, through this, the potential to improve care and produce better outcomes.

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.
Summary of Program and Policy Options

Various sectors and entities — consumers, health professionals, providers, purchasers, employers, and State government — have roles in promoting health literacy. Each of these entities will at various points be either responsible for implementing new programs or policies or will be an audience for such changes.

A. Strategies to Support Consumers as “Co-Producers of Care”

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 management tasks. Providers, as well, need to coach patients to be more involved. These goals could be achieved by:

• Creating simplified, more comprehensible materials for health communication.
• Training providers to communicate more effectively.
• Redesigning health care systems so that providers have adequate time to communicate effectively with patients.
• Incorporating nurses, pharmacists, and ancillary providers into the health care team to provide more resources and more points of contact for patient education.
• Elevating the role of health educators in the design of materials and training of providers.
• Reforming payment and reimbursement practices on the part of purchasers and payers so that adequate time with patients, effective communication and better health outcomes are standards for payment.

B. Strategies to Support Consumers as “Evaluators of Care”

The “evaluator of care” role refers to the trend toward including patients’ perspectives in measuring the care they receive. Here, consumers are a source of information for determining the quality of care and assessing outcomes. This can be done by:

• Asking consumers to evaluate their care and the degree to which they were supported in their co-producer role.
C. Strategies to Support Consumers “Informed Choice” Role

Employers, purchasers and providers, can educate and motivate consumers to use quality information by:

- Increasing awareness and the advantages of using quality data.
- Reducing the complexity of quality information, in part through expanded use of non-print and interactive technologies.
- Designing reports that are relevant to needs identified by consumers.
- Establishing the independent credibility of reported data through an external, unbiased entity.
- Achieving consistency of quality measures across different reports.
- Assuring the comparability of data elements across plan types (HMOs, PPOs, indemnity).
- Promoting year-round reporting of quality information.

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

- **Articulate what Constitutes the “Standard of Care” and “Informed Consent”**

  Usually, reasonable care means care rendered in accordance with the standards of the profession. Providers may fail below this standard if there are documented low-risk, inexpensive approaches to limited health literacy that are not used by health providers.

  The IOM has documented that the readability of informed consent documents exceed the average reading levels of the majority of U.S. adults. Important ethical and legal implications are raised if there is ambiguity about whether a patient has in fact given informed consent.

  Because of these potential problems, standards of care and informed consent should be more clearly defined.

- **Leverage the State’s Role as Purchaser and Regulator**

  In 2002, the Council of State Governments undertook a national research project that resulted in the publication of *The State Officials Guide to Health Literacy*. A number of states are involved in activities that make it easier for someone with low health literacy to navigate public assistance programs, such as simplifying enrollment materials and procedures and building such standards into Medicaid managed care contracts.

  These standards are 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.
The Department of Employee Trust Funds could promote health literacy among state employees as part of its purchasing and cost containment strategies.

The Department of Health and Family Services could launch a health literacy initiative as part of its health promotion programs, cutting across programs such as maternal and child health and chronic disease.

The Office of the Commissioner of Insurance could require and enforce health literacy provisions among insurers and HMOs.

- **Adopt Public and Private Reporting and Monitoring**
  State and private efforts to promote quality, patient education, and consumer engagement in health care might look to national standards that measure and evaluate health literacy accommodations among providers and health plans. The IOM has called on public and private accreditation bodies (including Medicare, the National Committee for Quality Assurance, and the Joint Commission on Accreditation of Health Care Organizations) to incorporate health literacy into their accreditation standards. The Wisconsin Collaborative for Healthcare Quality, the Wisconsin Hospital Association’s CheckPoint Program, as well as other private and public sector purchasers (DHFS and DETF), might follow this lead.

**E. Beyond the Health Care System**
Significant opportunities exist outside of the health care system to address the underlying challenges of health literacy.

- **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 standards detail the knowledge and skills that 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 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.

- The DHFS Minority Health Program could commit a portion of its grant program toward the priority goal of enhancing health literacy.
Wisconsin’s two medical schools could commit a portion of their Blue Cross/Blue Cross grant funds toward addressing health literacy.

**Initiate a Statewide Health Literacy Campaign**

Efforts to improve health literacy might include a social marketing campaign designed to create broad awareness among Wisconsin residents on quality indicators and performance measures, health insurance/benefits, self-care, and personal health decision-making. A report from the 2003 Wisconsin Economic Summit called on the University of Wisconsin System to spearhead such an effort, noting that UW Extension has a well-placed network of campuses and offices throughout Wisconsin. Wisconsin’s Governor, executive branch and legislative leadership could work in partnership with the UW System toward this statewide mission.
# Building Health Literacy and Engaging Consumers:

## Summary of Potential Program and Policy Interventions

Consumers in Roles of Informed Choice, Co-Producers, and Evaluators of Care

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<thead>
<tr>
<th>Action</th>
<th>Audience</th>
<th>Responsibility for Implementation</th>
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<tbody>
<tr>
<td><strong>Materials for Individual and Mass Communication</strong></td>
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<tr>
<td>Create simplified, more comprehensible health information</td>
<td>consumers</td>
<td>providers, plans, state agencies, purchasers</td>
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<tr>
<td>Develop and utilize non-print materials and methods</td>
<td>consumers</td>
<td>providers, plans, state agencies, purchasers</td>
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<tr>
<td><strong>Patient-Provider Relationship</strong></td>
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<tr>
<td>Train health professionals to communicate more effectively</td>
<td>health professionals</td>
<td>professional organizations, education and training programs</td>
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<tr>
<td>Redesign health care encounters and systems to support effective communication</td>
<td>health systems</td>
<td>health systems, provider groups, purchasers</td>
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<tr>
<td>Develop tools to allow consumers to evaluate their own care</td>
<td>consumers</td>
<td>plans, purchasers</td>
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<tr>
<td><strong>Educate and Motivate Consumers to Use Quality Information</strong></td>
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<td>Develop quality indicators for sub-groups of consumers</td>
<td>consumers</td>
<td>purchasers, plans, BHI, Quality Collaborative, Checkpoint, others</td>
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<tr>
<td>Engage an independent entity as the source of credible, unbiased information</td>
<td>consumers</td>
<td>purchasers, plans, BHI, Quality Collaborative, Checkpoint, others</td>
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<tr>
<td>Develop standard measures and possibly a unified report format</td>
<td>consumers, purchasers</td>
<td>purchasers, plans, BHI, Quality Collaborative, Checkpoint, others</td>
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<td>Standardize measures across health plan types</td>
<td>consumers</td>
<td>purchasers, plans, BHI, Quality Collaborative, Checkpoint, others</td>
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<td>Engage community venues for publication, updating and distribution of info</td>
<td>consumers</td>
<td>purchasers, plans, BHI, Quality Collaborative, Checkpoint, others</td>
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<td><strong>Law and Regulation</strong></td>
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<td>Articulate what constitutes “Standard of Care”</td>
<td>providers</td>
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<td><strong>Enforcement and Monitoring: Leverage State Role as Purchaser and Regulator</strong></td>
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<td>Incorporate health literacy into contract standards</td>
<td>plans and providers</td>
<td>DHFS, DETF</td>
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<td>Require and enforce regulatory standards on insurers and health plans</td>
<td>plans and providers</td>
<td>Office of the Commissioner of Insurance</td>
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<tr>
<td>Incorporate health literacy into private accreditation and assessment</td>
<td>plans and providers</td>
<td>Quality Collaborative, Checkpoint, other private sector entities</td>
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<td><strong>Statewide Education and Outreach</strong></td>
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<td>Spearhead statewide health literacy campaign</td>
<td>WI residents</td>
<td>UW System, UWEX, state agencies</td>
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<td>Implement national health standards in K-12 education programs</td>
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<td>Incorporate health literacy into Adult Education programs</td>
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<tr>
<td>Build partnership and outreach through community venues</td>
<td>at-risk communities</td>
<td>DHFS, UW and MCW BC/BS grant programs</td>
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Endnotes


7 Health Care Cost Crisis in Wisconsin: An Economic Development Prognosis. Paper Presented to the Wisconsin Economic Summit IV, October 28, 2003, Milwaukee, Wisconsin. Available at http://www.wisconsin.edu/summit/papers/HealthCare.pdf (This specific link may expire as future summits are held, but the paper will still be archived on the Wisconsin System webpage.)