## Low Health Literacy: Implications for National Health Policy

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Executive Director Public Health and Government Pfizer Inc **Health Literacy:** The Institute of Medicine 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."

**A Failing Grade:** The 2003 U.S. Department of Education National Assessment of Adult Literacy (NAAL) contained, for the first time, a Health Literacy Component. The survey finds that 36 percent of the adult U.S. population has Basic or Below Basic health literacy levels.

An Economic Drain: Low health literacy is a major source of economic inefficiency in the U.S. healthcare system. An initial approximation places the order of magnitude of the cost of low health literacy to the U.S. economy in the range of \$106 billion to \$238 billion annually. This represents between 7 percent and 17 percent of all personal healthcare expenditures.

**The Financial Burden in Perspective:** The savings that could be achieved by improving health literacy – a lower bound of \$106 billion and an upper bound of \$238 billion – translate into enough funds to insure every one of the more than 47 million persons who lacked coverage in the United States in 2006, according to recent Census Bureau estimates.

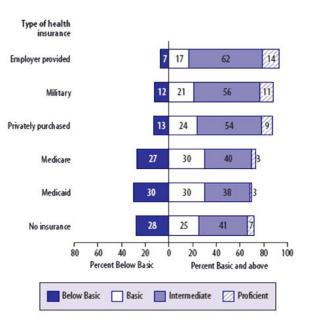
A Huge Burden for Future Generations: When one accounts for the future costs of low health literacy that result from current actions (or lack of action), the real present day cost of low health literacy is closer in range to \$1.6 trillion to \$3.6 trillion. This measure is relevant to guide choices about where the social investment might go today.

**A Wrong Assumption:** While ethnic minority groups are disproportionately affected by low health literacy, the majority of those with low health literacy skills in the United States are white, native-born Americans, as the latter group represents the largest segment of the population.

An Opportunity for Change: Addressing the low health literacy problem as part of national health reform can be expected to result in major savings, as well as better health. Furthermore, the lack of stable coverage and reliable healthcare access, two pillars of appropriate healthcare, are significantly associated with low health literacy, as both problems keep people from learning to use health care appropriately and in their own best interests.

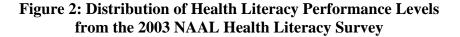
# I. <u>Health Literacy: Current State</u>

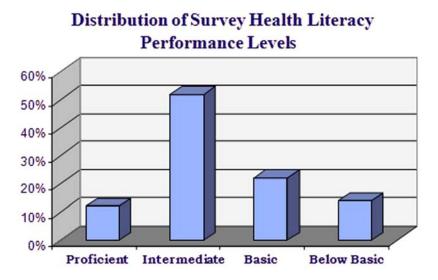
Securing appropriate healthcare hinges on having the necessary skills to read and fill out medical and health insurance forms, communicate with healthcare providers, and follow basic instructions and medical advice. At virtually every point along the healthcare services spectrum, the healthcare system behaves in a way that requires patients to read and understand important healthcare information. This information is dense, technical, and has jargon-filled language. Examples include completing health insurance applications, reading signs in hospitals and clinics about where to go and where to sign in, and following written and oral instructions in brochures and pamphlets, as well as prescription medication directions. The healthcare system itself can pose a serious barrier to appropriate care. Fear, embarrassment, and a non-user-friendly health care system are likely to inhibit many people from seeking clarification regarding what is meant by treatment instructions or medical advice. Cultural and language barriers, as well as low general literacy levels, can further exacerbate the problem of effective communication between patients and the health care system. Not having dependable health insurance is a significant deterrent to literacy in its own right, because uninsured persons are significantly less likely to use healthcare and, thus, may be that much more inexperienced in navigating the system.



#### Figure 1 NAALs Health Literacy Level by Type of Insurance

The National Assessment of Adult Literacy (NAAL) is overseen by the U.S. Department of Education and measures literacy among adults, using categories recommended by the National Research Council's Board on Testing and Assessment. The 2003 NAAL, for the first time, studied health literacy in the United States, finding that only 12 percent of the more than 19,000 adults surveyed demonstrated what is considered to be *Proficient* health literacy. Fifty-two percent had what the Department of Education classified as *Intermediate* health literacy; and 22 percent and 14 percent were determined to have *Basic* or *Below Basic* health literacy, respectively. The NAAL also identified that adults covered by Medicare or Medicaid, as well as persons with no health insurance, are more likely to have Basic or Below Basic or Below Basic in Figure 2.





The four tier health literacy performance categories used in the NAAL reflect the ability of patients to undertake increasingly complex tasks within the healthcare system. For example, individuals considered to have Below Basic health literacy would not be able to recognize a medical appointment on a hospital appointment form, nor would they be able to determine from a clearly written pamphlet containing basic information how often a person might have a specified medical test. Persons with Basic health literacy would have trouble providing two reasons why someone with certain symptoms might have a specified test, even when they used information from a clearly written, accurate pamphlet.

Individuals with Intermediate health literacy would be able to use an over-the-counter drug label in order to identify substances that might cause an adverse drug interaction. They also

would be able to find the proper age range when certain vaccines might be given to children, using a childhood immunization chart. Those with proficient literacy are able to calculate an employee's share of health insurance costs for a year, using a table that shows how the employee's monthly cost varies depending on income and family size; they can find the information required to define a medical term by searching through a complex document and evaluate information to determine which legal document is applicable to a specific healthcare situation.



# II. <u>Impact of Health Literacy on Health Outcomes and</u> <u>Expenditures</u>

Conceptually, health literacy can be understood as one of the essential determinants of whether individuals can use healthcare to achieve good health. "Good health" is what individuals expect will be the result of healthcare. This concept of producing good health through health literacy is termed "health capital production," a concept introduced by Grossman in 1972 through seminal research designed to show how individuals make decisions about their health. These health decisions involve seeking medical care and treatment, adopting healthy or unhealthy lifestyles, and managing one's overall state of health and physical wellbeing. Health literacy is a critical aspect of health, because it determines the efficiency with which patients seek care and receive treatment. Barriers to healthcare based on poor communication, inadequate information, and instructions that are not understandable, suggest that low health literacy levels may lead to vast inefficiencies in the production of health capital.

Some of the important features of this model, along with a fuller explanation of the relationship between health literacy levels, health outcomes, and resource expenditures, are summarized below.

#### Conceptual Model:

The conceptual model of health literacy assumes that, in combination with other factors such as education, income, and gender, health literacy affects an individual's ability to essentially "produce health," that is, to stay healthy. It also assumes that the demand for medical care is one of the ingredients that produces health and thus depends on health literacy.

Research shows certain direct links between health literacy, health outcomes, and health care expenditures. Evidence from research into health literacy suggests that literacy is an independent factor in the timing between preventive and curative treatment; how well patients can search for best treatment given a medical condition; whether they can search for the best medical providers; and how well they can find the best diagnostic services.

The evidence also shows a number of important indirect links between health literacy, outcomes and expenditures, in particular, insurance status, education, and family income.

Recent research and empirical evidence support this model of health literacy and its influence on healthcare expenditures and health outcomes. Examples are highlighted below.

#### Empirical Research and Evidence:

- Nielsen-Bohlman, Panzer, and Kindig (2004) found that individuals with limited health literacy reported poorer health status and were less likely to use preventive care.
- Baker et al (1998; 2002) and Schillinger et al (2002) found that individuals with low levels of health literacy were more likely to be hospitalized and to experience bad disease outcomes.
- Howard (2004) estimated that inpatient spending increased by approximately \$993 for patients with limited health literacy.
- Baker et al (2007) found that, within a Medicare managed care setting, lower health literacy scores were associated with higher mortality rates, after controlling for relevant factors.
- Friedland (2002) estimated that low functional literacy may have been responsible for an additional \$32 billion to \$58 billion dollars in healthcare spending in 2001. A substantial part of these expenditures is financed by Medicaid and Medicare.
- Weiss (1999) found that adults with low health literacy are less likely to comply with prescribed treatment and self-care regimens, make more medication or treatment errors, and lack the skills needed to navigate the healthcare system.

## III. <u>The Economic Cost of Low Health Literacy</u>

The empirical evidence on the links between health literacy levels and poor health outcomes and unnecessary healthcare resource utilization is extensive. However, only Friedland (2002) has attempted to estimate the aggregate cost of low health literacy in the U.S. His analysis was undertaken prior to the release of the 2003 NAAL which, as previously mentioned, for the first time contained a health literacy component. As a result, he had to rely on measures of adult illiteracy to proxy low health literacy — a reasonable approach in the absence of specific health literacy data. One of the objectives of this policy brief is to update this estimate using contemporary healthcare expenditure data from the Medical Expenditure Panel Survey (MEPS), and the newly released NAAL survey of U.S. health literacy levels. Thus, we have adopted Friedland's assumptions and modeling methodology to guide our own calculations. Our intent is to approximate only the order of magnitude of the economic costs of low health literacy in the U.S. The value of such approximations is for just this purpose: to raise awareness of the relative size and magnitude of the economic costs involved. It is from this perspective, and within this context only, that our estimates might be considered.

## Annual and Present Value Cost Estimates

### Our principal findings are as follows

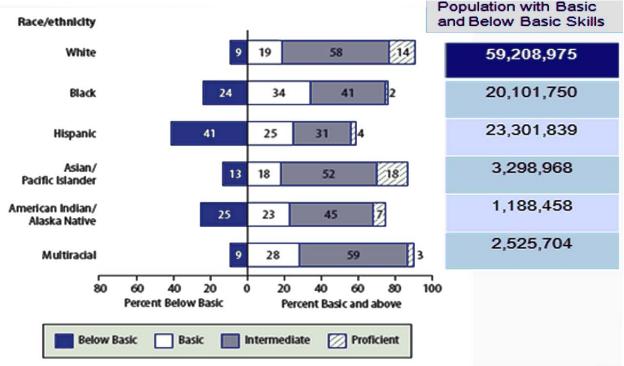
Among 242 million adults in 2003, the health literacy estimates from the 2003 NAAL Health Literacy survey suggest that 36 percent of the adult U.S. population has Basic or Below Basic health literacy levels, which we define as low health literacy. Thus, approximately 87 million U.S. adults have low health literacy.

Using 2003 MEPS data and Friedland's (2002) modeling assumptions, we estimate that the annual cost of low health literacy ranges from \$106 billion (lower bound) to \$238 billion (upper bound).

When one accounts for the future costs of low health literacy that result from current actions (or lack of action), the real present day cost of low health literacy is closer in range to \$1.6 trillion to \$3.6 trillion. This measure is relevant to guide choices about where the social investment might go today.

Ethnic minority groups are disproportionately affected by low health literacy. At the same time, however, the majority of people with low literacy skills in the U.S. are white, native-born Americans, who represent the largest segment of the population. Others who are especially vulnerable to low health literacy are older patients, recent immigrants, people with chronic diseases, and those with low socioeconomic status. **Figure 3** shows the racial and ethnic characteristics at various levels of health literacy by population percentage, and by the actual number of people in each sub-population grouping.

**Figure 3** Health Literacy by Race and Ethnicity, U.S. Population





# IV. <u>Health Policy Considerations and Recommendations</u>

Recent research documents both (1) the prevalence of low health literacy among adults in the U.S. and (2) the links between low health literacy and health outcomes and medical expenditures. The economic costs are likely to be very substantial. Efforts to improve the health literacy of the U.S. population will go a long way towards eliminating some of the inefficiencies in the provision of healthcare in the U.S. and empowering patients to better manage their own healthcare (preventive or otherwise). Low health literacy is at a crisis level; it has only recently been uncovered in a systematic way through the 2003 NAAL health literacy survey and analysis.

Public policy plays an important role in addressing low health literacy and its effects. Conversely, the failure to act carries high costs in terms of individual health, healthcare spending, and the economic well-being of the nation as a whole.

This research underscores that low health literacy carries real costs to the healthcare system that can be quantified and projected over society as a whole. The health literacy research on

which this analysis rests also suggests several important policy directions for reducing the economic, social, and health burdens of literacy.

Providing the U.S. population with access to affordable coverage creates a more level playing field among those who are and are not health literate. To the extent that low health literacy is associated with the absence of health insurance, it is important that policymakers address this underlying and confounding problem. It is particularly challenging to improve literacy among populations who lack affordable access to timely and appropriate health care.

Beyond the issue of coverage, however, it is clear that low health literacy is a problem that transcends insurance status. This study suggests that 75 percent of the low literacy population is, in fact, insured. Although strengthening health insurance coverage appears to be a key factor associated with improving health literacy, our estimates also underscore the fact that health insurance alone is not sufficient. Indeed, we estimate that the majority of persons with low health literacy levels report some level of health insurance coverage. For this reason we make recommendations that are designed to reach all persons, regardless of health insurance status. Additional reforms are merited overall as a means of directly addressing the problem of health literacy:

- First, health insurers and healthcare professionals might be incentivized to identify and address health literacy-related problems in the healthcare system. This means ensuring that patients understand instructions and are able to navigate throughout the healthcare system.
- Second, both public and private health insurers might recognize and build costs into their payment systems associated with adapting healthcare services in ways that promote literacy, including translation and interpreter services, and the development of oral instructions and written materials that can be understood by all patients regardless of reading levels.
- Third, federal policymakers might increase funding for research into innovative clinical and health interventions in various health and healthcare settings to improve health literacy, particularly with respect to populations at elevated risk for health disparities.
- Fourth, the federal government could encourage health literacy by creating centers of excellence to promote its study and the adoption of best practices and known interventions that improve health literacy. Particular emphasis might be placed on funding activities by state and local health agencies, community health centers, Ryan White Care Act Programs, the Indian Health Service, and other health system entities that care for populations at highest risk for adverse health outcomes.
- Fifth, health literacy skills might become a basic component of federally supported health professions education and training programs, particularly programs that train

professionals in the fields of medicine, nursing, pharmacy, and other direct patient interaction.

• Finally, federal policymakers might consider revising their approach to estimating the impact of federal policy reforms to incorporate a "health literacy impact" assessment. This would yield "scorable" estimates of the effects of federal policy reforms on population literacy.



# **IV.** Conclusion

The results of this first-ever analysis of data from the 2003 NAAL Health Literacy Survey underscore the enormous costs of low health literacy to the U.S. health system. These costs can be measured in both human and financial terms: premature mortality, avoidable morbidity, racial, ethnic and socioeconomic disparities in health and healthcare and enormous avoidable costs. The cost of low health literacy – a lower bound of \$106 billion and an upper bound of \$238 billion, and trillions of dollars over a long-term period – represents an amount equal to the cost of insuring every one of the more than 47 million persons who lacked coverage in the United States in 2006, according to recent Census Bureau estimates.

These findings underscore the value of two basic types of policy interventions. The first intervention is elimination of disparities in health insurance coverage. The lack of health insurance acts as a fundamental confounder in designing interventions to improve the way in which people relate to and use healthcare, because of its significant impact on the timely and appropriate use of health services. There exist numerous approaches to achieving stable, fair, and equitable coverage; what is missing at the present time is the societal commitment to achieving such change.

The second set of policy interventions focuses on specific actions to improve the ways in which health insurers and healthcare providers relate to and interact with patients, through the use of financial incentives, targeted research, better patient education, and specific healthcare workforce training improvements.

There are, of course, caveats regarding the extent to which savings from improved health literacy might translate into a greater ability to invest in health insurance improvements. First, eliminating low health literacy will itself require a major commitment of resources by society in education and system reforms. This cost would have to be measured against the benefit of eliminating low health literacy. Second, the health system itself must invest in making changes needed to make it easier to navigate. These investments would need to be taken into account in estimating the savings, and thus the net benefit, that could be invested in affordable insurance.

Second, our figures are derived from the estimated cost of low health literacy. These estimates are preliminary and would need to be refined. This refinement is not possible without the release of person-specific health literacy data which, to date, have not been made available by the federal government to health services researchers.

Third, our estimates of net benefit also do not take into account the costs associated with extending health insurance to currently uninsured persons. As individuals gain coverage, utilization rises for both acute and preventive services. This factor that must be taken into account when calculating the true costs associated with shifting national expenditures away from excess spending linked to low literacy and into investment in more appropriate healthcare for the population. At the same time, of course, even if spending on uninsured persons were to rise as coverage is realized, the net benefit to society of investing in efforts to produce a healthier population also would need to be taken into account.

Despite these caveats, we believe that it is fair to suggest that low health literacy exacts enormous costs on both the health system and society, and that current expenditures could be far better directed through a commitment to improving health literacy.



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Dr. Vernon is a professor in the Department of Finance in the School of Business at the University of Connecticut. Dr. Vernon holds PhDs in economics and management science. He is the former Senior Economic Policy Advisor to the Office of the Commissioner at the U.S. Food and Drug Administration. He is a Faculty Research Fellow with the National Bureau of Economic Research (NBER), and will be a Visiting Professor at the Wharton School of Business at the University of Pennsylvania in 2008. Dr. Vernon has testified before the U.S. Senate on several occasions, and advises the both government and industry on regulatory and anti-trust issues.

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Professor Trujillo is a health economist with a specialization in health disparities across cultures. He holds a PhD from the University of North Carolina at Chapel Hill, and is an expert in statistical and econometric methods. He is the first researcher, with John Vernon and colleagues, to simultaneously consider instrumental variable estimation results with propensity score matching methods. Professor Trujillo presents his research globally, and is a leader in analysis of health issues affecting Latin American countries.

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Professor Rosenbaum is the Harold and Jane Hirsh Professor of Health Law and Policy, and Chair of the Department of Health Policy at the George Washington University School of Public Health and Health Services. As a scholar, an educator and a national leader, she has dedicated her career to promoting more equitable and effective healthcare policies in this country, particularly in the areas of Medicaid and Medicare, managed care, employee health benefits, maternal and child health, community health centers, and civil rights in health care systems. Professor Rosenbaum's commitment to strengthening access to care for low-income, minority and medically underserved populations has had a transforming effect on the lives of many Americans, particularly children.

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Dr. DeBuono is Executive Director, Public Health and Government, at Pfizer Inc. She is a corporate leader in the area of public health policy and healthcare; she has helped shape policies for important health issues such as access to care, breast cancer screening and quality assurance, and HIV/AIDS surveillance and prevention. She is a leader in public health thinking and has initiated many novel programs, such as the Pfizer-sponsored CDC Experience: A Fellowship for Medical Students in Applied Epidemiology. Dr. DeBuono is one of the nation's thought leaders in the area of health literacy, and leads Pfizer's Clear Health Communication Initiative.