



**Wisconsin Public Health & Health Policy Institute**

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

*Better Health Through Informed Policy*

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# Wisconsin Health Policy Forums

Wisconsin Health Policy Forums is a project of the Wisconsin Public Health and Health Policy Institute. Our goal is to inform state health policy debates with the best evidence and thinking available. We strive to be comprehensive, practical, relevant and fair in our selection and treatment of topics, avoiding academic jargon and partisan politics. University based, and closely linked to public and private policy makers throughout the state, we are a resource for bridging research and practice and we provide a safe forum for all voices to be heard.

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# Table of Contents

<b>Introduction.....</b>	<b>1</b>
<b>Part I: The Demographics, Epidemiology, and Economics of the Problem.....</b>	<b>3</b>
IA. Definition and Scope of “Health Literacy” .....	3
IB. Who has Health Literacy Challenges?.....	3
IC. Growing Recognition of a Longstanding Problem .....	5
ID. Literacy Challenges in Consumers’ Emerging Roles and Responsibilities .....	6
IE. Literacy and Health Outcomes .....	6
IF. The Financial Cost of Low Health Literacy .....	7
<b>Part II: Program and Policy Interventions: Options, Audiences, and Actors .....</b>	<b>8</b>
IIA. Support Consumers as “Co-Producers of Care” .....	8
A1. Create Simplified, More Comprehensible Materials for Health Communication .....	8
A2. Train Health Professionals to Communicate More Effectively.....	9
A3. Redesign Health Care Encounters and Systems .....	9
IIB. Support Consumers as “Evaluators of Care” .....	10
IIC. Support Consumers “Informed Choice” Role.....	11
IID. Public & Private Sector Standards: Enforcement and Monitoring...	13
D1. Patient Rights, Health Literacy, and Health Law.....	13
1a. Articulate what Constitutes the “Standard of Care” .....	13
1b. Articulate what Constitutes “Informed Consent” .....	14
D2. Leverage the State’s Role as Purchaser and Regulator .....	14
D3. Adopt Public and Private Reporting and Monitoring .....	15
IIE. Beyond the Health Care System.....	16
E1. Implement National Health Education Standards in K-12 Education .....	16
E2. Find teachable opportunities to enhance adult literacy .....	16
E3. Build Partnerships and Outreach through Community Venues..	17
E4. Initiate a Statewide Health Literacy Campaign.....	17
<b>Building Health Literacy and Engaging Consumers: Summary of Potential Program and Policy Intervention.....</b>	<b>18</b>
<b>Endnotes.....</b>	<b>19</b>



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

## Introduction

**A**t least 14% of Wisconsin 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.<sup>3</sup> 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.<sup>4</sup> As much as \$73 billion<sup>5</sup> may be 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.

This *Information Paper* discusses the challenges of health literacy and potential policy and program initiatives in the corporate and public sectors. Health literacy is receiving increased attention as a critical component for managing personal health and navigating the health care system. Newly released landmark studies from the Institute of Medicine<sup>6</sup> and the Agency for Healthcare Research and Quality<sup>7</sup> 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.<sup>8</sup>

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.

"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*<sup>1</sup>

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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.

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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.<sup>9</sup> While patients typically express high preferences for information about their illness and its treatment,<sup>10</sup> preferences for participating in treatment decisions are mixed.<sup>11</sup>

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.<sup>12</sup> They require comparison of multiple plans on multiple performance dimensions. And consumers have other information to factor into their choices: plan type, benefits and coverage levels, provider panel, geographic locations, and costs. The trade-offs among the plans add to the level of complexity in decision-making.

Nonetheless, consumers have a critical role to play in improving quality of care and health outcomes. One of the leading researchers on the role of consumers is Judith Hibbard, a professor at the University of Oregon.

Hibbard<sup>13</sup> and her colleagues have written extensively about the potential that consumers hold to bring about change within the health care system. One role that consumers play is that of making "informed choice." Employers and purchasers, expecting to motivate providers to improve quality (and, perhaps lower cost), are promoting consumer use of comparative quality information in their health care decisions.<sup>14</sup>

Beyond making informed choices, Hibbard identifies two other roles for consumers to improve the quality of their care and of the system as a whole: co-producer and evaluator. 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 managing, selecting, and evaluating their care and, through this, the potential to improve care and produce better outcomes.

This *Information Paper* reviews the challenges to health literacy as detailed by the IOM, while focusing on consumers' current and growing roles as outlined in Hibbard's paradigm — those of informed choice, co-producer of health, and evaluator of health care services.

# Part I: The Demographics, Epidemiology, and Economics of the Problem

## IA. Definition and Scope of “Health Literacy”

### IOM Finding 2.3:

Health literacy includes a variety of skills beyond reading and writing, including numeracy, listening and speaking, and relies on cultural and conceptual knowledge.

To define health literacy, the Institute of Medicine (IOM) draws from the U.S. *Healthy People 2010*,<sup>15</sup> the document that reports the federal government’s national health objectives: “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” The IOM emphasizes that health literacy goes well beyond reading level, to include numeracy, listening, as well as myriad social and individual factors.

Prior to this, the American Medical Association’s Council on Scientific Affairs more specifically defined functional health literacy as “the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials required to successfully function as a patient.”<sup>16</sup> Educators as well do not associate literacy with reading alone, but also with writing, basic math calculations, and speech and comprehension skills.<sup>17</sup>

Routine health and health care tasks are often complicated and may require more literacy skills than those needed to meet the demands of everyday life. Print literacy has dominated the discussion of health literacy to date, focusing on readability of materials and the ability of people to read them. Research findings over three decades demonstrate that health materials exceed the reading skills of most high school graduates.<sup>18</sup>

## IB. Who has Health Literacy Challenges?

The 90 million adults with limited literacy likely lack the necessary skills in English needed to obtain and understand the health related information they will encounter at home, at work, and in their communities. The majority of these adults are native-born English speakers. Literacy levels are lower among the elderly, those who have lower educational levels, those who are poor, minority populations, and groups with limited English proficiency, such as recent immigrants.<sup>19</sup>

Beyond the definitions noted above, however, the concept of health literacy is also intended to address the processing and use of recent innovations in data and information for navigating the health care system. This broadens the prevalence of low health literacy considerably, counting among the at-need populations those that academic literature has only begun to document: consumers and patients who — even when presented with the opportunity for acting in the roles of informed choice, co-producer, and evaluator — have not effectively used the tools available.

### IOM Finding 6.1:

Demands for reading, writing, and numeracy skills are intensified due to health care systems’ complexities, advancements in scientific discoveries, and new technologies. These demands exceed the health literacy skills of most adults in the United States.

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“Illiteracy rates continue to rise in part not because more people are unable to read but because the level of skills needed to survive in society continues to rise.”

Wisconsin Department of Public Instruction, 2003

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“Literacy Services of Wisconsin estimates that there are more than 300,000 adults with literacy needs in Wisconsin.”

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- Even the most educated people have trouble with complex consent forms and health insurance statements.
- Those with more limited literacy skills may not be able to understand a drug dosing chart or read a bus schedule to find a clinic or hospital.
- Over 300 studies have shown that health information cannot be understood by most of the people for whom it was intended.

Health literacy problems affect people from all backgrounds. Identifying patients who may have limited health literacy can be difficult.<sup>20</sup> Years of schooling may not be a reliable indicator. One study reports that adults typically read three to five grade levels below the highest grade of schooling completed.<sup>21</sup> Also, patients with low levels of literacy may not recognize the problem or, if they do, may be too ashamed to reveal it to others. Another study of patients with low functional literacy, found that 40% felt shame; 67% had never disclosed their situation to their spouses; 53% never told their children; and 19% had never told anyone.<sup>22</sup>

## Literacy in Wisconsin<sup>23</sup>

The National Institute for Literacy's 1992 National Adult Literacy Survey estimated that 14% of Wisconsin adults read at the very lowest levels. Data from the U.S. Census Bureau for 2000 indicate that the illiteracy rate may be slightly higher. Census figures show that 15% of the Wisconsin adult population over the age of 25 (518,000 people) did not complete high school and do not have an equivalency degree. Of those, 186,000 have fewer than nine years of formal education.

Literacy Services of Wisconsin, Inc., a Milwaukee-based literacy agency, estimates that there are more than 300,000 adults with literacy needs in Wisconsin, 160,000 of them in the Milwaukee area. As well, Wisconsin's growing number of immigrants and burgeoning Spanish-speaking population further challenge both the health care and educational systems.

Table 1

### Educational Levels in Wisconsin, 2000 Census

Less than ninth grade	8 %
Between ninth and twelfth grade	13 %
High school diploma or equivalent	36 %
Some college, no degree	20 %
Associate degree	7 %
Bachelor's degree	11 %
Attended graduate school	5 %

## IC. Growing Recognition of a Longstanding Problem

Literacy has long been a focus in health education arenas and in patient care, particularly in the fields of nursing and pharmacy.<sup>24</sup> In the late 1990s, the American Medical Association undertook a review of academic literature relating to the effects of health literacy, reviewing 216 published articles.<sup>25</sup> Its 1999 report<sup>26</sup> acknowledged the limited literacy skills of many Americans and the need for improved communication between patients and providers.

The Institute of Medicine, in its 2001 seminal report *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*,<sup>27</sup> proposed re-organizing the complex health system toward a “patient centered” approach, ensuring that patients have a full understanding of all of their options.

This was followed in 2003 with *Priority Areas for National Action: Transforming Healthcare Quality*.<sup>28</sup> Here, the IOM identified twenty priority areas for improving health care quality over the next five years, areas that might “serve as the starting point for restructuring our health care delivery system.” Two of the priority areas — care coordination and self-management/health literacy — were identified as crosscutting. That is, improvements in these areas could benefit patients with many different health problems. Improved health literacy was put forward as a condition necessary to enable active self-management by patients for most conditions. This report called for strategies at both the micro (individual) and macro (population) levels to improve health literacy.

In June 2003, the Foundation for Accountability (FACCT) produced a “how-to-guide” called “*Who’s in the Driver’s Seat? Increasing Consumer Involvement in Health Care*”<sup>29</sup> that describes 48 different strategies in use by employers. These include disease management programs, purchasing coalitions teaching enrollees about quality, improving doctor-patient communications, consumer organizations relying on members’ expertise to develop communication materials, and researchers studying how people acquire and use information to improve their health.

The emergence of “consumer driven” or “consumer directed” health plans has further elevated the importance of consumer literacy and consumer self-efficacy in navigating a complex arena of information and decision making. In this model, employers seek to improve consumer health behavior and affect consumer utilization. Employers may “increase financial tension”<sup>30</sup> through cost-sharing (high deductibles and co-payments) or “defined contribution,” while providing information and tools to help consumers factor in quality and cost in their use of health care services and their choice of providers. The expectation is that such incentives will produce value-conscious purchasers and, in turn, a more efficient and responsive system.<sup>31</sup>

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Health literacy is increasingly recognized as a critical part of improving health care quality, increasing the effectiveness of consumers’ health purchasing decisions, and strengthening consumers’ management of their own health.

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### **IOM Finding 6.2:**

Health literacy is fundamental to quality care, and relates to three of the six aims of quality improvement described in the IOM *Quality Chasm* Report: safety, patient-centered care, and equitable treatment. Self-management and health literacy are identified as cross-cutting priorities for health care quality and disease prevention.

Beyond this, consumer roles are expanding with new health insurance vehicles including flexible spending accounts, medical savings accounts, and the new federal “health reimbursement accounts.” These specific insurance products are still too new to assess their impact and effectiveness, and some are skeptical about consumers’ ability to utilize these in a way that will have the intended or promised results.<sup>32, 33</sup>

Nonetheless, many people in both the public and private sectors see increased consumer involvement in coverage and care decisions as a major force in addressing cost and quality. With this trend, the responsibilities of all consumers, including those with limited health literacy, will only continue to increase.

## **ID. Literacy Challenges in Consumers’ Emerging Roles and Responsibilities**

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Consumers help to “produce” health by acting as partners with providers in the care process. Consumers act as evaluators by providing data on health provider and system performance and by defining what quality is.

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Hibbard,<sup>34</sup> writing for the National Quality Forum, argues that the success of recent employer efforts depend on the degree to which several consumer roles are encouraged and supported. Consumers, when they actively select, manage, and evaluate their care, have the potential to directly or indirectly produce better care and better health outcomes. Hibbard terms the roles those of “informed choice,” “co-producer,” and “evaluator” in health care.

Many current efforts are underway to produce the necessary comparative information and encourage consumers to use it for informed choice. However, the other two roles, those of co-producer and evaluator require a new level of health literacy. The co-producer role refers to patients helping to “produce” health by acting as effective partners with providers in the care process. The evaluator role refers to consumers providing data on provider and system performance and participating in defining the parameters of quality.

Thus far, evidence suggests a need to greatly strengthen consumers’ underlying skills before they can begin to fulfill these roles.

## **IE. Literacy and Health Outcomes**

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People with low health literacy are less likely to successfully navigate the health system to obtain needed care.

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The federal Agency for Healthcare Research and Quality recently released a comprehensive review of academic literature looking at literacy and health utilization, cost, and outcomes.<sup>35</sup> This rigorous review affirms the conclusions of earlier studies on the clear relationship between low reading skill and poor health. However, the conclusions of earlier studies on the effectiveness of interventions remain less well supported.

### **Health Literacy and Care Management**

Low functional literacy has serious consequences for individual health and the health care system. People are less likely to understand written or verbal information from their health care providers, to follow medication directions or appointment schedules, or to successfully navigate the health system to obtain needed care.<sup>36</sup>

Studies of patients with compromised health literacy have found the following:

- They are at risk for increased hospitalization and use of emergency services, even after adjusting for health status.<sup>37, 38</sup>
- They more often demonstrate poor control and management of chronic conditions such as diabetes<sup>39</sup> or asthma.<sup>40</sup>
- Poor compliance with medication and care regimens often result because patients cannot understand self-care instructions and prescription labels.<sup>41</sup>
- Low functional health literacy among the elderly is of particular concern, even for those elderly that are more affluent and educated than the national norm.<sup>42</sup>
- Inadequate literacy is an independent risk factor for hospital admission among elderly managed care enrollees.<sup>43</sup>

People with low functional literacy are often eligible for or depend on publicly-financed programs.<sup>44</sup> But less literate patients are also challenged with filling out intake forms, enrolling in insurance programs for which they may be eligible, getting services once enrolled, or giving informed consent. In two separate studies, three-quarters of patients did not understand if they were eligible for financial aid<sup>45</sup> or free care.<sup>46</sup>

## IF. The Financial Cost of Low Health Literacy

One study attributed \$29 billion per year in additional healthcare resources to inadequate health literacy, which would have grown to \$69 billion if even half of the “marginally literate” were also considered not health literate. Another source reports that in 2001, low functional literacy added \$32 to \$58 billion to health care costs,<sup>47</sup> while yet another put the costs as high as \$73 billion.<sup>48</sup>

People with low functional literacy appear to use more health care services, even after adjusting for socio-demographic factors. A 1998 study reports that adults with very low functional literacy were more than 1.5 times more likely to visit a physician and have three times as many prescriptions filled than adults with higher functional literacy.<sup>49</sup>

Beyond patient utilization, consumers influence system costs in choosing plans and providers. Health literacy has a significant impact on their ability to make these decisions. Indeed, this has become the focus of intense interest by business, insurance, government, and health care systems, as they seek to engage consumers in advancing quality and value-based purchasing.

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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.

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Estimates of the cost of low health literacy range from \$29 billion to \$73 billion annually.

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# Part II:

## Program and Policy Interventions: Options, Audiences, and Actors

### IOM Finding 2.1:

The health care system “carries significant opportunity and responsibility to improve health literacy.”

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.

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

### IIA. Support Consumers as “Co-Producers of Care”<sup>50</sup>

Consumers, in their role as patients, may be active partners with providers throughout diagnosis and treatment. Evidence indicates that collaborative care results in improved health outcomes,<sup>51</sup> including increased functioning and reduced pain, as well as reduced costs.<sup>52</sup> 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.<sup>53</sup> Providers, as well, need to coach patients to be more involved.<sup>54</sup>

This change of paradigm, and patients’ acquisition of needed health literacy skills, will not come easy. While patients typically express high preferences for information about their illness and its treatment,<sup>55</sup> preferences for participating in treatment decisions are mixed.<sup>56</sup> 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.<sup>57</sup>

### A1. Create Simplified, More Comprehensible Materials for Health Communication

The National Work Group on Literacy and Health<sup>58</sup> recommends health materials be written at a 5<sup>th</sup> grade readability level with recognition that this is still too difficult for about 25% of the population. Individuals at all reading levels prefer materials that are easy to read. Numerous resources are available to help produce such materials.<sup>59</sup>

Non-print resources are under-utilized. Oral and visual tools help patients absorb new information, which increases learning.<sup>60</sup> Significant enhancements in health communications are possible through emerging technologies. These might include interactive tutorials and touch-screen computer programs, diagrams, pictures, audio- and videotape and other visual formats.

## A2. Train Health Professionals to Communicate More Effectively

Communication between a health care provider and patient during outpatient visits may be compromised by several related factors: relative infrequency and brevity of visits, language barriers, differences between providers' and patients' agendas and communication styles, lack of trust, overriding or competing clinical problems, lack of timeliness of visit in relation to a disease-specific problem, and the complexity and variability of each patient's health status.

Providers must be taught to verify that patients understand and to uncover health beliefs and tailor teaching to the patient. Providers and systems can also create a “shame-free” environment where low-literacy patients can seek help without feeling stigmatized. Some methods of achieving this include:<sup>61</sup>

- Speaking clearly, slowly, and with appropriate vocabulary, avoiding medical jargon.
- Providing surrogate readers or suggesting to patients in advance of an appointment that they might bring a family member. As well, telling the patient in advance of an appointment what information will be needed.
- Verifying the patient's understanding by having the patient repeat what he or she is to do and why<sup>62</sup> — in other words “teach back.”<sup>63</sup>

The Partnership for Clear Health Communication, a coalition of national health organizations, has developed a campaign to reach both health providers and patients. Participating organizations include the American Medical Association Foundation, American Nurses Association, American Pharmacists Association, American Public Health Association, National Medical Association, and the National Council on the Aging. The coalition's “Ask Me 3” program centers on three questions that providers should encourage from their patients: 1) What is my main problem?; 2) What do I need to do?; and 3) Why is it important for me to do this?

## A3. Redesign Health Care Encounters and Systems

Limitations on provider time present a major impediment to appropriate communication. The failure of physicians to acknowledge patients concerns, provide explanations of care, and spend sufficient time with patients affects quality, cost effectiveness, and patient satisfaction.<sup>64</sup>

### IOM Finding 5.3 :

Health Professionals and staff have limited education, training, continuing education, and practice opportunities to develop skills for improving health literacy.

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Health care providers should encourage patients to ask three questions: 1) What is my main problem?; 2) What do I need to do?; and 3) Why is it important for me to do this?

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According to the Institute Of Medicine, “the result of poor communication and abbreviated or no patient education is higher use of emergency services, greater severity of illnesses, failure to follow instructions and use medications properly, and other ‘errors’ which ultimately results in increased health care costs.”

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## Patient Safety and Health Care Quality

The IOM's 2000 report on medical errors, *To Err is Human*, clarifies the links between miscommunication and medical and health errors and adverse events. These include failure to get accurate medical histories, failure to obtain informed consent, poor treatment adherence, medication errors, lower utilization of preventive and other health care services, and poor patient satisfaction. *Crossing the Quality Chasm*<sup>65</sup> subsequently proposed a “patient centered” approach to health care. Six of the IOM's ten proposed redesign rules allude to cultural context and five relate to health literacy.

Possible reforms include:

- Health systems, provider entities, and health plans should support a structure that allows ample time for discussion between patients and health care providers.
- Nurses, pharmacists, and ancillary providers should be incorporated into the health care team to provide more resources and more points of contact for patient education.
- The role of health educators in the design of materials and training of providers should be elevated.
- Reform 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.

## IIB. 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. A number of tools exist that are intended to help consumers evaluate the degree to which their care was clinically successful. Now, however, consumers are asked to evaluate their experiences and the degree to which they were supported in their co-producer role in the care process.<sup>66</sup> Such measures would allow patients to rate the degree to which they:

- had the opportunity and information to be involved in decisions about their own care.
- had the opportunity to gain skills in self-management.
- sensed that their control with regard to care is increasing over time.
- were supported and encouraged to be involved.

Ultimately, the evaluator role has the potential to engage consumers and further overall health literacy by:

- emphasizing that consumers are consequential actors in their own care.
- increasing the salience and perceived value of comparative performance measurement.
- making it more likely that reports are used by consumers.

## IIC. Support Consumers “Informed Choice” Role

To date, there is only limited use of comparative information by consumers.<sup>67</sup> Efforts are underway to support consumers' use of quality measures as key criterion for making provider, plan and hospital selections. There are several barriers to and potential remedies in this regard.<sup>68</sup>

**Increased Awareness and Perceived Advantage.** Only 30% of consumers report having seen quality comparisons within the last year.<sup>69</sup> Even among employees who were sent quality reports, only 40-50% remember seeing them<sup>70</sup> Repeated exposure over time to quality reports appears to increase awareness and perceived value of the reports.<sup>71</sup> Among consumers who are aware of comparative reports and have a choice of plans, quality reports typically are viewed as at least moderately useful.<sup>72</sup>

In order to motivate consumers to use quality information, the consumer needs to understand that health care quality, at both the plan and provider level, does differ, and that these differences can and will have an impact on their personal health.

To improve quality, consumers must have genuine choice among plans and providers. However, choice is limited by several factors. In some markets, it is common for health providers to be part of several different health plans, reducing the differences between the plans. Approximately 35% of consumers who get their coverage through their employer have no choice at all.<sup>73</sup> And, consumers in rural, or other underserved areas, may face access barriers that limit choice.

**Reduced Complexity.** As already noted, the amount of information in most report cards is beyond what humans can effectively process and use.<sup>74</sup> So called “short-cut” strategies, such as computer decision aids, can reduce complexity and burden for consumers and increase the likelihood that consumers will use data in their choices.<sup>75</sup>

**Compatibility and Relevance to Consumers' Felt Needs.** Various studies<sup>76, 77</sup> have looked at what messages motivate consumers to demand, seek out, and use quality information. They have demonstrated that framing health plan data in a possible loss or risk (“protect yourself from problems in health plans”), significantly increases how well the comparative information is understood, how much it is valued, and how much weight it receives in decisions. That is, at this point consumers have a “felt need” to avoid problems, but not yet to “maximize quality.”

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There are many barriers to the effective use of quality information by consumers.

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Consumers define quality differently than purchasers (or even researchers), often focusing on service rather than on actual clinical quality.<sup>78</sup> Consumers to date do not migrate to the health plans with better performance on the quality measures. To appeal more to consumers' felt needs, the federal Quality Interagency Coordination Task Force (QulC) has recommended the development of quality indicators for sub-groups of consumer and for different purposes. Examples of subgroups might include consumers with chronic conditions, those interested in behavioral health, or others needing specialty services.

**Independent Credibility.** Consumers are suspicious that purchasers' primary motivation in providing health care information is to move consumers to lower cost health plans or providers. Consumers may thus place less credibility on information they receive. Providers and purchasers could identify an independent source to establish the credibility of quality data. They should consider using non-purchasers, such as independent accrediting agencies, local coalitions, or other impartial entities as a source of unbiased information for consumers.

**Consistency and Standard Measures Across Reports.** Reasons for variation in quality scores between two report cards include different measures used within a category, assignment of different weights to measures within categories, and differences in the underlying distribution of the data in the aggregate set of plans. And, if various report cards show different ratings along the same or similar dimension of performance, the consumer will likely question the validity of the report and ultimately disregard it.

In 1998, the big-three U.S. auto manufacturers, the United Auto Workers, the Greater Detroit Area Health Council, and the State of Michigan (both as an employer and as a purchaser of services for Medicaid enrollees) worked to develop a common guide to alleviate the problem of conflicting information about health plan performance. Other major Michigan purchasers, including Detroit Edison, Meijers, and the AFL-CIO, also adopted the common consumer guide.

**Comparable and Standard Measures Across Health Plan Types.** Current measures are not comparable across types of managed care plans and member satisfaction information are not available outside of the non-managed care environment. There remains a need for community-wide data gathering efforts that incorporate shared measures that allow for comparisons across various kinds of systems and plan types, including indemnity, PPO, POS, and HMO.

**Strategic Timing and Pertinence.** The reporting of quality measures often occurs during health plan open enrollment periods. But consumers find it difficult to anticipate their future health needs.<sup>79</sup> Consumers need access to quality measures throughout the year, so that when they need it and seek it out, it will be available. Those providing quality information could consider a community venue for publication, ongoing updating, and year-round distribution of health care quality information.

# IID. Public & Private Sector Standards: Enforcement and Monitoring

## D1. Patient Rights, Health Literacy, and Health Law<sup>80</sup>

The Institute of Medicine's identification of health literacy as a cross-cutting contributor<sup>81</sup> to health service quality may have an impact on future statutory law (legislation) and common law (record of court decisions). In the absence of a single national policy, each state will decide how to weigh health literacy law and regulation. Two areas that are central to health literacy are standards of reasonable care and the informed consent process.

### 1a. Articulate what Constitutes the "Standard of Care"

Health care providers — the person writing instructions or a prescription — currently must ensure that patients understand the information they receive well enough to apply it. The Food and Drug Administration, Joint Commission on Accreditation of Healthcare Organizations, and the National Committee for Quality Assurance all require that health care institutions be able to document evidence of patient understanding of the medical information provided to them.<sup>82</sup>

Usually, reasonable care means care rendered in accordance with the standards of the profession. And while current laws do require health-care providers to furnish translators for patients who do not speak English, and interpreters to patients who have seeing or hearing disabilities, they do not address the problems of patients with limited literacy.

In this regard, the IOM concludes that "...if future health-literacy research supports the existence of associations between low-risk, inexpensive approaches to limited health literacy and reduced morbidity or mortality, the rule that a profession (or a large percentage or it) may be found negligent, could apply to the failure to use health-literacy interventions in clinical settings," including provision of patient instructions on self care, administering medications or other health information. "Providers could also be responsible when their knowledge indicated that a lack of patient understanding would expose the patient to an unreasonable risk of harm."<sup>83</sup>

The reverberations of the "standard of care" extend well beyond the individual patient encounter and patient education. At the health care system level, limited literacy may have legal ramifications for application of the Health Insurance Portability and Accountability Act (HIPPA), as well as in State interpretation and enforcement of access standards in managed care networks. At a minimum, there may be ethnical considerations in distributing information to people who may not be able to use it due to lack of choice of providers or plans in their area or lack of access due to financial, cultural, or geographic barriers.<sup>84</sup>

#### **IOM Finding 6.3:**

The readability levels of informed consent documents (for research and clinical practice) exceed the documented average reading levels of the majority of adults in the U.S. This has important ethical and legal implications that have not been fully explored.

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A signature on a consent form is not adequate evidence that informed consent has been obtained. Courts may also consider whether information was conveyed to the patient by a means that was likely to enable patient comprehension.

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## 1b. Articulate what Constitutes “Informed Consent”

The doctrine of informed consent obligates physicians to inform patients of the risks, benefits, and alternatives to undergoing or refusing to undergo the treatment recommended by a physician. Yet consent forms for treatment and research are written at a level beyond the skills of most patients, often contributing to information overload and poor understanding. Patients who sign consent documents often report their understanding of the research or treatment and satisfaction with the consent process, but may not in fact fully understand the consent given.

This owes in part to the inherent complexity of legal consent forms. But, it also relates to the psychosocial, ethical, and situational factors that surround the need for informed consent, such as hospitalization, surgery, participation in clinical trials, or genetic testing.

In many cases, patients and providers may disagree about the need for and adequacy of consent. Patients tend to see consent as necessary more frequently than providers, hold different views on whether true informed consent was obtained, and may be less than satisfied with the amount of information exchanged.<sup>85</sup> These differences may not be recognized, but nonetheless affect the patient's right to self-determination.

## D2. Leverage the State's Role as Purchaser and Regulator

In 2002, the Council of State Governments undertook a national research project that resulted in publication of *The State Officials Guide to Health Literacy*.<sup>86</sup> 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 standards of care and accessibility into Medicaid managed care contracts. Others are increasing health literacy by setting health education standards in both K-12 and adult literacy classes.

Many states' experience with mandatory Medicaid managed care suggest that, when resources are dedicated to providing basic information, Medicaid beneficiaries are more likely to understand their options and are more likely to choose plans and providers rather than be auto-assigned.<sup>87</sup> This suggests potential for broader efforts to engage low income and otherwise challenged populations in health care decision-making.

Wisconsin's Medicaid managed care contract does address some literacy and language related issues. For example, the contract specifies that materials must be at the 6<sup>th</sup> grade reading grade level. But, each managed care organization determines if its patient information meets this requirement and the Medicaid contract does not specify any method to determine adherence.

Wisconsin's Medicaid contract specifies that HMOs address the needs of enrollees needing specific "culturally competent services." HMOs must have specific policy statements on these topics and communicate them to subcontractors. The contract further specifies that health related educational materials produced or used by the HMO must "reflect sensitivity to the diverse cultures served... Enrollee Handbooks...shall be made available in at least the following languages: Spanish, Lao, Russian, and Hmong." And, the HMO must "[p]rovide interpreter service for enrollees as necessary..."

Such 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. For example:

- 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.

### D3. 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 are being adopted to measure and evaluate health literacy accommodations among providers and health plans.

The IOM recommends including cultural and linguistic competency as an essential measure of quality of care. In Wisconsin, such measures can be incorporated into reporting by the Wisconsin Collaborative for Healthcare Quality, the Wisconsin Hospital Association's CheckPoint Program, and others. Public sector purchasers (DHFS and DETF) might use such measures in reporting the quality of their contracting providers.

There are several sources for help in developing health literacy standards, including the two main private organizations in the U.S. for accreditation and review of health care facilities and providers, the Joint Commission on Accreditation of Health Care Organizations (JCAHO) and the National Committee for Quality Assurance (NCQA). Both of these organizations are developing additional health literacy standards. JCAHO standards include assessing patient and family involvement in care and care decisions, the informed consent process, and hospital patient education tailored to patients' assessed needs, abilities, learning preferences, and readiness to learn.

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The state could improve health literacy both in its role as purchaser of health services as well as a regulator of the insurance industry.

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#### **IOM Recommendation 6.3:**

Health literacy assessment should be part of health care information systems and quality data collection. Public and private bodies... should clearly incorporate health literacy into their accreditation standards.

NCQA assesses managed care plan performance on 1) whether it adjusts the availability of practitioners in its network to meet the cultural, ethnic, racial and linguistic needs of its members and 2) whether it provides translation services within its member services and telephone function based on the linguistic needs of its members. But, NCQA has been unable to create a valid and reliable literacy measure that is feasible to apply at either the health plan or provider level.

Finally, the Consumer Assessment of Health Plan Survey (CAHPS) asks whether the member looked for written or Internet information about a health plan, and asks how much of a problem, if any, it was to find or understand this information.

## **IIE. Beyond the Health Care System**

Significant opportunities exist outside of the health care system to address underlying challenges in health literacy.

### **E1. 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 describe the knowledge and skills students should attain by the end of grades 4, 8, and 11. They provide a framework for curricula development and student assessment. In Wisconsin, the standards for health literacy are much more broad and less defined.<sup>88</sup>

### **E2. Find teachable opportunities to enhance adult literacy**

Programs in the U.S. adult basic education and literacy system provide classes in topics that support health literacy, including basic literacy and math skills, English language, and high school equivalence. This provides an opportunity to insert health literacy content into the curricula, while reaching a group of highly motivated learners.<sup>89</sup>

For example, the Health Education and Adult Literacy Project in Massachusetts incorporated information on breast and cervical cancer into pre-GED and GED classes. Evaluations of this multi-year effort have found that students' literacy skills improve because they are motivated to learn important content that is relevant to their every day lives.<sup>90</sup>

People who attend adult education classes are the early adopters that most health interventions hope to target. They are individuals seeking new information, wishing to improve their condition, and who can communicate what they have learned back to their communities.

#### **IOM Finding 5.2:**

Opportunities to implement programs... currently exist in adult education programs and provide promising models for expanding programs. Studies indicate a desire on the part of adult learners and adult education programs to form partnerships with health communities.

## **E3. Build Partnerships and Outreach through Community Venues**

At present, people with more education and financial resources are more likely to be active partners in their care by researching their options and through challenging clinical diagnoses and decisions. Programs also need to engage hard-to-reach populations, especially minority and low-income communities, in their health care.

Community organizations can help consumers maneuver through the health care system and can be important allies in establishing trust. Faith communities, immigration and citizenship organizations, advocacy groups, ethnic media, and even traditional healers can help disseminate messages about health and health care quality. Outreach activities should be tailored to the needs and culture of specific communities. For example, one strategy involves working with hair styling salons to reach those women who may spend several hours getting services.<sup>91</sup> In Wisconsin:

- 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 Shield grant funds to addressing health literacy.

## **E4. 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 of quality indicators and performance measures, health insurance/benefits, self-care, and personal health decision-making. A report from the 2003 Wisconsin Economic Summit<sup>92</sup> 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

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

## ENDNOTES

- <sup>1</sup> Institute of Medicine (IOM). 2004. *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academy Press.
- <sup>2</sup> Huntington B, Swanson C. 2003. *Adults with Special Needs, A Resource and Planning Guide for Wisconsin's Public Libraries*. Madison, WI: Wisconsin Department of Public Instruction. [www.dpi.state.wi.us/dlcl/pld/pdf/sn09.pdf](http://www.dpi.state.wi.us/dlcl/pld/pdf/sn09.pdf)
- <sup>3</sup> Kaestle, CF, et al. 2001. *Adult Literacy and Education in America*. National Center for Education Statistics, U.S. Department of Education. 2001. [nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2001534](http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2001534)
- <sup>4</sup> Kirsch I.S., et al. 1993. *Adult Literacy in America: A First Look at the Results of the National Adult Literacy Survey*. National Center for Education Statistics, U.S. Department of Education. [nces.ed.gov/pubsearch/pubsinfo.asp?pubid=93275](http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=93275)
- <sup>5</sup> National Academy on an Aging Society. *Fact sheet: Low health literacy skills increase annual health care expenditures by \$73 billion*. [www.agingsociety.org/agingsociety/publications/fact/fact\\_low.html](http://www.agingsociety.org/agingsociety/publications/fact/fact_low.html)
- <sup>6</sup> Institute of Medicine (IOM). 2004. *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academy Press.
- <sup>7</sup> Berkman ND, et al. *Literacy and Health Outcomes. Summary Evidence Report/Technology Assessment No. 87* (Prepared by RTI International-University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016). AHRQ Publication No. 04-E007-1. Rockville, MD: Agency for Healthcare Research and Quality. January 2004. [www.ahrq.gov/news/press/pr2004/litpr.htm](http://www.ahrq.gov/news/press/pr2004/litpr.htm)
- <sup>8</sup> Schloman, B. 2004. *Health Literacy: A Key Ingredient for Managing Personal Health*. Online Journal of Issues in Nursing. [www.nursingworld.org/ojin/infocol/info\\_13.htm](http://www.nursingworld.org/ojin/infocol/info_13.htm)
- <sup>9</sup> Frosch DL, Kaplan RM. *Shared decision making in clinical medicine: past research and future directions*. Am J Prev Med 1999;17:285-294.
- <sup>10</sup> Beisecker AE, Beisecker TD. *Patient information-seeking behaviors when communicating with doctors*. Med Care 1999; 28:19-28.
- <sup>11</sup> Degner LF, Sloan JA. *Decision making during serious illness: what role do patients really want to play?* J Clin Epidemiol 1992; 45: 941-950.  
  
Hack TF, et al. *Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis*. Soc Sci Med 1994;39:279-289.
- <sup>12</sup> Slovic P. 1982. *Toward understanding and improving decisions*. In: Howell WC, Fleishman EA, eds. *Human performance and Productivity, Volume 2: Information Processing and Decision Making*. Hillsdale, NJ: Erlbaum; pp. 157-183.

- <sup>13</sup> Hibbard JH. *Engaging Health Care Consumers to Improve the Quality of Care*. Medical Care Volume 41(1):1-61-1-70. 2003.
- <sup>14</sup> Hibbard JH, et al. *Does publicizing hospital performance stimulate quality improvement efforts?* Health Affairs, March/April 2003; 22(2): 84-94.
- <sup>15</sup> U.S. Department of Health and Human Services. *Healthy People 2010*. 2002.
- <sup>16</sup> Center for Health Care Strategies. 2003. *What is Health Literacy*. [www.chcs.org/usr\\_doc/hl1.pdf](http://www.chcs.org/usr_doc/hl1.pdf)
- <sup>17</sup> Kirsch IS. 2001a. *The Framework used in developing and interpreting the International Adult Literacy Survey (IALS)*. European Journal of Psychology of Education. 16(3): 335-361.
- <sup>18</sup> Rudd R, et al. 2000. *Health and Literacy. A review of medical and public health literacy*. In: Coming J, Garners B, Smith C, eds., *Annual Review of Adult Learning and Literacy*. New York: Jossey-Bass.
- <sup>19</sup> Institute of Medicine (IOM). 2004. *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academy Press.
- <sup>20</sup> Parker R, Williams MV, and Davis T. 1999. *Low Health Literacy — You Can't Tell by Looking*. American Medical Association Foundation.
- Parikh NS, et al. *Shame and health literacy: The unspoken connection*. Patient Education and Counseling 1996; 27.
- <sup>21</sup> Doak CC, et al. 1996 *Teaching patients with low literacy skills* (2<sup>nd</sup> edition). Philadelphia: Lippincott.
- <sup>22</sup> Parikh ND, et a; 1996. *Shame and health literacy: The unspoken connection*. Patient Education and Counseling 27: 33-39.
- <sup>23</sup> The data in this section are drawn from Huntington, B and Swanson, C. 2003. *Adults with Special Needs, A Resource and Planning Guide for Wisconsin's Public Libraries*. Madison, WI: Wisconsin Department of Public Instruction. [www.dpi.state.wi.us/dlcl/pld/pdf/sn09.pdf](http://www.dpi.state.wi.us/dlcl/pld/pdf/sn09.pdf)
- <sup>24</sup> Selden CR, et al. 2000. *Health Literacy (Current Bibliographies in Medicine 2000-1)*. National Library of Medicine, National Institute of Health.
- <sup>25</sup> Schloman, B. 2004. Information Resources Column: "Health Literacy: A Key Ingredient for Managing Personal health." Online Journal of Issues in Nursing. [http://nursingworld.org/ojin/infocol/info\\_13.htm](http://nursingworld.org/ojin/infocol/info_13.htm)
- <sup>26</sup> American Medical Association Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs. 1999. *Health Literacy: Report of the Council on Scientific Affairs*. JAMA, 281: 552-557.
- <sup>27</sup> Institute of Medicine (IOM). 2001. *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*. Washington, DC: National Academy Press.

- 28 Institute of Medicine (IOM). 2003. *Priority Areas for National Action: Transforming Healthcare Quality*. Washington, DC: National Academy Press.
- 29 FAACT (Foundation on Accountability). 2002. *Who's in the Drivers Seat? Increasing Consumer Involvement in Health Care*. [http://www.facct.org/facct/doclibFiles/documentFile\\_528.pdf](http://www.facct.org/facct/doclibFiles/documentFile_528.pdf)
- 30 *New Reality, New Choices. Ninth Annual National Business Group on Health/Watson Wyatt Survey 2004*. [www.watsonwyatt.com](http://www.watsonwyatt.com)
- 31 Gabel J, et al. January 2003. *Consumer Driven Health Plans: Are They More Than Talk Now?* The New York: Commonwealth Fund.
- 32 Fronstin, P (ed). 2002. *Consumer Driven Health Benefits: A Continuing Evolution?* Washington, DC: Employee Benefit Research Institute (EBRI).
- 33 Gabel J, et al. *Employers' Contradictory Views About Consumer-Driven Health Care: Results from a National Survey*. Health Affairs, Web Exclusive. April 21, 2004. <http://content.healthaffairs.org/webexclusives/index.dtl?year=2004>
- 34 This section's discussion is drawn entirely from Hibbard, J. *Engaging Health Consumer to Improve the Quality of Care*. Medical Care Vol. 41, Number 1, Supplement, pp. I-61-I-70. 2003.
- 35 Berkman ND, et. al. *Literacy and Health Outcomes. Summary Evidence Report/Technology Assessment No. 87* (Prepared by RTI International-University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016). AHRQ Publication No. 04-E007-1. Rockville, MD: Agency for Healthcare Research and Quality. January 2004. <http://www.ahrq.gov/news/press/pr2004/litpr.htm>
- 36 Baker DW, et al. *The Health Care Experience of Patient with Low Literacy*. Archives of Family Medicine, 1996; 5(6).
- 37 Friedland R. *New estimates of the high costs of inadequate health literacy*. In: Proceedings of Pfizer Conference "Promoting Health Literacy: A Call to Action," October 7-8, 1998, Washington, DC: Pfizer, Inc., pp. 6-10.
- 38 Baker DW, et al. 1998. *Health literacy and the risk of hospital admission*. Journal of General Internal Medicine. 13(12): 791-798.
- 39 Schillinger D, et al. *Association of Health Literacy with Diabetes Outcomes*. JAMA, 2002; 288.
- 40 Williams MV, et al. *Inadequate Literacy is a Barrier to Asthma Knowledge and Self-Care*. Chest, 1998; 114(4).
- 41 For a review of key literature on the topic, see Center for Health Care Strategies. *Health Literacy Facts*. [www.chcs.org/usr\\_doc/hl\\_biblio.pdf](http://www.chcs.org/usr_doc/hl_biblio.pdf)

- <sup>42</sup> Benson JG, Forman WB. 2002. *Comprehension of written health care information in an affluent geriatric retirement community: Use of the Test of Functional Health Literacy*. *Gerontology*, 48: 93-97.
- <sup>43</sup> Baker DW. *Functional Health Literacy and the Risk of Hospital Admission among Medicare Managed Care Enrollees*. *American Journal of Public Health*, 2002; 92.
- <sup>44</sup> Gazmararian JA, et al. *Health Literacy among Medicare Enrollees in a Managed Care Organization*. *JAMA* 1999; 281(6).  
Weiss BD, et al. *Illiteracy among Medicaid Recipients and its Relationship to Health Care Costs*. *Journal of Health Care for the Poor and Underserved*, 1994; 5(2).
- <sup>45</sup> Williams MV, et al. *Inadequate Functional Health Literacy Among Patients at Two Public Hospitals*. *JAMA*, 1995; 274(21).
- <sup>46</sup> Baker DW, et al. *The Relationship of Patient Reading Ability to Self-Reported Health and Use of Health Services*. *American Journal of Public Health*, 1997; 87.
- <sup>47</sup> Center for Health Care Strategies. 2003. *What is Health Literacy*. [www.chcs.org/usr\\_doc/hl1.pdf](http://www.chcs.org/usr_doc/hl1.pdf)
- <sup>48</sup> National Academy on an Aging Society. *Fact sheet: Low health literacy skills increase annual health care expenditures by \$73 billion*. [www.agingsociety.org/agingsociety/publications/fact/fact\\_low.html](http://www.agingsociety.org/agingsociety/publications/fact/fact_low.html)
- <sup>49</sup> Center on an Aging Society, Georgetown University. 1998. *Tabulations from the Medical Expenditure Panel Survey*. Available from the Center via phone at (202) 687-9840.
- <sup>50</sup> Hibbard JH. *Engaging Health Consumers to Improve the Quality of Care*. *Medical Care* Vol. 41, Number 1, Supplement, pp I-61-I-70. 2003.
- <sup>51</sup> Lorig K, Sobel DS, et al. *Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial*. *Med Care* 1999;37:5-14.
- <sup>52</sup> Von Korff M, Katon W, et al. *Treatment costs, cost offset, and cost-effectiveness of collaborative management of depression*. *Psychosom Med* 1998;60:143-149.
- <sup>53</sup> Madden J, Sathysse S, Barchas J, eds. 1992. *Adaption, Learning and Affect: Self-efficacy Mechanisms In Physiological Activation and Health Promotion Behavior*. New York, NY: Raven Press.
- <sup>54</sup> Kaplan S, Greenfield S, et al. *Assessing the effects of physician-patient interactions on the outcomes of chronic disease*. *Med Care* 1989; 3(suppl):110-127.
- <sup>55</sup> Beisecker AE, Beisecker TD. *Patient information-seeking behaviors when communicating with doctors*. *Med Care* 1999; 28:19-28.

- <sup>56</sup> Degner LF, Sloan JA. *Decision making during serious illness: what role do patients really want to play?* J Clin Epidemiol 1992; 45: 941-950.
- Hack TF, Degner LF, Dyck DG. *Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis.* Soc Sci Med 1994; 39:279-289.
- <sup>57</sup> Frosch DL, Kaplan RM. *Shared decision making in clinical medicine: past research and future directions.* Am J Prev Med 1999;17:285-294.
- <sup>58</sup> National Work Group on Literacy and Health. 1998. *Communication with patients who have limited literacy skills: Report of the National Work Group on Literacy and Health.* Journal of Family Practice, 46: 16;8-176.
- <sup>59</sup> Doak CC, et al. 1996. *Teaching patients with low literacy skills* (2<sup>nd</sup> Edition). Philadelphia: Lippincott. Also U.S. National Cancer Institute. 2003. *Clear and simple. Developing effective print materials for low-literate readers.* [www.cancer.gov/cancerinformation/clearandsimple](http://www.cancer.gov/cancerinformation/clearandsimple)
- <sup>60</sup> Houts PS, et al. *Using Pictographs to Enhance Recall of Spoken Medical Instructions.* Patient Education Counseling, 1998;35(2).
- <sup>61</sup> Center for Health Care Strategies. 2003. *What is Health Literacy.* [www.chcs.org/usr\\_doc/hl1.pdf](http://www.chcs.org/usr_doc/hl1.pdf)
- <sup>62</sup> Schillinger D et al. *Closing the loop: physician communication with diabetic patients who have low health literacy.* Arch Intern Med. 2003 Jan 13;163(1):83-90.
- <sup>63</sup> Osborne, H. 2001. *Overcoming communication barriers in patient education.* Gaithersburg, MD: Aspen Publishers.
- <sup>64</sup> Federman AD, et al. 2001. *Intention to discontinue care among primary care patients: influence of physician behavior and process of care.* Journal of General Internal Medicine. 16(10): 668-674.
- <sup>65</sup> Institute of Medicine (IOM). 2001. *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century.* Washington, DC: National Academy Press.
- <sup>66</sup> Bonomi AE, et al. 2001. *Assessment of Chronic Illness Care (ACIC): A Practical Tool to Measure Quality Improvement.* Seattle, WA: MacColl Institute for Healthcare Innovation Center for Health Studies.
- <sup>67</sup> Marshall M, et al. *What do we expect to gain from the public release of performance data? A review of the evidence.* JAMA 2000; 283:1866-1874.
- <sup>68</sup> Hibbard JH. *Engaging Health Care Consumers to Improve the Quality of Care.* Medical Care Volume 41(1):I-61-I-70. 2003.
- <sup>69</sup> Kaiser Family Foundation. 2000. *National Survey on Americans as Health Care Consumers: An Update on the Role of Quality Information.* Menlo Park, CA: Kaiser Family Foundation.

- <sup>70</sup> Hibbard JH, et al. *The impact of the CAHPS report on employee knowledge, beliefs, and decisions*. *Med Care Res Rev* 2002;59:103-115.
- National Committee on Quality Assurance. *Do Consumers Use Health Plan Report Cards? Findings from Two Evaluations*. Washington, DC: NCQA; 1998.
- <sup>71</sup> Knutson DJ, et al. *Impact of report cards on employees: a natural experiment*. *Health Care Fin Rev* 1998;20(1):5-27.
- <sup>72</sup> Hibbard JH, Jewett JJ. *Will quality report cards help consumer?* *Health Affairs (Millwood)* 1997;16:218-228.
- <sup>73</sup> Kaiser Family Foundation. 2000. *National Survey on Americans as Health Care Consumers: An Update on the Role of Quality Information*. Menlo Park, CA: Kaiser Family Foundation.
- <sup>74</sup> Slovic P. 1982. *Toward understanding and improving decisions*. In: Howell WC, Fleishman EA, eds., *Human performance and Productivity, Volume 2: Information Processing and Decision Making*. Hillsdale, NJ: Erlbaum; pp. 157-183.
- <sup>75</sup> Hibbard JH, et al. *Strategies for reporting health plan performance information to consumers; evidence from controlled studies*. *Health Serv Res* 2002; 37:291-313.
- <sup>76</sup> Hibbard JH, et al. *Increasing the impact of health plan report cards by addressing consumer concerns*. *Health Affairs (Millwood)* 2000;19:138-143.
- <sup>77</sup> National Committee on Quality Assurance. 2000. *State of Managed Care Quality Report*.
- <sup>78</sup> Veterans Hospital Administration. *Qualitative Consumer Research: Development of Quality Measurement and Reporting Program, Final Report, May 2000*.
- <sup>79</sup> Hibbard J, et al. *Informing Consumer Decisions in Health Care: Implications from Decision-Making Research*. *The Milbank Quarterly* 1997; 75:390.
- <sup>80</sup> This section summarizes the material presented by Frank McClellan to the IOM, as summarized in the pre-publication copy of Institute of Medicine (IOM). 2004. *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academy Press.
- <sup>81</sup> Institute of Medicine (IOM). 2003. *Priority Areas for National Action: Transforming Healthcare Quality*. Washington, DC: National Academy Press.

- <sup>82</sup> Brandes W, et al. *Literacy, Health, and the Law: An Exploration of the Law and the Plight of Marginal Readers within the Health Care System: Advocating for Patients and Providers*. Health Promotion Council of Southeastern Pennsylvania, Inc., 1996.
- Farley D. *Label Literacy for OTC Drugs*. U.S. Food and Drug Administration, 1997.
- “Patient and Family Education.” *Accreditation Manual for Hospitals*. Joint Commission on Accreditation of Healthcare Organizations, 1996.
- Review Guidelines for the Accreditation of Managed Care Organizations*. National Committee on Quality Assurance, 1995.
- <sup>83</sup> Institute of Medicine (IOM). 2004. *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academy Press.
- <sup>84</sup> Paranjpe, S. *Informing Employed Consumers About Health Care Quality*. Discussion Paper. *Informing Consumers About Health Care Quality: New Directions for Research, Conference Summary*. December 2000. Agency for Healthcare Research and Quality, Quality Interagency Coordination Task Force (QUIC). [www.quic.gov/consumer/conference/index.htm](http://www.quic.gov/consumer/conference/index.htm)
- <sup>85</sup> Bray JK, Yentis SM. 2002. *Attitudes of patients and anaesthetists to informed consent for specialist airway techniques*. *Anaesthesia*. 57(10): 1012-1015.
- Cox K. 2002. *Informed consent and decision-making: patients' experiences of the process of recruitment to phase I and II anti-cancer drug trials*. *Patient Education and Counseling*. 46(1): 31-38.
- King J. 2001. *Consent: the patients' view — a summary of findings from a study of patients' perceptions of their consent of dental care*. *British Dental Journal*. 191(1): 336-40.
- <sup>86</sup> Matthews TL, Sewell JC, 2002. *State Official's Guide to Health Literacy*. Lexington, KY: The Council of State Governments.
- <sup>87</sup> Kaplan S, et al. *Educating Medicaid Beneficiaries About Managed Care: Approaches in 13 Cities*. New York: Commonwealth Fund. May 2000.
- <sup>88</sup> Wisconsin Department of Public Instruction Wisconsin Statute 118.33 High School Graduation Standards. [www.dpi.state.wi.us/dlsis/cal/pi1803.html](http://www.dpi.state.wi.us/dlsis/cal/pi1803.html)
- <sup>89</sup> Huntington B, Swanson C. 2003. *Adults with Special Needs, A Resource and Planning Guide for Wisconsin's Public Libraries*. Madison, WI: Wisconsin Department of Public Instruction. [www.dpi.state.wi.us/dlcl/pld/pdf/sn09.pdf](http://www.dpi.state.wi.us/dlcl/pld/pdf/sn09.pdf)
- <sup>90</sup> Rudd R. *National Center for the Study of Adult Learning and Literacy: Report #5*. Harvard University. 1998.

- <sup>91</sup> Molnar C. *Informing Consumers with Special Communication Needs About Health Care Quality*. Discussion Paper. *Informing Consumer About Health Care Quality: New Directions for Research, Conference Summary*. December 2000. Agency for Health Care Research and Quality. Quality Interagency Coordination Task Force. [www.quic.gov/consumer/conference/molnar.htm](http://www.quic.gov/consumer/conference/molnar.htm)
- <sup>92</sup> *Health Care Cost Crisis in Wisconsin: An Economic Development Prognosis*. Paper presented to the Wisconsin Economic Summit IV, October 28, 2003, Milwaukee, Wisconsin. <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.)