

Appendix C

Commissioned Paper

Integrating Health Literacy into Primary and Secondary Prevention Strategies

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INTEGRATING HEALTH LITERACY INTO PRIMARY AND SECONDARY PREVENTION STRATEGIES

Leaders from around the world recently endorsed a need for health literacy action at governmental levels. Culminating a year of the United Nations Economic and Social Council focusing on “Implementing the internationally agreed goals and commitments in regard to global public health,” Ministers agreed in a declaration that: “We stress that health literacy is an important factor in ensuring significant health outcomes and in this regard call for the development of appropriate action plans to promote health literacy” (July 9, 2009).

In addition to dialogue at the United Nations, the European Union, OECD, United States, China, United Kingdom, and other countries have begun to address health literacy. In the United States, legislation has been introduced in the last Congress with a Senate Bill (National Health Literacy Act of 2007 (S. 2424)). HHS included health literacy as a Healthy People 2010 objective; and agencies including AHRQ, FDA, and CDC have some references to health literacy. Currently, health reform legislation includes references with health literacy and 12 states are developing legislation and/or coalitions related to health literacy.

Health literacy is a critically important, but often overlooked, determinant of health. Low health literacy skills are associated with less healthy choices, riskier behaviors, poorer health, more hospitalizations and higher healthcare costs (IOM, 2004).

Health literacy is “the capacity to obtain, interpret and understand basic health information and services and the competence to use such information and services to enhance health.” (IOM, 2004; Ratzan and Parker, 2000)

The purpose of this paper is to describe ways that health literacy can be effectively integrated into primary and secondary prevention in the United States. The most obvious strategy is to leverage any existing programs in health care and public health, and to reform health policy. There are many issues and challenges, but also many potential entry points, from direct to the individual to messages for broader society, through ethical health communication. Illustrative ideas are presented for policy-making consideration at the multiple levels—institutional, community, national and regional—that shape the social and structural factors which advance public health. This paper also presents a galvanizing opportunity to advance health literacy in relation to primary and secondary prevention to serve as a provocative challenge for the IOM Roundtable.

HISTORY AND BACKGROUND—CONCEPTUAL CONSTRUCTS

Winslow's definition of public health put forth 90 years ago serves as a benchmark of what we are trying to accomplish with health literacy:

Public health is the science and art of preventing disease, prolonging life and promoting physical health and efficacy through organized community efforts for the sanitation of the environment, the control of communicable infections, the education of the individual in personal hygiene, the organization of medical and nursing services for the early diagnosis and preventive treatment of disease, and the development of social machinery which will ensure every individual in the community a standard of living adequate for the maintenance of health; so organizing these benefits in such a fashion as to enable every citizen to realize his birthright and longevity. (Winslow, 1920)

Further, the IOM definition put forth in the *Future of Public Health*, (now over 20 years old) defined the mission of public health as “fulfilling society's interest in assuring conditions in which people can be healthy” (IOM, 1988). Health literacy fits these 20th century ideals, with an opportune time for 21st century interventions.

Linking the ideas of prevention and wellness with health literacy may seem obvious, but do not seem to have been a focus of research. Historically, there has been political dialogue on the topic. The 1951 President's Commission on the Health Needs of the Nation, formed by President Truman to provide recommendations about how to meet the nation's immediate and long-term health care requirements, published a landmark work touching on issues of health promotion (as opposed to disease treatment) entitled the Magnuson Report (named for the Commission's chairman, Dr. Paul A. Magnuson). It was holistic in that it concluded that if a person's social environment involved a lack of basic security such as food, shelter, or employment, the achievement of positive health (and wellness) was much more difficult than if these were not a source of stress. This suggested that social capital that included a network of supportive social and cultural institutions were necessary to support the individual in his quest to achieve high level wellness. Further, in 1961, Halbert Dunn introduced the idea of high-level wellness as “an integrated method of functioning which is oriented toward maximizing the potential of which the individual is capable. It requires that the individual maintain a continuum of balance a purposeful direction within the environment where he is functioning” (Dunn, 1961; Ratzan, 2009).

Years later, the health field model became the basis of the IOM (1997) report titled *Improving Health in the Community: A Role for Performance Monitoring*. The model, as described by Evans and Stoddart (1994), suggested multiple determinants of health in a dynamic relationship, linking the social environment, physical environment, genetic endowment,

an individual's behavioral and biologic responses, disease, health care, health and function, well-being, and prosperity. This "field" model builds on the earlier health field framework of Blum and Lalonde (see also Collins, 1995; Hancock, 1993; Mustard and Frank, 1991). This model has been advanced recently as a "21st century field model" (Ratzan et al., 2000).

While it is beyond the scope of this article to address comprehensive theoretical developments for advancing health, the field model demonstrates the relationships between the elements that contribute to health. Health literacy can be the most important contributor to health as it presents an opportunity for health literacy application in addressing the necessary skills and abilities in synch with the demands and complexity of the system. Improving a population's health literacy promotes health and can prevent a great amount of disease and disability. Understanding what you need to do to "be healthy" and building systems of care and services that are navigable and accessible are foundational and fundamental for improving population health. Efforts to enhance population health literacy, and primary and secondary prevention are intricately linked and together create a double helix as a foundation for health reform. Such a health literacy helix serves as the fabric for improving health in America as it translates primary and secondary prevention into (1) what we need to know and do to stay healthy, and (2) detecting and treating disease early to get better and/or live with disease. In this paper, relevant findings from health literacy research help develop a framework for action, with specific recommendations for policymakers.

RELEVANT LESSONS FROM HEALTH LITERACY RESEARCH

The lack of health literacy in the U.S. population has been well-documented in the 2004 IOM report, *Health Literacy: A Prescription to End Confusion*. Only 12 percent of adults have proficient health literacy. According to the NAAL, nearly 9 out of 10 American adults lack the skills needed to take care of their own health, and most do not know how to prevent disease. This is concerning for the health of most Americans but also for the burden it places on our health care system. Limited health literacy is estimated to cost the nation between \$100 and \$200 billion a year (Vernon et al., 2007). Today, chronic diseases—such as cancer, diabetes, and heart disease—are among the most prevalent, costly, and preventable of all health problems. Health literacy is at the center of both preventing chronic disease and adhering to treatment plans once diagnosed. Furthermore, obesity related conditions account for 9.1 percent of medical spending or \$147 billion—extra expenses of diabetes and other ailments that are more common in an overweight population could be addressed

with health literacy interventions. This can translate into significant savings as medical spending averages \$1,400 more a year for an obese person than for someone of normal weight (Finkelstein et al., 2009).

There have been over 1,000 studies on health literacy that address prevalence, outcomes, and costs to society and the individual (Rudd, 2006). The IOM and AHRQ have also comprehensively reviewed the literature in the last 5 years on health literacy and health outcomes and “concluded that limited health literacy is negatively associated with the use of preventive services like mammograms or flu shots; management of chronic conditions such as diabetes, high blood pressure, asthma, and HIV/AIDS; and self-reported health” (Berkman et al., 2004; IOM, 2004). Studies have also linked limited health literacy to misunderstanding of prescription medication instructions, medication errors, poor comprehension of nutrition labels, and mortality (Baker et al., 2008; Davis et al., 2006a, 2006b; Rothman et al., 2006; Wolf et al., 2006).

Finally, as much as 88 percent of adults have difficulty with the way health information is currently presented and most do not have the ability to recognize and understand risk, sort through conflicting information, act upon information, and navigate our frequently complex health systems (WHCA, 2009). Given the importance for individuals to interpret and act upon critical public health alerts, along with a system that needs to simplify and clarify communication to address emerging threats, a lack of health literacy increases the risk for the entire population during acute health crises, such as the 2009 novel H1N1 pandemic.

Today, we have the knowledge to begin to address health literacy with interventions. Health literacy has been defined, plausible models of antecedent factors and causes elucidated, and now we are ready to develop and test intervention strategies, implement policies and communication, and evaluate and refine those interventions. Health literacy strategies need to be woven into prevention efforts at all levels, and building one’s health literacy should be thought of as a lifelong process. Even simple, small initiatives and interventions can dramatically improve health literacy and outcomes and associated costs.

LINKING HEALTH LITERACY AND PREVENTION

Preventive care . . . is one of the best ways to keep our people healthy and our costs under control. Remarks of President Barack Obama—as prepared for delivery address to Joint Session of Congress, February 24, 2009.

While ethical premises and age old adages suggest prevention of disease as preferential to treatment, reducing risk and promoting healthful behaviors have not been the foundation for the U.S. health system.

Primary prevention programs and strategies that provide access to health information that is clear, easy-to-understand and meaningful to the individual and that address common risk factors for chronic disease such as obesity, physical inactivity, and blood pressure control could be addressed through a health literacy prism. Such programs help individuals identify modifiable risk and protective factors for diseases/disorders/injuries; and assess risk, including genetic susceptibility.

Secondary prevention seeks to stop or slow down existing disease and its effects through early detection and appropriate treatment. This would include efforts such as screening and management of diabetes, heart or respiratory diseases or early detection of cancer. Even seemingly highly educated patients can have trouble understanding basic health information. We need to build bridges between what we as health professionals know, and what our patients understand.

In looking at the recent literature on health literacy and prevention, relatively few studies examined low health literacy and its effect on primary prevention efforts that target risk factors for chronic disease (such as obesity, blood pressure) and few studies describe health literacy interventions in this specific area. Yet, there are many studies that measure and validate the malleable lifestyle factors that serve as variables in the Field Model and conceptual underpinning of health literacy. For example, recent large studies published in the *Archives of Internal Medicine* (Jiao et al., 2009; Mozaffarian et al., 2009) identified five lifestyle factors as contributors to pancreatic cancer and diabetes. These five factors alone accounted for a 58 percent reduction in risk of developing pancreatic cancer, and attributability for diabetes incidence in 90 percent of new cases. These 5 variables include smoking, alcohol use, diet, body mass index, and physical activity. Other studies have suggested that adding variables such as fasting blood sugar, blood pressure, cholesterol levels, immunization(s) and other areas (cancer screening) also could translate into better health outcomes and reduced health costs.

Given the plethora of evidence from a variety of fields (e.g., communication, public health, medicine, etc.) an evidence-informed approach to primary and secondary prevention efforts could be advanced within these domains (*Journal of Health Communication*, 2006). In 2006, U.S. Surgeon General Ken Moritsugu summed this up well in a speech on disparities; “more research is needed, but there is already enough good information that we can use to make practical improvements in health literacy.”

Where to Start—The Model

Health literacy can be achieved through the lens of a simple model (Figure C-1): when individuals skills and ability are appropriately aligned

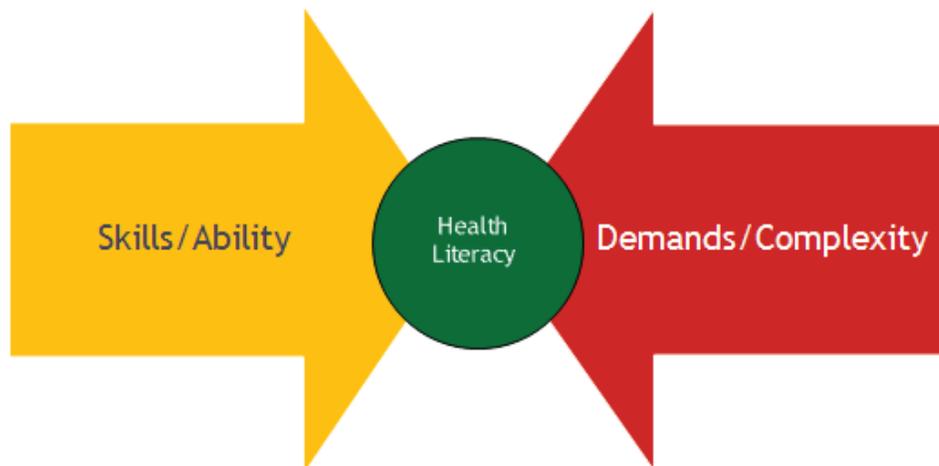


FIGURE C-1 Health literacy framework.
SOURCE: Parker, 2009.

with system demands and complexity (IOM, 2004; WHCA, 2009). Skills are cognitive (knowledge), behavioral (functional), and advocacy (pro-active).

Health literacy occurs when the skills and ability of those requiring health information and services are aligned with the demand and complexity of information and services. While we continue to support efforts to improve the skills and ability of all through educational efforts, we intervene by improving the navigability and understandability of that which is required for better health. The model indicates that the skills and ability of individuals (yellow) slow one down as they approach tasks, as many lack the skills to understand and do what they need to do for health. However, it is the demands and complexity of health information and task (red) that stop many from being able to do what they need to do for health. Interventions to simplify and improve the demands and complexity are the top priority for action, and we must work to systematically make health more understandable and services more navigable for patients. To be “patient centered” and to improve quality, the alignment of skills and ability with the demands and complexity of essential tasks advances a health literate populace (green).

Kickbusch and Maag (2008) have suggested 6 principal domains that affect how people make daily decisions that affect their health: the health care system, home, the community, the workplace, the market place (i.e., the media) and the political arena. To create a road map to strengthen health literacy in the United States in the areas of primary and secondary prevention, this paper is organized by clustering these domains into three areas: (1) prevention within the health care system, (2) educational

system, home community and workplace, and (3) media and new technology. For each, we look at how efforts can work simultaneously to systematically address the demand and complexity of tasks and advance the population's skills to obtain, process and turn good information into action. Further, to best advance health literacy with primary prevention in these areas, a parsimonious idea is first presented: a "scorecard" that could possibly reflect an individual or population's level of alignment of predetermined goals and actual level of health achievements. Such "scorecards" could be proxies for reflecting what an individual or population understands and sets as their health goals, and how close they are to actually achieving these goals.

A Simple (Parsimonious), But Big Idea

On the area of measuring health, there have been ideas to develop some sort of galvanizing index that captures health and wellness. In the last decade the IOM has had two committees addressing this: Leading Health Indicators for Healthy People 2010 (final report in 1999) and State of the USA (final report in 2009).¹ The recommendations from these IOM committee reports offered ideas and policy directions; at this point, neither have been instituted.

The "new" idea here is to develop a measureable health literacy scorecard. Such a scorecard could add significant value in spurring action on health literacy that could facilitate individual and system monitoring of health literacy. The individual scorecard would identify a limited number of key health indicators that are associated with a healthy physical and mental state. A composite score could include fasting blood sugar (diabetes), body mass index (obesity), cholesterol (cardiovascular disease), blood pressure (hypertension), smoking/tobacco use (cancer and CVD), immunizations (vaccine preventable disease), and cancer screenings (age and gender specific). Individuals could get a "score" and rate themselves against a standard that could have predictive value for age and disease probability. The score could be developed with formative research that could be presented in the form of a grade A-F, percentile, gradation, color scheme, all-or-none or other easy-to-understand and galvanizing level for action (Nolan and Berwick, 2006). The challenge here will be to ensure that the variables selected could be addressed with interventions to build

¹ The author served on the IOM Leading Health Indicator Committee and suggested a potential framework that would address health and wellness entitled POISE "a balance—physical, occupational, intellectual, social/spiritual and emotional approaches" as dimensions for health. While this was discussed as a framework for the committee, it principally became a theoretical construct in health communication joining other wellness-related contexts with health communication teacher-scholars ontology.

health literacy (e.g., communication, policy and system engineering) so that the nexus of this score could be a reflection of the skills and ability of the individual and the demands and complexity of the system that foster a better “score.” These could be packaged in a way such that a “personal” health score could give people a general idea of what these mean, dialogue points to discuss with their physician and ample interest to get their “score” both on the individual measures and the composite, into a range that would translate into better health (and possibly lower costs and health spending [e.g., premiums]). Of course, as this is science and evidence based, health literate people would feel better, be sick less, be more productive at work and home and strengthen the new “personalized population health” (with a double helix of health literacy and prevention).

These scorecards and variable could be developed and updated on a national level with appropriate evidence and expertise from multistakeholders—pediatric health literacy chaired by AAP, maternal health literacy by ACOG, secondary prevention for people with diabetes by ADA, (see commissioned paper appendix for an example on the D5) etc., as well as a list suggested by IOM selected from the preventive services task force recommendations and other evidence/consensus based approaches. This scorecard could be viewed as a reflection of personal or population skills to understand evidence based goals and the degree of alignment health systems have to make these goals understandable, navigable, and accessible to those seeking them. Health literacy “scorecards” thus would reflect the alignment of skills and task demands and complexity. Additionally, such a scorecard or composite index at multiple levels could reflect the health literacy status of individuals and groups to further inform and motivate health communication campaigns, programs and resources (Ratzan, 2009; WHCA, 2009).

Furthermore, the scorecard could be tailored, endorsed and diffused in the three areas discussed in the next section of this paper.

Domain One:

Prevention and Health Literacy Within the Healthcare System

The health care system has a major role in developing individual and population health literacy skills. The influence of the health care system can be seen through the services it provides, the way its workers are trained and interact with individuals, the ease of navigation for patients, and the way the system supports an individual’s ability to get the information he or she needs and acts upon it in an appropriate manner. The health care system can foster (and hinder) obtaining information and services for individuals with all levels of health literacy skills. A large part of prevention lies in the responsibilities of the health care system and

health professionals to communicate in such a way so that those we serve, can hear, understand, embrace, and act upon the science/evidence-based professional advice provided for them, so they can make better health decisions. This becomes even more critical when addressing prevention of chronic diseases.

The health system can be a cornerstone with interventions that promote healthful behaviors with the provision of health information addressing common risk factors for chronic disease such as diet, physical inactivity and blood pressure control and interventions that help patients (and the public) understand how to manage their existing disease and its effects through early detection and appropriate treatment.

“The greatest opportunities for reducing health disparities are in empowering individuals and changing the health system to meet their needs” (HHS, 2000). As Moritsugu stated “without clear communication and easier access to services, we can’t expect people to adopt the health behaviors and take the actions we champion . . . the promises of medical research, health information technology, and advances in health care delivery cannot be realized without also addressing health literacy. Limited health literacy is not an individual deficit but a systematic problem that should be addressed by ensuring that health care and health information systems are aligned with the needs of the public” (Moritsugu, 2006).

Understanding Health Information

It can be difficult for anyone, no matter the literacy skills, to remember instructions or read a label when sick. Health care professionals, public health officials, and the media often present information in ways that make information and services more difficult to understand and use than they need to be. Some of these elusive skills are basic: such as reading, writing, and numeracy, and the ability to communicate and question. Even for people with basic health literacy, patient education brochures, informed consent forms, notices of privacy protection, patient bills of rights, and labels on medications can be too complex (previous IOM reports). Ineffective communication between health providers and patients can result in medical errors due to misunderstandings about medications and instructions.

A groundbreaking achievement of the IOM health literacy report was the acknowledgement that the epidemic of poor health literacy actually reflects a problem in the way health information is communicated to people what they must do to take care of their health. This framing of health literacy shifts the focus from improving individual patient health literacy skills to encouraging broader system change. Are essential tasks for promoting, protecting, and managing health clearly defined,

described, and communicated so that they are understandable and actionable? Is the use of technical jargon in both written and spoken language minimized? The overall objective of health literacy is to align the required tasks and demands with the skills and ability of patients and consumers. At present we have significant misalignment.

At all levels of preventive care, health materials that are easier to read along with meaningful personal interactions with healthcare providers can advance understanding. Patients struggle to articulate what is wrong with them and doctors struggle equally to convey information that is understandable. Often, the very same patients with limited health literacy are also those individuals and groups without access to providers. Whereas in the past, health management was left to the physician, many health systems now encourage individuals to take more responsibility for their own health. To make appropriate “self-management” decisions, people must locate health information, evaluate the information for credibility and quality, and analyze risks and benefits. Furthermore, people must be able to understand the available medical information, ask pertinent questions and express health concerns clearly by describing symptoms in ways the providers can understand (IOM, 2004).

Patient education is an important focus for prevention of costly hospital readmissions. Patients are prescribed medications, but without the ability to comprehend the instructions, they make frequent errors or do not adhere correctly to important regimens. In addition there is a difference between adherence (patient reports of following regimen) and concordance (clinician-patient agreement regarding regimen). A lack of functional health literacy has been found to impair patient’s understanding in both written and oral communication with caregivers (Schillinger, 2006). To advance better understanding, health literate disease management programs could be designed for patients with varying literacy skills.

Ease of Use/Navigation of the Health System

It is critical for patients to understand their own health system and its demands and requirements for primary and secondary prevention. A recent national survey of older adults who receive Medicare measured familiarity with health insurance terminology and proficiency with using the Medicare program. They found that the overall level of health insurance literacy among this population was low to moderate, with the oldest adults with poorer health and lower income levels at the lower end of that spectrum of literacy (McCormack et al., 2009). There are assessment tools to evaluate the extent to which a health service meets the needs of patients with limited health literacy skills. One example, applied to a pharmacy setting, was found to be a vital component of evaluating

patient understanding of medications and adherence to prescribed regimens. Also, the tool raised pharmacy staff awareness of health literacy issues and detected barriers that may have prevented individuals with limited literacy skills from accessing, comprehending, and using health information and services provided by the organization (Jacobson, 2008).

The health care system needs to be more proactive and take responsibility to meet the needs of the people it serves. Reducing the health literacy demands placed on individuals by such actions as modifying consent processes (Sudore et al., 2009); redesigning forms in advance to meet low literacy needs (Sudore et al., 2007); and emphasizing the importance of health literacy training for health care professionals will be steps toward this goal.

Training Providers in Communication

Health systems and the tasks they require of patients must continue to be simplified and physicians and other providers need to be prepared to handle the communication needs of growingly diverse patient populations, educating providers on how best to communicate with patients with widely divergent health literacy (Berkman et al., 2004). Health professionals and administrators must closely examine how patients engage their clinics and affiliated organizations, and work toward a truly patient-centered process.

Treating low health literacy as a “universal precaution” and training health providers, schools, and local community organizations in high risk areas in health communication “best practices” as a rule (Paasche-Orlow et al., 2006), and employing strategies to improve patient education and clinician-patient communication approaches benefit all patients, and harm none (Pignone et al., 2005). If the content and delivery of essential patient information is standardized (if not regulated) patients will be able to better form certain expectations of their health care experience.

Paasche-Orlow et al. (2006) suggest many ways that the health system can address limited literacy. Promoting better interactions between patients and providers, reorganizing, streamlining health care delivery; embracing a 21st-century field model approach with a community level and ecological perspective that acknowledges the various factors influencing health and health care for those with limited literacy. Each of these factors affects how we communicate, understand, and respond to health information.

As stated in an AHRQ review of health literacy, “it is often assumed that improved written communication can improve health outcomes. However, research suggests that improving information delivery alone may not mitigate the observed relationship between low literacy and

poor health. Addressing other important factors, such as self-efficacy, self-care, trust, or satisfaction, may increase our understanding of effective strategies for addressing poor health outcomes” (Berkman et al., 2004). For example, a recent study shows that providing patients with literacy-appropriate information, coupled with counseling is effective for improving self management of diabetes (Wallace et al., 2009). This suggests the types of strategies we might work toward for prevention and ongoing support for chronic disease (see commissioned paper appendix).

Domain Two: Educational System, Home, Community, and Workplace

We are increasingly challenged to make sound health decisions in the context of everyday life. As we read and interpret product labels and warnings; make lifestyle choices regarding eating, activity, smoking and drugs; evaluate the safety of chemicals in products we buy, find and interpret trustworthy health information on the Internet, we use our health literacy skills. Such everyday demands require individuals to be able to assess their current health and recognize the many socioeconomic factors and cultural values that influence it. For all this they need to have health literacy competencies and learned abilities that allow them to take responsibility for their own and their family’s (and, where necessary, their community’s) health (Kickbusch and Maag, 2008).

Health literacy is linked across sectors. At present, few healthcare professionals receive formal training in communication, particularly in working with people with limited literacy. In recent years, the National Board of Medical Examiners has added a one-day exam for all medical students that includes an assessment of communication and interpersonal skills. However, the clinical skills test does not specifically address how limited health literacy affects interactions with patients. And most healthcare professionals already in practice have not had formal training in improving communication skills. A growing number of continuing medical education courses in health literacy are available. The American Medical Association and the federal Health Resources and Services Administration both have training available for professionals who provide healthcare services. Imagine if every medical student, resident and physician were taught to present cases and ensure patients understood their prevention needs and actions as a standardized part of clinical presentations. The Subjective, Objective, Assessment, and Plan could add a P for “Prevention” to become SOAPP. If this intervention/measure were added, with commensurate measurement and reimbursement (short and long term) to attain such a quality standard, there might be some movement that would match policy with practice.

Increasing patient skills across the lifespan through all levels of the education system is critical. School-age children should be taught about nutrition, hygiene, vaccinations and common symptoms/illness as part of their elementary curriculum; prevention and screening for cancer screening information could be added (breast self examinations, testicular examinations, annual pap smears) to reproductive health classes as children age to adolescents. Teaching accurate, standards-based, culturally and developmentally appropriate health and science education should start in early childhood education and continue through the university level. We also need to support and expand local efforts to provide adult education, English language instruction, and health information services in the community (see commissioned paper appendix).

With the increase in the number of people living with chronic disease, we are shifting toward a model of the medical home. In this model, families take on a greater burden in health care. People with chronic diseases have more health literacy demands including the need for self management, coordinating care with multiple providers, managing multiple life-long prescription medications, yet often have fewer health literacy skills. We need to equip families and communities with self care strategies. Low caregiver literacy is common and is associated with poor preventive care behaviors and poor child health outcomes. Culturally appropriate and important health information is critical to allow families to engage in health promotion, prevention, and self care activities. Family caregivers could be a key component to achieving a better health outcome, and their health literacy must also be considered when they receive health information along with the patient (Bevan and Pecchioni, 2008). “Future research should aim to ameliorate literacy-associated child health disparities” (Sanders et al., 2009).

Health literacy in the workplace can lead to accident prevention as well as the avoidance of industrial or occupational diseases. Health-promoting work environments go further and can address lifestyle choices and stress factors, including an adequate work–life balance. Much can be done in this area to promote an infrastructure that facilitates and supports access to understandable and actionable health information and services. As the current health insurance system is largely employment based, this puts employers in the role of shaping the health information and services available to Americans. There is value in a “health literate workforce.” Employers are positioned to know the skills of their workforce and can use this knowledge about their employees to create on-site programs that build employees’ health literacy skills and help insurance companies and health information providers create employee-friendly information and services. They can provide training for employees to improve their health information seeking and decision-making skills. Prioritizing well-

ness initiatives and developing policies that improve health information and services for employees and their families ultimately benefits both the employer and employee with fewer days lost to sick leave. Here is another area where a “Health Literacy Scorecard” can be introduced as a tool for advancing wellness and prevention through education. Further, over time, both the health literacy status, health outcomes, productivity and other financial variables could be collected to reflect the health literacy status of the workforce and their dependents.

There are many ideas and emphases in primary and secondary prevention with evidence based suggestions for health awareness, behavior change, employee engagement and supportive environments. Ideally, demonstration of health outcomes (including productivity, absenteeism vs. presenteeism, etc.) could be coupled with economic incentives to advance a health literate workforce. As there is increasing dialogue about an infectious disease outbreak such as H1N1, reaching people at the workplace and in their workplace networks with a health literate approach has increased salience and timeliness.

Domain Three: Media and New Technology

Technology is evolving into a mechanism by which many people access and research health issues. Interventions need to be developed to reach people through communication technology. Programs are in place to use text-messaging to deliver prenatal care messages (i.e., vaccinations, folic acid supplementation, etc.) and states are piloting programs to use technology to reach their underserved populations (see commissioned paper appendix).

The media presents a health information marketplace within communities that shapes people’s perceptions, behaviors, and choices. Notices of recalls, imminent pandemics, even labeling changes on medications, are first experienced via multiple media channels and through family and friends. Yet most individuals do not have the ability to recognize and understand risk and sort through conflicting information, so what are they to make of news reports that lack guidance on how they are to act upon the given information? A 2008 survey by the Missouri School of Journalism found that only 18 percent of journalists surveyed had specialized training in health reporting and 50 percent were not familiar with health literacy (Smith, 2008). Yet, this is who a large part of the population relies upon for health information. Adults at all levels of health literacy use multiple sources to obtain health information. But, for all levels of health literacy, no single type of print material was as important as non-print sources, such as radio or television. Adults at the below basic level

of literacy were the least likely to use any written material to obtain information on health topics. At the below basic level, 43 percent used written information infrequently (HHS, 2008).

Within the media marketplace, effective communication strategies frame issues for the public of what they should think about. Communicators, public health advocates, educators, promoters, and journalists can use a wide range of technologies, media, and social marketing approaches to get independent evidence-based information to stand out and help shape people's perceptions, choices and behaviors.

Credible, reliable, accessible and understandable and actionable information is needed so that individuals can select, modify and/or avoid risky behaviors related to lifestyle choices, mental well-being, the control of infectious diseases, and environmental threats to health. Such interventions can help raise people's understanding of risks and strengthen their abilities to make healthy choices. The challenge in designing effective and understandable health communication is to determine the optimal context, channels and content which reflect the realities of people's everyday lives, situations and communication practices (IOM, 2003). The viewpoints and experiences of the targeted population need to be included in the design, implementation and evaluation of all interventions (IOM, 2004).

The Foundation: Policy and the Political Arena

Policies shape the institutional, community, and structural factors which determine health literacy and health. Active citizens can "speak-up" when institutional, community, and governmental policies and structures need to be changed. "Political" health literacy competencies include advocacy skills that promote policy change, informed voting behavior in the political arena, knowledge of health rights, and participation in civil society such as community, patient and health organizations. The economic realities are also with us; and as the hard policy choices are made, these must be part of the calculus. An informed and involved populace is critical in developing and implementing these policies. In research, practice, and policy there must be shared and integrated responsibility and involvement, with the person at the center.

CONCLUSION

Strategies to provide understandable information about realistic, achievable options to obtain optimal health that can be implemented at home, work, and in the greater community require practical supports at the individual and community level to overcome barriers. Ideally, a

solid foundation of health literacy would prevent disease, but it must be acknowledged that a large part of our population is already dealing with the effects of chronic disease (e.g., diabetes) and close attention must be paid to developing strategies that stop or slow down existing disease and its effects through early detection and appropriate treatment.

Real health reform must move toward prevention as a goal while still remaining prepared for appropriate intensive and specialty care. The trend is toward a medical home where decisions are shared and negotiated by all parties in health care, with the interests of the patient and families in the center.

One of the key ideas articulated in this paper that has not been fundamentally addressed in prior dialogues or publications is the idea of a health literacy scorecard. As the world is developing a greater interest in advancing health and wellness and preventing disease, we need measures of what people need to know and do—individually at work and at home, in the community, and as citizens. A health literacy scorecard can help us aspire to making the grade with our actions in disease prevention. Such an approach would be a new way of assessing societal progress by explicitly capturing how people can view their own health, measuring progress and success at multiple levels and demonstrating the value of health in society. Rather than an economic based approach, it would be multidisciplinary and an ethical and evidence informed approach to policy-making. Finally, it also could galvanize our global institutions, national governments, civil society, the private sector, and the public to act and address issues and antecedent factors to prevent disease and advance health.

In an era of economic and political challenges, advancing health literacy is a reasonable and achievable public health goal and policy imperative in the United States. Health literacy initiatives could garner bipartisan support that can be advanced with minimal incremental investments and redirection of funding. Further, with impending challenges of pandemic flu and the challenges of educating and mobilizing a number of people with limited or poor health literacy, the exigency to advance a national health literacy action plan is timely. Moreover, most Americans are aware of this issue as they have faced problems at some point understanding health information for themselves or for a family member. And, finally, a fundamental tenet of humankind to advance health and prevent disease can drive people to action with appropriate health literate interventions that suggest what people need to know and do among a system that can simplify demands and complexity for action. By addressing “health literacy policies as fundamental for health reform” the United States can move forward and make a difference on a key underlying health care problem—and on an issue that resonates with virtually everyone.

Recommendations for Action to Support Health Literacy

Recommendation 1

Relevant agencies should develop, test and implement health communication approaches to advance wellness and prevention so that skills and abilities of the population can be aligned with the demands and complexity of the tasks required for health. Health literacy can be attained with existing and innovative communication approaches on health behaviors, as social media, tailored communication and community interventions.

Recommendation 2

The U.S. government should set a high level health literacy agenda at the Office of the Surgeon General and/or Domestic Policy Council to convene and guide agencies to fund and create a Health Literacy P-scorecard (or a variety of scorecards based upon demographic and psychographic variables) in each state at a minimum to meet basic prevention and wellness awareness and behaviors such as the population knowledge and skills and a system that supports attainment of the prevention activities.

Recommendation 3

The National Governors' Association, mayors, civic organizations, and other leading organizations could similarly address and adopt health literacy measures of their constituents that integrate primary and secondary prevention into sustainability and other social sector goals. Private public partnerships could be fostered to create demonstrations and incentives. (These could be modeled after the WHO Healthy Cities Consortium.)

Recommendation 4

HHS and public and private funders should support the development, testing, and use of simple, culturally appropriate new measures of health literacy that incorporate prevention objectives. A National Institutes of Health, IOM, or other federally supported task force should convene a consensus panel to develop the P-score or health literacy index that would initiate the development of simple (no more than 10) operational measures of primary and secondary prevention that would be relevant to age, gender, cultural, genetic, contextual, epidemiological, and geographic location.

Recommendation 5

Health care systems should develop programs that incorporate in- and outpatient approaches to simplify the demands and complexity of participants practicing prevention. Centers for Medicare and Medicaid Services (CMS) can take the lead in developing a scorecard for Medicaid and Medicare patients. Incentives could be created with health literacy strategies for better communication with seniors. Pediatric health literacy (measures and goals) could be integrated into State Children's Health Insurance Program (SCHIP) materials.

Recommendation 6

With the goal for the population to attain basic health literacy, Federal agencies responsible for addressing disparities should support the development of new quality standards that reduce the demands and complexities of the health system. The ultimate goal is to make it simple and clear what individuals must "do" to access and utilize necessary health services.

Recommendation 7

The Department of Education (at federal, state, and local levels) should develop a health literacy competency base for levels of elementary and secondary education that includes the necessary education and measurement that could be integrated into standardized testing (a score). This scorecard could be reported at various grade intervals across traditional education grades to demonstrate the health literacy knowledge skills and practice of prevention and behaviors.

Recommendation 8

Congress should adopt a healthy workplace policy for all companies that advances primary and secondary prevention that is consistent with evidence based research and strategies. An attainable scorecard with economic incentives for employees and employers such as tax credits should also be hallmark to advance adoption of health promoting behaviors

Recommendation 9

The AAMC and other accrediting boards for health professional schools and professional continuing education programs in health and related fields, including medicine, dentistry, pharmacy, social work,

anthropology, nursing, public health, communication, and journalism should incorporate primary and secondary prevention health literacy into their curricula, practice, accreditations, and areas of competence.

Recommendation 10

New Activities in Comparative Effectiveness including those in development with the Federal Coordinating Committee (CMS, FDA, NIH, VA, and Defense) should integrate health literacy among the six interventions under consideration—notably the behavior change and prevention areas of interest.

COMMISSIONED PAPER APPENDIX OF CASES IN HEALTH LITERACY AND PREVENTION

DOMAIN ONE: HEALTH SYSTEMS

Case 1

Pittsburgh Regional Health Initiative—Proper use of chronic obstructive pulmonary disease medications requires many steps that are difficult to remember and do correctly. Case managers spent one hour per week for 7-8 weeks teaching patients correct use of their inhalers. In just three months, this teaching resulted in a 35 percent reduction in hospital readmissions (2008, Pittsburgh Regional Health Initiative).

Case 2

The Integrated Health Network (IHN) is a group of eight providers who serve over 200,000 uninsured and underinsured residents in St. Louis, Missouri. An IHN initiative, called the Health Education and Literacy Program, uses lay health coaches to reach uninsured and underinsured residents to empower them to take control of their health, communicate with providers, and become more confident in navigating the health delivery system. Despite barriers to healthcare among this population, including transportation access, financial obstacles, and lack of trust in the healthcare system, results of a qualitative study to determine the effectiveness of health coaches were positive. Preliminary findings revealed a significant increase in the percentage of patients who had a primary care provider after working with a health coach (from 57 percent to 81 percent). Moreover, after working with a health coach, 27 percent of chronic disease patients (up from 1 percent) are now able to discuss their self management plan.

Case 3

Chronic Disease Management Program (IOM, 2004)—Researchers and practitioners at the University of North Carolina have developed several chronic disease management programs that are designed to identify and overcome literacy-related barriers to care. The programs, which include interventions for diabetes, heart failure, chronic pain, and anticoagulation, are led by clinical pharmacist practitioners and trained health educators, who use evidence-based algorithms, a computerized patient registry, and literacy-independent teaching techniques to facilitate effective self-care and assure receipt of effective services and medications. In each area, the program organizers have systematically measured literacy as well as relevant health outcomes. For diabetes and anticoagulation, completed studies have found that these programs can offset the adverse effects of low literacy.

DOMAIN TWO: EDUCATIONAL SYSTEM, HOME, COMMUNITY, AND WORKPLACE

Case 1

Head Start Program Health Literacy Study—Parents of 20,000 children in 35 states were provided with health information and training to help them address their children's health needs. Prior to the training, 60 percent of the parents said that they did not have a health book at home to reference. Parents reported being "very confident" about caring for their sick children, yet 69 percent reported taking a child to a doctor or clinic at the first sign of illness and nearly 45 percent said they would take their child to a clinic or emergency room for a cough rather than provide care at home, even for a mild temperature of 99.5°F. Parents were given training and a medical guide to refer to when their children became sick. After training, parents using the medical guide as a first source of help jumped from 5 percent to 48 percent, indicating a better understanding and higher comfort level in dealing with common childhood illnesses. Visits to a hospital ER or clinic dropped by 58 percent and 42 percent, respectively, adding up to a potential annual savings to Medicaid of \$554 per family in direct costs, or about \$5.1 million annually. This translated into a 42 percent drop in the average number of days lost at work (from 6.7 to 3.8) and 29 percent drop in days children lost at school (from 13.3 to 9.5). Parents also reported feeling more confident in making health care decisions and in sharing knowledge with others in their families and communities (UCLA study).

DOMAIN THREE: MEDIA AND NEW TECHNOLOGY

Case 1

Mobile Health—The United States has the second worst infant mortality rate in the developed world. Given the challenge, later in 2009, a Text4Baby will begin with a design to leverage the more than 280 million mobile phones in the United States to deliver timely, relevant, and appropriate information to pregnant women and new mothers—particularly those in underserved populations—to improve the health of mothers and babies. Although basic maternal health information that can help reduce the chances of preterm labor and improve the health of mothers and babies is readily available in baby books and on web sites for women with access, it is not getting to the women who need it most. There is a unique opportunity for reaching lower-income women with cell phones as they are more than twice as likely to have a cell phone as broadband Internet (63 percent to 31 percent). Additionally, Hispanics and African Americans are much more likely to use their cell phones for SMS and other data services (73 percent vs. 68 percent vs. 53 percent). The Text4Baby service will send free SMS text messages to pregnant women who opt into the program with tips and information on how to take care of themselves and their babies. The evidence-based messages will answer questions like When do I need to visit a clinic?; What are signs I’m going into labor?; When should my baby be vaccinated? With formative research to confirm frequency and messages, participants will receive 3-5 messages per week based on stage of pregnancy telling what to expect, what to avoid, and what to do to help get through pregnancy safely. After the baby is born, the new mom will receive messages based on her baby’s age reminding her about important check-ups, vaccinations, and tips to keep her and her baby healthy.

Case 2

Arizona’s Medicaid program, the Arizona Health Care Cost Containment System (AHCCCS) is using eHealth technology to address health literacy. E-learning programs are developed specifically to address chronic conditions or other problems. The goal is to deliver education in a much more personal and culturally sensitive manner, tailoring the important content of that education to the various needs of the population and using messengers who are similar to and can relate to members of various populations. The basic website has a mission “to build health and wellness literacy in members so that they make decisions that improve their health care quality and reduce preventable health care costs through the utilization of interactive, personalized health education and health

literacy competency.” This website will be used to deliver many of the eHealth tools. Each beneficiary must have an e-mail address and/or document how he or she will access the Internet. If an individual does not have a way to access the Internet, then the program will take responsibility for devising a way to provide access. In this future vision, once a patient accesses his or her personal health account, the physician will be able to view the information and make sure that the patient understood the individual e-learning programs, since patient responses will be automatically uploaded to the electronic health record (EHR).

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