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## *White Paper on Health Literacy*

*Indian Health Service  
Health Literacy Workgroup*

Second Edition

## Letter of Introduction

Each member of our clinical and administrative staff throughout the Indian Health Service (IHS) has a role to play in providing clear and understandable health information that will enable patients, their families, and members of our Tribal communities to make informed decisions about their health.

Health literacy is a significant public health issue that affects almost 9 out of 10 adults in the United States (U.S.).<sup>1</sup> We recognize this statistic includes American Indian and Alaska Native (AI/AN) people. Evidence reveals that limited health literacy is associated with less use of preventive services such as mammography and cancer screenings and less controlled management of chronic conditions such as blood pressure and glucose.<sup>2</sup>

To advance health literacy and support patients seeking resources to help them make informed health decisions, the IHS's Health Literacy Workgroup developed a "*White Paper on Health Literacy*" that features "*Call to Action*" strategies to improve our communication with patients and their families by using plain language and commonly used terms. When communicating with our AI/AN patients, families, and communities, it is important to use teach-back techniques to enhance patient understanding, ensure patient forms are understandable, and provide a welcoming lobby that represents the local culture.

Let us work together to practice and implement the strategies outlined in this report to more effectively enhance informed decision-making by our patients.

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<sup>1</sup> Nielsen-Bohlman, L., Panzer, A. M., & Kindig, D. A. (Eds.). (2004). Health literacy: A prescription to end confusion. Washington, DC: National Academies Press.

<sup>2</sup> Kutner, M., Greenburg, E., Jin, Y., & Paulsen, C. (2006). The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy. NCES 2006-483. *National Center for Education Statistics*. <https://nces.ed.gov/pubs2006/2006483.pdf>

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## Introduction

Health Literacy is a significant public health issue. Many institutions have addressed the problem of low health literacy: the Institute of Medicine (IOM), the U.S. Department of Health and Human Services (HHS) - including the Indian Health Service (IHS), and the American Medical Association (AMA), to name a few. According to the U.S. Department of Education, Institute of Education Sciences, 2003 National Assessment of Adult Literacy, “Seventy-seven million adults have basic or below basic health literacy. More than a third of adults were in the basic (47 million) and below basic (30 million) health literacy groups. The majority of adults (53 percent) had intermediate health literacy skills.”<sup>3</sup>

The IHS recognizes that these statistics include many American Indian and Alaska Native (AI/AN) people. While low health literacy affects people from all facets of life, it is disproportionately burdensome on vulnerable populations, such as AI/AN people.

Persons with limited health literacy skills make greater use of services designed to treat disease complications and less use of services designed to prevent complications. The primary purpose of this paper is to focus the issue of the need to improve health literacy on the AI/AN population.

## What is Health Literacy?

In developing “[Healthy People 2030](#),” the HHS Secretary’s Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2030 expanded Healthy People’s view on health literacy. After carefully considering all input and suggestions, the Definitions Committee drafted two new definitions that together constitute health literacy that the Health Communication and Health Information Technology Workgroup and the Health and HHS Health Literacy Workgroup endorsed.

- **Personal health literacy** is the degree to which individuals can find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

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<sup>3</sup> AHRQ Health Literacy Universal Precautions Toolkit. Content last reviewed September 2020. Agency for Healthcare Research and Quality, Rockville, MD. <https://www.ahrq.gov/health-literacy/improve/precautions/index.html>

- **Organizational health literacy** is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others (US. Department of Health and Human Services and Office of Disease Prevention and Health Promotion (n.d.). *History of Health Literacy Definitions*. Healthy People 2030).<sup>4</sup>

Health literacy should not be confused with literacy; in fact, health literacy depends on many variables and is not necessarily related to years of education or general reading ability. Health literacy requires the patient to follow instructions, analyze the given information, and make well-informed decisions in health situations. Health literacy includes, but is not limited to, accessing services, reading prescription labels, properly taking prescription medication, and filling out medical forms.

Organizations have the responsibility to make it easier for patients to access clear understandable information, to be able to navigate the health system and know how to access services, to be engaged in the health care process, and to manage their health. Navigating the health care system is complex, and the demands on patients is steadily increasing (McCray, 2005). Every day, the medical community expects patients to describe their symptoms accurately, weigh the risks and benefits of various procedures, interpret test results, and understand spoken and written medical advice about treatment directions. For patients with low health literacy, seeking health care can be overwhelming.

## The Pervasiveness of the Problem

### Health literacy statistics

A 2003 U.S. National Assessment of Adult Literacy (NAAL) revealed that 36 percent of Americans had basic and below introductory health literacy rates (Hersh, Salzman, & Snyderman, 2015). Furthermore, some population groups are more likely than others to experience limited health literacy. For example, according to the [HHS National Action Plan to Improve Health Literacy](#), the following populations are most likely to experience limited health literacy:

- Adults over the age of 65 years
- Racial and ethnic groups other than White
- Recent refugees and immigrants
- People with less than a high school degree or General Educational Development

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<sup>4</sup> CDC Health Literacy [What Is Health Literacy? | Health Literacy | CDC](#)

- People with incomes at or below the poverty level
- Non-native English speakers (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010).

As an example of how some of these factors may affect the health literacy of AI/AN populations, education levels vary by race and ethnicity. For instance, according to the National Center for Health Statistics, report showed that the adjusted cohort graduation rate for 2021-2022 school year was lower for AI/AN at 74 percent, compared to 81 percent for Blacks, and 83 percent for Hispanics. The Nation's Report Card (2019) showed that among 12th-grade students, 77 percent of American Indians and Alaska Natives scored below proficient in reading compared to 53 percent of Whites, 83 percent of Blacks, and 75 percent of Hispanics. The report also showed that for education as a whole, adults with less than a high school education are approximately 16 times more likely to be assessed at a below-basic health literacy level than adults with a bachelor's degree or higher.

### How to determine basic or below-basic health literacy

There are numerous methods developed to test the literacy skills of patients that take time to administer. Murphy et al. (1992) noted that one of the most popular tests is the Rapid Estimate of Adult Literacy in Medicine (REALM). The REALM tests the patient's ability to pronounce 66 common medical words and lay terms for body parts and illnesses, and is administered in less than two minutes. Other tests include the Newest Vital Sign (NVS) or Test of Functional Health Literacy (TOFHLA; Rathnakar, 2013). However, administering tests is not the best way to evaluate patients in a medical setting, as it may discourage patients from seeking necessary medical treatment.

Past studies identified less direct evaluations of a patient's literacy skills (Murphy et al., 1992). Some of the less direct methods used to identify patients with low literacy skills include the following:

- Hand the brochure to the patient upside down and see if they correctly align the page to read it.
- Ask the patient if the print on the brochure is clear enough to read.
- Determine if the patient entirely and correctly completes registration forms or other forms.
- Notice if the patient gives excuses when asked to read something (e.g., forgot reading glasses, has a headache).
- Observe if the patient gives medical brochures or materials to the person accompanying them.
- Verify the patient can describe how to take medications.

The best practice is to implement health literacy universal precautions by assuming that all patients may have difficulty understanding and accessing health services (Agency for Healthcare Research and Quality (AHRQ) Health Literacy Universal Precautions Toolkit). Using plain (everyday) language and confirming patient comprehension, helps to improve the patients' ability to navigate the clinic and/or hospital, and supports the improvement of patient health literacy and patient health.

## Impact on the Health Care System

### Health and cost implications

Research shows a correlation between health literacy and health outcomes (Kutner et al.,2006). Limited health literacy is associated with less use of preventive services (e.g., mammography and cancer screenings); less controlled management of chronic conditions (e.g., diabetes and high blood pressure); and self-reported lower overall health. Additionally, limited health literacy is linked to an increase in preventable hospital visits and admissions. The net effect of low health literacy-related outcomes on the U.S. economy is estimated to be in the range of \$106 billion to \$238 billion annually (Vernon et al., 2007).

### Implications for American Indian and Alaska Native populations

In a blog post, Madhavan, (2017) states, “because health literacy is closely linked to poverty, AI/ANs are disproportionately impacted. According to the 2016 American Community Survey, the median household income was \$39,719 for AI/AN households and \$63,155 for Non-Hispanic White households, and 21.74 percent of AI/AN households lived below the Federal Poverty Line, compared to 6.36 percent for Hispanic White households.”<sup>5</sup>

In addition, AI/AN populations have experienced significant health disparities compared to other Americans resulting in lower life expectancy and greater disease burden. According to the Centers for Disease Control and Prevention (2023), AI/AN populations have higher rates of chronic diseases than other ethnic groups in the U.S. For example, the AI/AN population are twice as likely to be diagnosed with diabetes, have a greater prevalence of obesity, and are more likely to be smokers. Another research conducted by Schillinger et al. (2002) supported that “among primary care patients with type 2 diabetes, inadequate health literacy is independently associated with worse glycemic control and higher rates of retinopathy. Inadequate health literacy may contribute to the disproportionate burden of diabetes-related problems among disadvantaged populations.” Researchers van der Gaag et al. (2022)

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<sup>5</sup> [Health Literacy and American Indian/Alaska Natives – Region 5 Blog \(nnlm.gov\)](#)

concluded that “some clear difficulties of patients with limited health literacy emerged, predominantly in the area of medical management (especially adherence), communication, and knowledge.”

## Cultural diversity

When there is a significant gap in cultural understanding between patients and health care providers, the communication of health care information may be adversely affected. Cultural and language difference interact with and contribute to low health healthy literacy (Shaw, et al., 2009). Research have shown that materials that are written at lower grade level for the general population may improve understanding; however, individuals from diverse population may not comprehend the material if the Western constructs of health and health care is assumed (Andrulis & Brach, 2007). To improve minority health, medical professionals need to understand that cultural beliefs play an essential role in health care (Williams et al., 1998). Failure to consider how a person’s culture will influence their actions may severely compromise communication and, ultimately the effectiveness of the care provider’s message. Some believe that providing information in a culturally relevant context will make the message more persuasive, while others think it will make the information more interesting for the patient (Kreuter et al., 2003). Making health information culturally relevant to the patient will make it more likely to be genuinely considered by the patient.

## Communication

Improving communication between patients and health care professionals is one of the best ways to combat low health literacy. Several online resources are available for health care professionals to improve patient communication, including the “HHS Think Cultural Health” and the “AHRQ Health Literacy Universal Precautions Toolkit, 3rd Edition.” The “HHS Think Cultural Health” training focuses on effective communication with culturally and linguistically diverse patients, while the “AHRQ Health Literacy Universal Precautions Toolkit (2024)” has a broad approach, highlighting four key drivers for improving health literacy, as follows: (1) improve spoken communication; (2) improve written communication; (3) improve self-management and empowerment; and (4) improve supportive systems.

As a communication skill example, the Universal Precautions Toolkit strongly recommends that health professionals use a communication technique called the teach-back method. With this method, after a health care professional explains a topic to a patient, the health care professional asks the patient to teach it back in the patient’s own words. This may allow the patient to clarify what they understand about the health topic and allow the health care professional an opportunity to assess the patient’s



understanding. This method and the Toolkit, in general, are designed to ensure that patients have access to accurate health information that they understand and can act upon.

Specific to communication with AI/AN populations, the National Resource Center on Native American Aging held a seminar with health professionals and Native Elders to discuss improving health literacy and communication. The summary report from this meeting provides strategies for healthcare professionals to improve communication with their patients (Center for Rural Health, n.d.). The advice is as follows:

From the health care professionals:

- Plan what to say in logical order one step at a time
- Use pictures and illustrations
- Define health care terms and explain acronyms
- Verify understanding: rephrase the message and have the patient explain instructions back to you (teach-back method)
- Adjust to patient needs
- Encourage participation
- Pay attention to non-verbal communication: What is the patient not saying?

From the Elders:

- Provide more time and allow for interaction
- Help elders form questions: What would you want to know if you were in their shoes?
- Be positive. Native healers are positive and supportive that a remedy will work.
- Define anatomy using patient-friendly terms
- Deal with biases (e.g., fear of doctors, denial, anger, etc.)
- Be attentive to non-verbal communication (e.g., silences, gestures). Eye contact may be considered rude.

Using simple language, the teach-back method, and addressing the patients' fears and needs will improve the patient's understanding and compliance with instructions (AHRQ Health Literacy Universal Precautions Toolkit, 2020).

### Appropriate written materials

Written materials can be an excellent supplement to oral communications to share with the patient and communities. Unfortunately, authors write most materials three to four grade levels above the reading

level of most patients. The Federal plain language guidelines (2011) provides recommendations for creating effective written materials, such as the following:

- Write for your audience
- Organize the information
- Choose your words carefully
- Use pictures and illustrations
- Be concise
- Keep it conversational
- Design for reading
- Follow web standards
- Test your assumptions

Wilson et al. (2003) supported that, specific to the audience, it is important for written materials to recognize the healing systems, practices, and food preferences or diet restrictions unique to minority groups.

### Indian Health Service Strategic Plan

The mission of the Indian Health Services is to *raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level*, and health literacy is evidenced in the following health quality and health communication goals of the IHS Strategic Plan fiscal year 2019-2023:

- Objective 2.2: *Provide care to better meet the health care needs of American Indian and Alaska Native communities* is centered on culturally responsive health care that is patient-centered and community-supported.
- Objective 3.1: *Improve communication within the organization with Tribes, Urban Indian Organizations, and other stakeholders, and with the general public* to address the critical need to enhance health-related outreach and education activities for patients and families (Indian Health Service Strategic Plan, 2019).

### Indian Health Services Health Literacy Call-To-Action Plan

Using available demographic and socioeconomic data, the IHS recognizes that low health literacy is disproportionately burdensome for AI/AN populations – especially for elders. It is clear that no single action and no single program can tackle this issue. .

This Call-To-Action is intended to continue the important discussion on how to improve health literacy to ensure we provide and communicate clear information to the AI/AN populations we serve. To meet health literacy challenges, we identified five priorities to improve health literacy:

- 1) Integrate health literacy into strategic planning, current initiatives, programs, and grant awards. Identify where health literacy could improve patient understanding of information and services that support their health and wellness.
- 2) Increase and improve patient-centered resources. Deliver person-centered health information, promote self-care management skills, resources, education, and support for patients to make informed health decisions.
- 3) Encourage clinics, hospitals, and community health programs to adopt health literacy universal precautions. Since we do not know the literacy level of each patient, the best approach is to treat all patients as if they are at risk of not understanding health information. Use plain language (everyday words) to communicate with patients and their families.
- 4) Recognize teams and individuals who are advancing health literacy. There are individuals and teams who are influencing change by implementing innovative, practical, effective solutions, and effective communications to reach those with limited health literacy.
- 5) Adopt and use health literacy best practices across all verbal, written, and visual communication that is appropriate for AI/AN populations. It is important to use plain language that people can understand to make informed decisions about their health.

## Resources

Name	Description
<a href="#">Federal Plain Language Guidelines</a>	Training and resources for writing plain language.
<a href="#">National Institutes of Health - Plain Language Training</a>	Self-guided plain language training is available through an online learning module and the HHS Learning Portal.
<a href="#">Agency for Healthcare Research and Quality - Health Literacy Universal Precautions Toolkit</a>	The toolkit offers primary care practices a way to assess their services for health literacy considerations, increase patient understanding of health information and raise the awareness of the office about the use of health literacy principles.
<a href="#">Office of Minority Health, HHS, Think Cultural Health Training</a>	Continuing education e-learning programs, each designed to help you provide culturally and linguistically appropriate services (CLAS).
<a href="#">IHS Health Literacy</a>	Website with IHS health literacy training video as well as links to additional resources.

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