

Health Literacy and Plain Language

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I. Health Literacy

Health literacy is a person's ability to find, understand, and use basic health information and services.¹ Health literacy skills help people access health information and services, communicate their needs and preferences, understand their choices, and make informed health decisions.² Many factors influence health literacy including a person's reading level, understanding of numerical concepts, and language proficiency as well as cultural factors. The language, format, style, and design of materials also affect health literacy. An individual's health literacy depends on the level of health literacy required within a given context as well as the individual's skills.³ For example, a person's health literacy proficiency may be limited after major surgery, during a period of distress, or when faced with a complex situation or set of materials. In other words, even those consumers and patients with generally proficient health literacy skills are likely to have difficulty understanding health information at some point in their lives.⁵

Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."⁴

In addition to consumers and patients, it is important for health care providers to have proficient health literacy skills. Providers with strong health literacy skills help people find and access information and services, communicate effectively about health and health care, understand what patients and families are asking for, and provide useful information and services.⁶

Health literacy is also important for agencies, organizations, and health care facilities. A health literate organization actively makes it easier for people to find, understand, and use health information and services. An organization can make the health care system more accessible by presenting information clearly and simply and by helping individuals improve their health literacy skills.⁷

"Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course."⁸

¹ See Centers for Disease Control and Prevention (CDC), *Learn About Health Literacy*, June 2014; Institute of Medicine (IOM), *Health Literacy: A Prescription to End Confusion*, 2004.

² See CDC, *Learn About Health Literacy*, June 2014.

³ Id.

⁴ See Ratzan and Parker, *National Library of Medicine Current Bibliographies in Medicine: Health Literacy*, 2000, National Institutes of Health, U.S. Department of Health and Human Services.

⁵ See IOM, *Health Literacy: A Prescription to End Confusion*, 2004.

⁶ See CDC, *Learn About Health Literacy*, June 2014.

⁷ See IOM, *Ten Attributes of Health Literate Health Care Organizations*, Cindy Brach et al., June 2012.

⁸ See Sørensen et al., *Health literacy and public health: A systematic review and integration of definitions and models*, BMC Public Health, 2012 12:80.

Limited health literacy: Health outcomes, utilization, and health care costs

Limited health literacy is associated with poorer health outcomes,⁹ differences in utilization of the health care system,¹⁰ and higher health care costs.¹¹

Research has shown that patients with limited health literacy have less knowledge about how to manage their medical conditions, decreased ability to share in decision making, lower adherence to some therapies, and lower self-reported health status.¹² Limited health literacy is associated with several adverse health outcomes, including increased incidence of chronic illness and poorer disease markers.¹³ For example, studies have found an association between limited health literacy and poor glycemic control among diabetics.¹⁴

Limited health literacy is also associated with differences in utilization.¹⁵ Multiple studies¹⁶ have shown that limited health literacy is associated with under-utilization of preventive health services, including cancer screening. One study¹⁷ found higher rates of hospitalization among patients with lower health literacy.

Furthermore, limited health literacy is associated with higher health care costs.¹⁸ One study¹⁹ found \$29 billion in health care costs in a single year attributable to inadequate reading skills. For a report entitled “Health Literacy: A Prescription to End Confusion,”²⁰ Institute of Medicine researchers conducted a secondary analysis of expenditure data collected in 2001.²¹ They found that predicted inpatient spending for a person with inadequate health literacy was almost \$1,000 higher than for a patient with adequate health literacy. Part of the predicted difference in spending was due to higher emergency care costs incurred by patients with poor health literacy as compared to those with better health literacy.

⁹ See U.S. Department of Health and Human Services (HHS), Office of Disease Prevention and Health Promotion, *National Action Plan to Improve Health Literacy*, 2010; Berkman et al., Agency for Healthcare Research and Quality, *Literacy and health outcomes*, 2004; Cho et al., *Effects of health literacy on health status and health service utilization amongst the elderly*, *Social Science & Medicine* 2008 66:8.

¹⁰ See IOM, *Health Literacy: A Prescription to End Confusion*, 2004.

¹¹ See Friedland, R.B., *Understanding health literacy: new estimates of the costs of inadequate health literacy*, National Academy on an Aging Society, 1998: 1-24; *Health Literacy: A Prescription to End Confusion*, 2004; Baker et al., *Functional Health Literacy and the Risk of Hospital Admission Among Medicare Managed Care Enrollees*, *Am J Public Health*, 2002 August 92(8): 1278–1283.

¹² See, IOM, *Health Literacy: A Prescription to End Confusion*, 2004.

¹³ Berkman et al., Agency for Healthcare Research and Quality, *Literacy and health outcomes*, 2004.

¹⁴ *Id.*

¹⁵ See, IOM, *Health Literacy: A Prescription to End Confusion*, 2004.

¹⁶ See, Berkman et al., Agency for Healthcare Research and Quality, *Literacy and health outcomes*, 2004.

¹⁷ See, Baker et al., *Functional Health Literacy and the Risk of Hospital Admission Among Medicare Managed Care Enrollees*, *Am J Public Health*, 2002 August 92(8): 1278–1283.

¹⁸ See, Friedland, R.B., *Understanding health literacy: new estimates of the costs of inadequate health literacy*, National Academy on an Aging Society, 1998: 1-24; IOM, *Health Literacy: A Prescription to End Confusion*, 2004; Baker et al., *Functional Health Literacy and the Risk of Hospital Admission Among Medicare Managed Care Enrollees*, *Am J Public Health*, 2002 August 92(8): 1278–1283.

¹⁹ See, Friedland, R.B., *Understanding health literacy: new estimates of the costs of inadequate health literacy*, National Academy on an Aging Society, 1998: 1-24.

²⁰ See, IOM, *Health Literacy: A Prescription to End Confusion*, 2004.

²¹ See, Baker et al., *Functional Health Literacy and the Risk of Hospital Admission Among Medicare Managed Care Enrollees*, *Am J Public Health*, 2002 August 92(8): 1278–1283.

These findings suggest that improving health literacy and helping people with limited health literacy navigate the health care system may be effective strategies to improve health outcomes and health status and to reduce the use of high cost hospital and emergency room services.

Health literacy in the United States

Health literacy is a significant problem in the United States (U.S.). Most adults in the U.S. do not have proficient health literacy skills.²² The National Assessment of Adult Literacy (NAAL)²³, a nationally representative assessment of English literacy conducted in 2003, found that only 12% of U.S. adults had proficient health literacy skills. According to the Department of Health and Human Services (HHS), approximately 77 million adults in the U.S. have difficulty with basic health tasks like following the directions on a prescription drug label.²⁴

Health literacy problems affect a broad range of adults. The NAAL identified populations with the highest prevalence of low health literacy. These included Hispanics (41% “below basic”), those with less than a high school education (49% “below basic”), the elderly (>75 years of age, 39% “below basic”), and people with Medicare, Medicaid, or no insurance (27-30% “below basic”).²⁵ While these groups are particularly at risk for poor health literacy, people from all racial and ethnic groups, education levels, ages, and insurance categories struggle with health literacy.²⁶ Most people will experience a health literacy barrier at some point during their lifetime.

Health literacy in Vermont

To our knowledge, comprehensive statewide data on health literacy in Vermont is not available. However, in 2014 the state included health literacy questions in its Household Health Insurance Survey²⁷ for the first time. Participants reported how confident they are that they understand health insurance-related terms and concepts. Participants’ confidence varied by term, with more than three quarters of participants “very confident” that they understand the terms “premium,” co-payments,” and “deductible,” and less than half “very confident” that they understand “co-insurance,” “health exchange or insurance exchange,” and “Advanced Premium Tax Credit.” While this set of questions gives some indication of Vermonters’ confidence in their understanding of health insurance terms,

²² See HHS, Office of Disease Prevention and Health Promotion, *America's Health Literacy: Why We Need Accessible Health Information*, 2008; HHS, Office of Disease Prevention and Health Promotion, *National Action Plan to Improve Health Literacy*, 2010; Williams et al., *Inadequate functional health literacy among patients at two public hospitals*, JAMA, 1995 Dec 6;274(21):1677-82.

²³ National Center for Education Statistics, *National Assessment of Adult Literacy*, 2003.

²⁴ See HHS, Office of Disease Prevention and Health Promotion, *America's Health Literacy: Why We Need Accessible Health Information*, 2008.

²⁵ Id.

²⁶ Id.

²⁷ See B. Robertson and M. Noyes, *2014 Vermont Household Health Insurance Survey Initial Findings*, Vermont Department of Financial Regulation Insurance Division, presented to the Health Reform Oversight Committee, Jan 6 2015.

participants' actual understanding of the terms was not evaluated and no validated measures of health literacy were included.

Two studies have examined health literacy in the state.²⁸ One study of 103 inpatients at Fletcher Allen Health Care²⁹ found that over half of patients had inadequate health literacy.³⁰ Inadequate health literacy means a patient is unable to perform basic health care tasks like reading and understanding a prescription label or appointment slip.³¹ In this study, patients with inadequate health literacy tended to be older, less educated, with lower earnings, and less often white.³² Another study of 1002 older adults with well-controlled diabetes found that 10% of patients had inadequate health literacy.³³ In this study, patients with inadequate or marginal health literacy were older, less educated, less likely to be married, had lower income, were less likely to have private insurance and more likely to have Medicare or Medicaid coverage.³⁴ While neither of these studies describes Vermont's entire population, they each indicate that health literacy is a problem in the state. Additionally, these studies suggest that certain populations, such as inpatients, the elderly, and low-income Vermonters may be more likely to have low health literacy.

Federal efforts to improve health literacy

In 2010, HHS released the National Action Plan to Improve Health Literacy.³⁵ The plan is based on two principles: 1) everyone has the right to health information that helps them make informed decisions, and 2) health services should be delivered in ways that are understandable and beneficial to health, longevity, and quality of life. The vision of the plan is to create a society that provides everyone with access to accurate and actionable health information, delivers person-centered health information and services, and supports lifelong learning and skills to promote good health. The plan includes seven goals as well as tools that organizations can use to develop their own health literacy plans.

²⁸ See Morris et al., *Prevalence of Limited Health Literacy and Compensatory Strategies Used by Hospitalized Patients*, *Nurs Res.* 2011; 60(5): 361–366; Morris et al., *Literacy and health outcomes: a cross-sectional study in 1002 adults with diabetes*, *BMC Family Practice* 2006, 7:49.

²⁹ Fletcher Allen Health Care was renamed the University of Vermont Medical Center in November, 2014.

³⁰ See Morris et al., *Prevalence of Limited Health Literacy and Compensatory Strategies Used by Hospitalized Patients*, *Nurs Res.* 2011; 60(5): 361–366.

³¹ See Morris et al., *Prevalence of Limited Health Literacy and Compensatory Strategies Used by Hospitalized Patients*, *Nurs Res.* 2011; 60(5): 361–366.

³² *Id.*

³³ Morris et al., *Literacy and health outcomes: a cross-sectional study in 1002 adults with diabetes*, *BMC Family Practice* 2006, 7:49.

³⁴ *Id.*

³⁵ See HHS, Office of Disease Prevention and Health Promotion, *National Action Plan to Improve Health Literacy*, 2010.

Goals of the National Action Plan to Improve Health Literacy

- 1) Develop and disseminate health and safety information that is accurate, accessible, and actionable
- 2) Promote changes in the healthcare delivery system that improve information, communication, informed decision-making, and access to health services
- 3) Incorporate accurate and standards-based health and developmentally appropriate health and science information and curricula into child care and education through the university level
- 4) Support and expand local efforts to provide adult education, English-language instruction, and culturally and linguistically appropriate health information services in the community
- 5) Build partnerships, develop guidance, and change policies
- 6) Increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy
- 7) Increase the dissemination and use of evidence-based health literacy practices and interventions

Additionally, in October, 2010 President Obama signed the Plain Writing Act of 2010.³⁶ (See *Plain Writing Act of 2010 below*)

II. Plain Language

Plain language is clear, concise, well-organized communication that the reader can understand the first time they read it. Plain language helps readers find and use the information they need.³⁷

The principles of plain language are based on research about what helps people read, understand, and use written information. Often, people are not able to read or understand documents because the writing is too complex. Even people with good literacy skills skip information, don't understand everything that is written, or don't bother to read a document that is too long or difficult.³⁸

According to the National Network of Libraries of Medicine, a person's reading ability is typically three to five grade levels below the last year of school completed. That means that people with a high school diploma typically read at a 7th or 8th grade reading level. For those who speak, write, and read English as a second language, the barriers to understanding written information are often greater. Using plain language is essential to successful communication.³⁹

³⁶ See Plain Writing Act of 2010, Pub. L. No. 111-274, 124 Stat. 2861 (2010).

³⁷ See Office of the Health Care Advocate, *Basic Guidelines for Writing in Plain Language*, 2014.

³⁸ Id.

³⁹ Id.

The importance of plain language health information

Much important health information is conveyed to patients and consumers in writing. For example, patients receive notices in the mail about their health coverage and health care, are asked to sign consent forms when they visit their providers, and are expected to read and follow written instructions on medication labels. Many people use the internet to find health information and to buy health insurance. When patients are unable to understand written materials, or do not read them because of their length or complexity, the opportunity to convey important information is lost. This can result in patients taking medications incorrectly, consenting to or abstaining from procedures without understanding benefits and risks, and purchasing health plans that do not meet their needs, as well as many other undesirable outcomes.

The use of plain language can make documents more cost-effective.⁴¹ A reader who understands a document is more likely to act upon the information provided, when appropriate, reducing the need for costly follow-up. Readers are also less likely to have questions about information that is presented clearly, resulting in less use of call centers and reduced staff and training needs.⁴²

Plain language health information also has the potential to be cost-effective over the long term. If patients can understand and act upon information like medication and hospital discharge instructions, it is logical that they will be less likely to experience complications like medication interactions or readmissions. If consumers understand their health plan options, they can choose plans that fit their needs, allowing them to access care and potentially preventing the need for high-cost acute care in the future. Plain language information empowers patients and increases the likelihood that patients will be engaged in their care. While transitioning to plain language requires some upfront investment, the potential for long term benefits far outweighs the costs.

Plain Writing Act of 2010

In October, 2010 President Obama signed the Plain Writing Act of 2010⁴³ into law. This law requires federal agencies to use clear communication that the public can understand and use. To achieve this, each agency must use plain writing in documents it issues or

Plain Language Example

Before: The Dietary Guidelines for Americans recommends a half-hour or more of moderate physical activity on most days, preferably every day. The activity can include brisk walking, calisthenics, home care, gardening, moderate sports exercise, and dancing.

After: Do at least 30 minutes of exercise, like brisk walking, most days of the week.⁴⁰

⁴⁰ See U.S. Food and Drug Administration, *Plain Language Principles*.

⁴¹ See B.Mazur, *Revisiting Plain Language*, Technical Communication, The Journal of the Society for Technical Communication, 2002.

⁴² *Id.*

⁴³ See Plain Writing Act of 2010, Pub. L. No. 111-274, 124 Stat. 2861 (2010).

substantially revises, train employees in plain writing, establish a process for overseeing compliance with the Plain Writing Act, create and maintain a plain writing section on its website, provide a mechanism for receiving and responding to public input related to plain writing, and designate plain writing points-of-contact.

The documents covered by this law include:

- Those needed to obtain federal benefits or file taxes
- Those that provide information about federal benefits or services
- Those that explain to the public how to comply with a requirement the Federal Government administers or enforces
- Letters, publications, forms, notices, and instructions



"Well, yes, I suppose I could explain the test results in 'plain English' – but then you'd know how sick you are."

Source:
www.nih.gov/clearcommunication/plainlanguage/

The law defines plain writing as “writing that is clear, concise, well-organized, and follows other best practices appropriate to the subject or field and intended audience.”

Every year, the Center for Plain Language (CPL),⁴⁴ a non-profit organization that helps government agencies and businesses write clearly, evaluates each federal agency on how well it is doing on plain language. CPL assigns each agency a grade between A and F for its compliance with the Plain Writing Act of 2010 and for its use of plain language. In 2013, only the Social Security Administration earned a grade of ‘A’ in both categories. The Department of

Health and Human Services earned a grade of ‘B’ in both categories. The Center for Plain Language also

offers tools and trainings that agencies and organizations can use to improve their written materials.

Plain language health information in Vermont

Vermont does not currently require the use of plain language in communication of health information to consumers. Many of the health-related notices, consent forms, websites, and other documents created by Vermont’s agencies and provider organizations are written in language that is not understandable by the average Vermonter. In 2014, the Office of the Health Care Advocate (HCA) consumer helpline received 305 calls related to confusing notices. In addition to helping these individuals, the HCA has helped a number

⁴⁴ See *Center for Plain Language website*.

of agencies and organizations improve the readability of notices and consent forms. However, too often these entities write documents in language far too complex for a consumer audience to understand.

State-level plain language initiatives

A number of states have passed laws requiring the use of plain language for some or all consumer communications. For example, New York requires the use of plain language in consumer transactions,⁴⁵ Connecticut and Pennsylvania require the use of plain language in consumer contracts,⁴⁶ Florida requires readable language in insurance policies,⁴⁷ and Minnesota requires plain language in materials relating to benefits.⁴⁸ Other states such as Washington have used executive orders to implement plain language policies.⁴⁹

In 2007, Oregon passed House Bill 2702 which required development of a plan to ensure that all written documents produced by executive department agencies conform to plain language standards. The Department of Consumer and Business Services (DCBS) began a two-phase implementation plan in 2007 and provided status reports to the Legislature in 2008 and 2009. During the first phase of implementation, six pilot agencies tested ways to implement plain language. In the second phase the pilot agencies made recommendations for implementing plain language statewide. While the state has not completed these recommendations in their entirety due to budget constraints, it has made important steps toward improving the readability of its agencies' websites and consumer communications.

III. Recommendations

To begin addressing the issue of inadequate health literacy, Vermont should embrace and act upon the seven goals outlined in the National Action Plan to Improve Health Literacy⁵⁰ (see *Goals of the National Action Plan to Improve Health Literacy* above).

We recommend that Vermont take the following steps:

- 1) Pass a law requiring the use of plain language for all consumer-facing health information.
- 2) Include measures of health literacy in all health needs assessments.
- 3) Implement health care initiatives that include plain language patient materials and health literacy support for health care providers, such as Choosing Wisely®.⁵¹

⁴⁵ See Tiersma, P., *Various Plain English Statutes*.

⁴⁶ Id.

⁴⁷ Id.

⁴⁸ Id.

⁴⁹ See D.H. Botka, "Plain Talk" in Washington.

⁵⁰ See HHS, Office of Disease Prevention and Health Promotion, *National Action Plan to Improve Health Literacy*, 2010.

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- 4) Empower patients to be active participants in their health care decisions by implementing patient-centered initiatives such as Shared Decision-Making.⁵²

Plain language law

A law requiring the use of plain language for health information is the only way to ensure that consumers have access to clear, understandable information about their health and health care. Because every Vermonter encounters health information, and a wide variety of state agencies and other entities produce health information, a comprehensive law is the most logical way to bridge the gap between the health literacy of our population and the reading level of most health information in our state.

A plain language law should include a requirement that every agency of state government and health care facility use plain language when communicating with the public or an individual about health or health care. Each agency should be required to:

- Assign a staff person to oversee the plain language initiative
- Ensure that the individual receives adequate training on plain language standards
- Prioritize nonconforming documents to be rewritten based on frequency of use, receipt of complaints or questions, errors arising from use of the document, complexity and lack of clarity
- Establish a schedule for rewriting nonconforming documents
- Track the agency's progress
- Incorporate the principles of plain language into employee training

⁵¹ See *Choosing Wisely*[®], an initiative of the ABIM Foundation.

⁵² See *Mayo Clinic Shared Decision Making National Resource Center*.