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Enhancing Assessments and Reducing Disparities

Claude Lopez, Bumyang Kim, and Katherine Sacks

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Introduction

Literacy plays a central role in health and health care. A person's level of health literacy influences their health-related behaviors along with their ability to navigate the complexities of the health-care system. The level of health literacy of individuals or communities often mirrors disparities in society. Low health literacy is frequently associated with other determinants: social and economic factors that reinforce health inequities. To close the gaps, ensuring adequate health literacy throughout a population is a priority of public health policy.

National and international bodies acknowledge such a necessity: WHO identified health literacy as key to achieving its goals in the 2030 Agenda for Sustainable Development. Similarly, the US Department of Health and Human Services (HHS) has included improved health literacy as a target in its decennial *Healthy People* reports since 2000 (National Center for Health Statistics, 2001; UN Department of Economic and Social Affairs, 2015).

Yet, as this report for the US will show, more needs to be done. Our systematic review of studies, surveys, and indicators provides a comprehensive overview of the US health literacy landscape. After examining the definitions, types of measurements, and initiatives and programs focused on health literacy, we identify three areas we believe should be priorities in the development of policies to tackle health literacy in the US. Finally, we offer a set of recommendations for moving forward.

These recommendations can be summarized as follows:

- **We need a systematic and recurrent population-wide assessment of health literacy in the US.** Building on similar assessments from other countries, the survey should take account of the US population's cultural and linguistic diversity to provide an objective picture of needs. This assessment will help in monitoring the effectiveness of new policies. It should focus on individuals and organizations, as both are essential and complementary in efforts to enhance the overall level of health literacy in American society.
- **We need user-friendly technology to enhance the usability of the information shared.** Easy accessibility of the technology—having access to a computer or a phone and to a network and knowing how to use it—is essential to ensure that technology contributes to the solution rather than aggravating inequities.
- **Improving health literacy requires more than just sharing information with patients and the public.** It involves the participation of the entire ecosystem around the targeted population. From ongoing training of health-care providers (HCPs) on topics such as cultural appropriateness to leveraging existing community networks, effective health-information sharing must be tailored to an audience's needs and designed to engage the audience's attention.

What Is Health Literacy?

The concept of health literacy—distinct from conventional literacy and essential to determining individual health—first gained traction in the 1970s, and health-literacy studies burgeoned in the 1990s (Quaglio et al., 2016; Xie, 2012). A widely accepted definition, cited in *Healthy People 2020*, 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” (Ratzan and Parker, 2000, vi). Table 1 lists other common definitions.

Table 1. Health Literacy Definitions

Author	Definition
Nutbeam (1998)/WHO (1998)	“Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.”
AMA Ad Hoc Committee on Health Literacy (1999)	“Health literacy is a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment. Patients with adequate health literacy can read, understand, and act on health care information.”
Ratzan and Parker (2000) cited in <i>Healthy People</i> (2010, 2020)	“...the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”
Berkman et al. (2010)	“The degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions.”
Sørensen et al. (2012)	“Health literacy is linked to literacy and entails people’s knowledge, motivation and competencies 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.”
<i>Healthy People</i> (2030)	“Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.” “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.”

Source: Milken Institute (2022)

Within the broader concept of health literacy, subdefinitions divide different elements of health literacy into their distinct parts. Don Nutbeam (2000) devised the best-known taxonomy, which identifies three aspects of health literacy: functional, communicative, and critical.

Functional health literacy, the narrowest definition, refers to reading, writing, and numeracy skills necessary to make everyday health decisions. It includes “the ability to perform basic reading and numerical tasks required to function in the healthcare environment...[to] read, understand, and act on health care information” (AMA Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999, 553).

Communicative or interactive health literacy refers to “more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances” (Nutbeam, 2000). This type of health literacy depends on the ability to read, write, and demonstrate effective inter-personal skills; it acknowledges the patient-provider relationship. A person’s health literacy is thus context-dependent, relying on the individual’s skills and ability to interact with the health system.

Critical health literacy requires “more advanced cognitive skills which, together with social skills, can be applied to critically analyze information, and to use this information to exert greater control over life events and situations” (Nutbeam, 2000). Much like communicative health literacy, critical health literacy depends on the individual’s characteristics and interactions with the environment. Health literacy is a prerequisite for a deeper understanding of health determinants and changing attitudes.

The definitions of both communicative and critical health literacy emphasize that health literacy is not an individual construct but depends on the system in which a person is making health-care decisions (Berkman et al., 2010). As a result, initiatives focusing on the community dimension, such as the cultural and linguistic environment, could improve these health literacies even if the underlying individual knowledge and ability (i.e., functional literacy) remained unchanged (Guzys et al., 2015). Similar efforts by institutions and health-care organizations can “help stakeholders find their way in the health system and support those people with limited individual health literacy” (Rathmann et al., 2020).

Health-literacy definitions have been expanding more and more to include the context in which an individual is making health decisions and receiving care. *Healthy People 2030* extended the definition to include organizational health literacy, emphasizing the responsibility of providers and health-related organizations to disseminate understandable information and eliminate health inequities (HHS, 2022a).

Why Is Health Literacy Critical?

When people have access to accurate, easy-to-use information, they can protect and promote their health by adopting healthy behaviors and following recommendations. Proficiency in health literacy improves health status, reduces health-service use and costs, and extends lives. Yet according to population-level estimates from 2003, the most recent available, 88 percent of US adults had limited health literacy (Kutner et al., 2006). Seventy-seven million Americans have

difficulty attempting to use health services, obtain quality care, and maintain healthy behaviors because their health literacy is inadequate (Polster, 2018).

Low health literacy can interact with established determinants of poor health, leading to adverse health outcomes (Mantwill et al., 2015). Inadequate health literacy results in lower adherence to preventive behaviors, weaker compliance with health interventions, and poor self-care (Kalichman et al., 2008; Lee et al., 2010b). People with low health literacy are more likely to be admitted for extended hospital stays, experience avoidable readmissions, and undergo unnecessary emergency care (Baker et al., 1998; Berkman et al., 2011; Cho et al., 2008). When groups with high and low health literacy were compared, limited literacy resulted in 6 percent more hospital visits and in hospital stays that were longer by two days. Patients with limited health literacy could expect to spend an additional \$143 to \$7,798 per year, or 3-5 percent of total health-care costs (Eichler et al., 2009). Increased spending associated with low health literacy cost the US economy up to \$238 billion every year, or 17 percent of all personal health-care expenditure (Vernon, 2007).

Health literacy is an intermediate social determinant of health in a model where individual-level characteristics interact with context-dependent determinants and structural attributes of complex health-care delivery systems. Health literacy also potentially moderates the relationships between health status and other social determinants of health (Logan, 2017). Thus, health literacy is a vital predisposing factor associated with people's divergent characteristics and health-care delivery settings.

Health literacy is closely related to health equity, and promoting health literacy has broader socioeconomic and complicated policy implications. Disparities in health literacy are disproportionately widespread among vulnerable populations, and addressing health literacy among those groups is fundamental to improving health status within and across communities. Lower levels of health literacy disproportionately affect older adults and those with limited English proficiency. Socioeconomic factors are also at play, as populations with lower incomes and educational attainment have lower health literacy, as do medically underserved people. With the use of evidence-based research, developing effective and efficient interventions for lower-health-literacy populations can resolve health disparities and inequities (Nutbeam and Lloyd, 2021; Villaire and Mayer, 2009). Improving health literacy is critical to achieving the objectives of the US national health agenda.

Improving Health Literacy in the US

Measures Available

The health-literacy problem is not necessarily visible or measurable; many people may conceal their limited health literacy out of embarrassment. Even people who are proficient in health literacy experience difficulties with the complicated architecture of the health-care system. Efforts to identify those with lower health literacy occur in the differing contexts of clinical evaluations and population sampling.

Clinical and diagnostic tools were developed for use by HCPs in the clinical setting, helping them tailor care based on a patient's ability to comprehend health information. These instruments, by necessity, consist of just a few questions or items, as they are intended for use mainly in the professional setting. The tools generally measure functional health literacy, focusing on patients' prose literacy, comprehension, and occasionally numeracy.

Of 217 instruments listed in the Health Literacy Tool Shed (an online database of health literacy measures), the following seven are most commonly used (see Appendix, Table A for more detail):¹

- Rapid Estimate of Adult Literacy in Medicine (REALM); revised 2003 (REALM-R) (Davis et al., 1991, 1993; Bass et al., 2003)
- Test of Functional Health Literacy for Adults (TOFHLA) (Parker et al., 1995; abbreviated version 1999, S-TOFHLA; Baker et al., 1999)
- Newest Vital Sign (NVS) (Weiss et al., 2005)
- Chew items, e.g., Brief Health Literacy Screen (BHLS) (Chew et al., 2004); Single Item Literacy Screener (Morris et al., 2006)
- eHealth Literacy Scale (eHEALS) (Norman and Skinner, 2006b)
- Health Literacy Questionnaire (HLQ) (Osborne et al., 2013).

Most questionnaires measuring health literacy were developed in English, although several have been translated into other languages. Despite wide availability, most of these instruments have not been validated for use in non-English-speaking populations. It has not been demonstrated that the translations have the same ability to evaluate health literacy in foreign languages as in English.² More recent instruments such as the Short Assessment of Health Literacy—Spanish and English and the Comprehensive Health Activities Scale have been developed for evaluations in languages other than English (Lee et al., 2010a; Curtis et al., 2015).

¹ Agency for Healthcare Research and Quality (2019a); Baker (2006); Cudjoe et al. (2020); Haun et al. (2014); Health Literacy Tool Shed (2022); Pleasant et al. (2011; 2019).

² A notable exception is eHEALS, which was validated in multiple languages (Chinese, Japanese and Dutch) and for different age groups, chiefly those older than 50 (Koo et al., 2012; Mitsutake et al., 2011; van der Vaart et al., 2011, Chung and Nahm, 2015).

Screening instruments are either self-reported or assessment-based. Self-reports ask patients to evaluate their own ability to understand health information with questions about, for example, their confidence in understanding information or how often they require help in following health instructions. On the other hand, assessment-based screeners are more objective evaluations of skills, asking patients to complete certain tasks and checking them for accuracy, or asking patients to indicate on a list the terms with which they are familiar.

Population samples are larger-scale attempts to measure health literacy in groups rather than individuals. These efforts, typically conducted for research purposes, are outside of patient-clinician interactions. Regrettably, much research has been conducted by simply deploying the health literacy instruments discussed above on a larger scale to measure health literacy in populations. However, because these tools were developed for use in the clinical setting, their validity for measuring functional health literacy in broader populations, rather than individuals, is questionable. The only national data currently available on the health literacy of the US population date from 2003.

The 2003 National Assessment of Adult Literacy (NAAL), conducted by the US Department of Education, assessed conventional literacy in a representative sample of 19,000 US adults (ages 16 and older) who spoke either English or Spanish with at least some English. Distinct from other population literacy assessments, NAAL included a section on health literacy that examined measures of quantitative, prose, and document literacy related to three health-care domains: clinical, preventive, and navigation of the system. Prior and subsequent population literacy assessments neglected to assess skills specifically related to health literacy. However, the latest population-level assessment of adult literacy, the Program for the International Assessment of Adult Competencies (PIAAC), includes background questions on health information-seeking behavior.³ Questions are drawn mainly from the background questionnaire of the NAAL and deal primarily with how often participants use various media as sources of health information (Hogan et al., 2016).

The Medical Expenditure Panel Survey is an alternative source for health literacy information (AHRQ, 2019b). Although not designed to provide objective information about the literacy skills of the population, this nationally representative survey by the AHRQ evaluates patients' experience of communications with HCPs. Respondents assess their experiences with language and information disseminated by HCPs and rate their level of understanding of the health information they received.

Health Literacy among Adults in the US

Surveys and assessments have repeatedly shown that health literacy among adults is strongly associated with other determinants of health disparities. Interactions with the health-care system are shaped by age, gender, race/ethnicity, religion, socioeconomic status, and language

³ The PIAAC was conducted in the U.S. between 2012 and 2017, with a second cycle scheduled to be conducted between 2022 and 2023. The assessment aims to capture measures of literacy, numeracy, and problem solving in more than 30 countries (Hogan et al., 2016; National Center for Education Statistics, n.d.; OECD, n.d.).

proficiency. Mismatches between individual culture and the health-care system can manifest as low health literacy and influence health disparities.

The key findings from representative population data and non-representative research are: ⁴

- At least 88 percent of adults living in the US have health literacy inadequate to navigate the healthcare system and promote their well-being (55 percent intermediate proficiency, 22 percent basic proficiency, and 14 percent below basic proficiency); only 12 percent are proficiently health literate.
- Adults with lower health literacy are more likely to return incomplete medical forms/assessment tools, miss appointments with health providers, and neglect follow-ups to required medical procedures.
- Adults at greater risk for low health literacy have difficulty explaining the purpose of preventive, diagnostic, and therapeutic procedures, and in reading the names and labels of prescribed medications.
- Adults with lower health literacy tend to postpone communications with health providers and have difficulty maintaining consistent medical histories.

More specifically, a review of the literature reveals the following factors contribute the most to health literacy:

Age: Those aged 65 and older have the lowest health literacy with the highest proportion of “below basic” level and the lowest “proficiency” (Figure 1A). Health literacy is higher among adults aged 25-39 than those 18-24, but tends to decrease after age 40. Older age is a stronger predictor of health literacy than socioeconomic status; health literacy is lower even for older adults with high levels of education and good health. Age-related decline in cognition is the likeliest reason for declining health literacy, rather than loss of vision or vocabulary. Older adults experience a growing disadvantage in adopting digital health resources.

Gender: Women are slightly more health literate than men overall (12 percent vs. 16 percent below basic competency).

Race/ethnicity: Adults identifying as Hispanic demonstrate the lowest health literacy of all groups examined (Figure 1B). White and Asian/Pacific Islander adults have higher average health-literacy levels than other racial/ethnic groups.

Culture: Adults who spoke only English at home before schooling have higher health literacy. In contrast, those who spoke only Spanish at home before schooling have the lowest average

⁴ Evidence from nationally representative data comes from Kutner et al., 2006; Cutilli and Bennett, 2009; Martin et al., 2009; Ownby et al., 2012; Rasu et al., 2015; Rikard et al., 2016; White and Dillow, 2005; Yin et al., 2009. Evidence from smaller studies on populations of interest, meta-analyses, and systematic reviews comes from Aghazadeh and Aldoory, 2020; Aguirre et al., 2005; Aljassim and Ostini, 2020; Baker et al., 2000; CDC, 2009; Davis et al., 2020; Latteck and Bruland, 2020; Liu et al., 2020; McKee et al., 2015; O'Neill et al., 2014; Stormacq et al., 2019.

health literacy of any population covered by the NAAL. In the African-American community, lower health literacy is more common among those with stronger religious beliefs.

Socioeconomic status: Health literacy increases with income and education level (Figure 1C). The lack of a high school diploma is associated with lower health literacy scores, on average, than living below the poverty line.

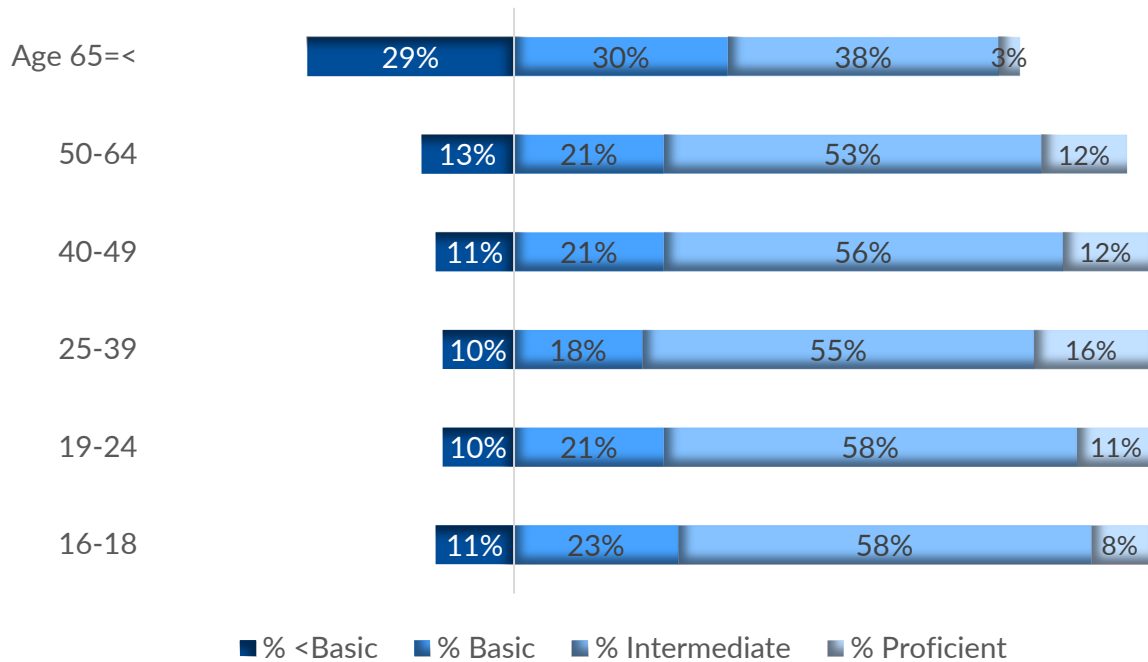
Health-insurance coverage: Americans with employment-based, military, or private insurance have higher health literacy on average than adults covered by Medicare or Medicaid or without insurance (Figure 1D).

Source of health information: Adults scoring lower in health literacy are more likely to obtain health information from non-print media (radio, television) and less likely to use printed/written sources (newspapers, internet). More health-literate adults are likely to communicate with and receive information from an HCP. People with proficient or intermediate health literacy are more likely to seek healthcare information from a variety of sources.

Health, social, and demographic factors have compounding effects. Minority populations, in particular, are vulnerable to the effects of low health literacy in old age. Health literacy is also associated with social factors related not to demographics but rather to social capital and practices, such as library use and voting. Health literacy is also positively correlated with self-reported health status; those who perceive themselves as healthier are more likely to have higher health literacy. Of those who rate their health as “poor” (the lowest category), 42 percent have health literacy below the basic level.

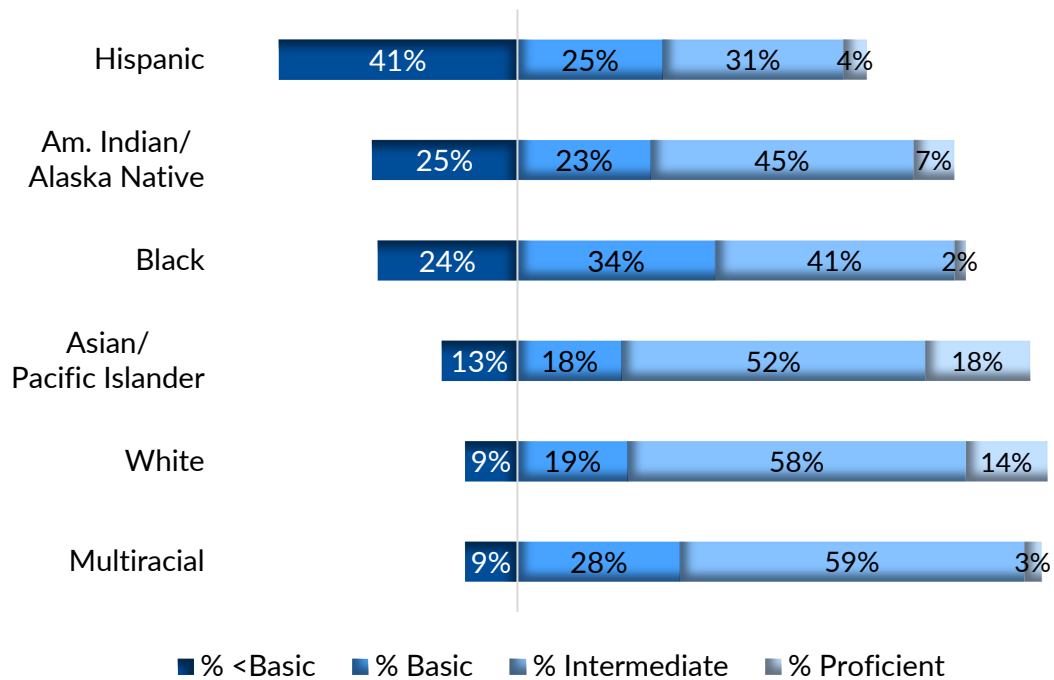
In Figure 2, the distribution of score gaps by all factors evaluated in the NAAL study shows that low health literacy is often associated with social disadvantage. Factors such as place of residence, race, ethnicity, culture, language, occupation, gender/sex, religion, education, socioeconomic status, and social capital play pivotal roles. Health literacy is also lower in people who traditionally require accommodations from the health-care system, for example, deaf ASL users or individuals with intellectual disabilities.

Figure 1A. Percent Health Literacy Level by Age



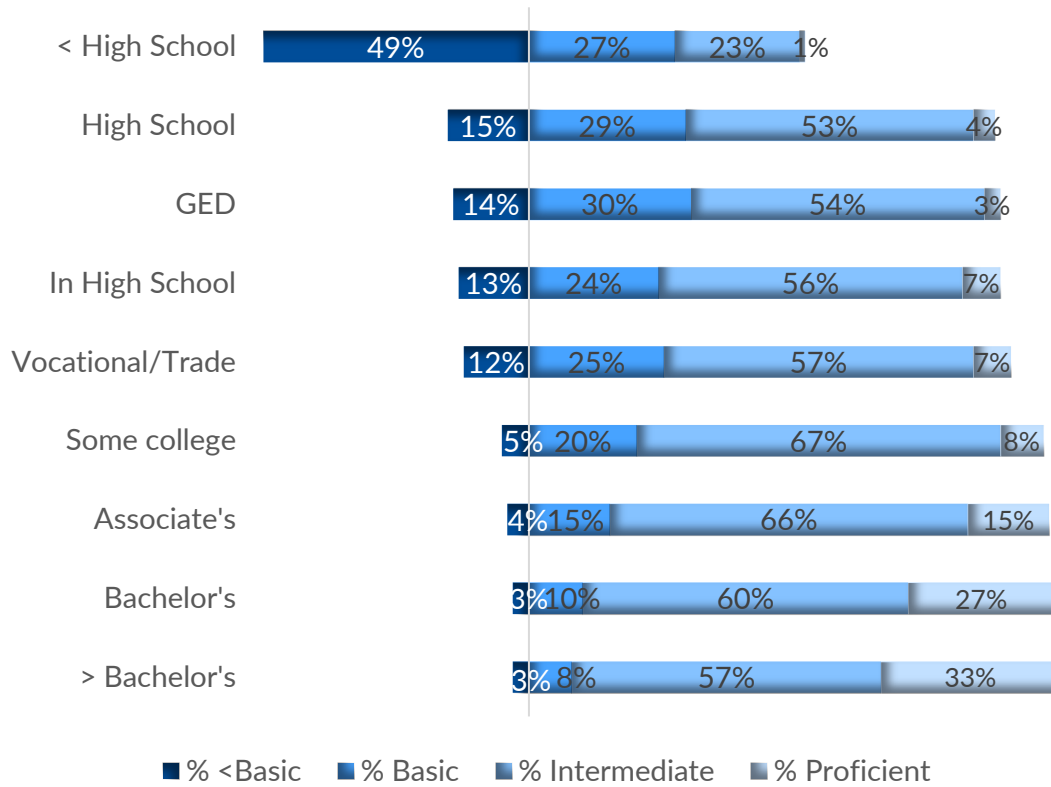
Source: NAAL (2003); Kutner et al. (2006)

Figure 1B. Percent Health Literacy Level by Race



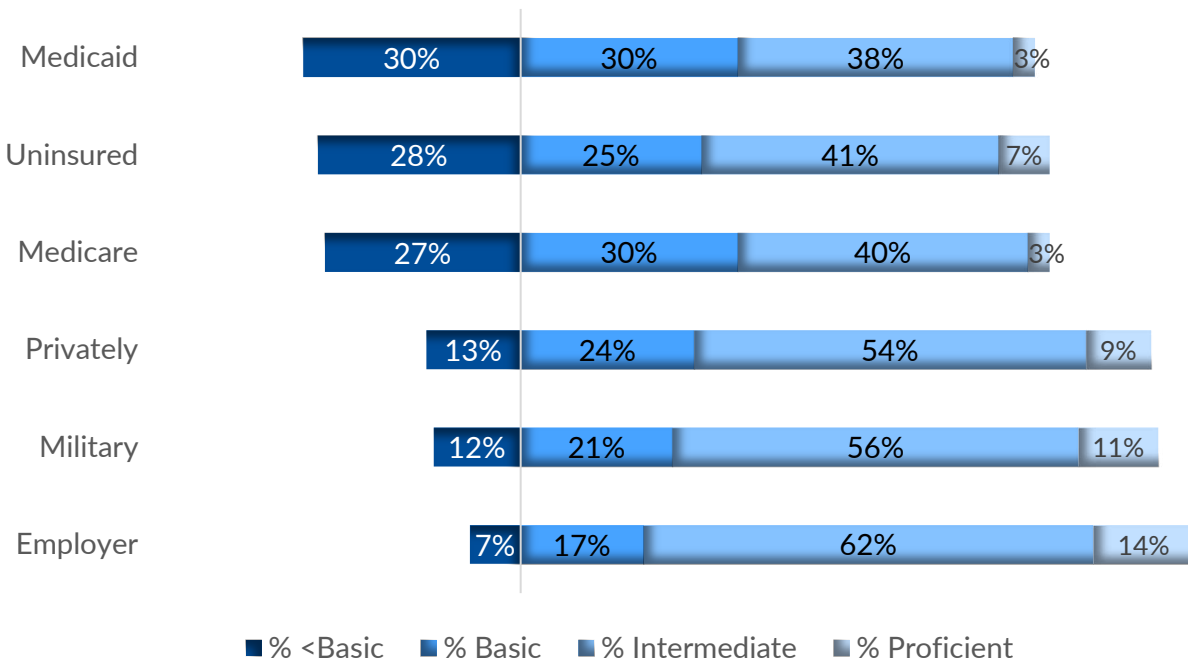
Source: NAAL (2003); Kutner et al. (2006)

Figure 1C. Percent Health Literacy Level by Education



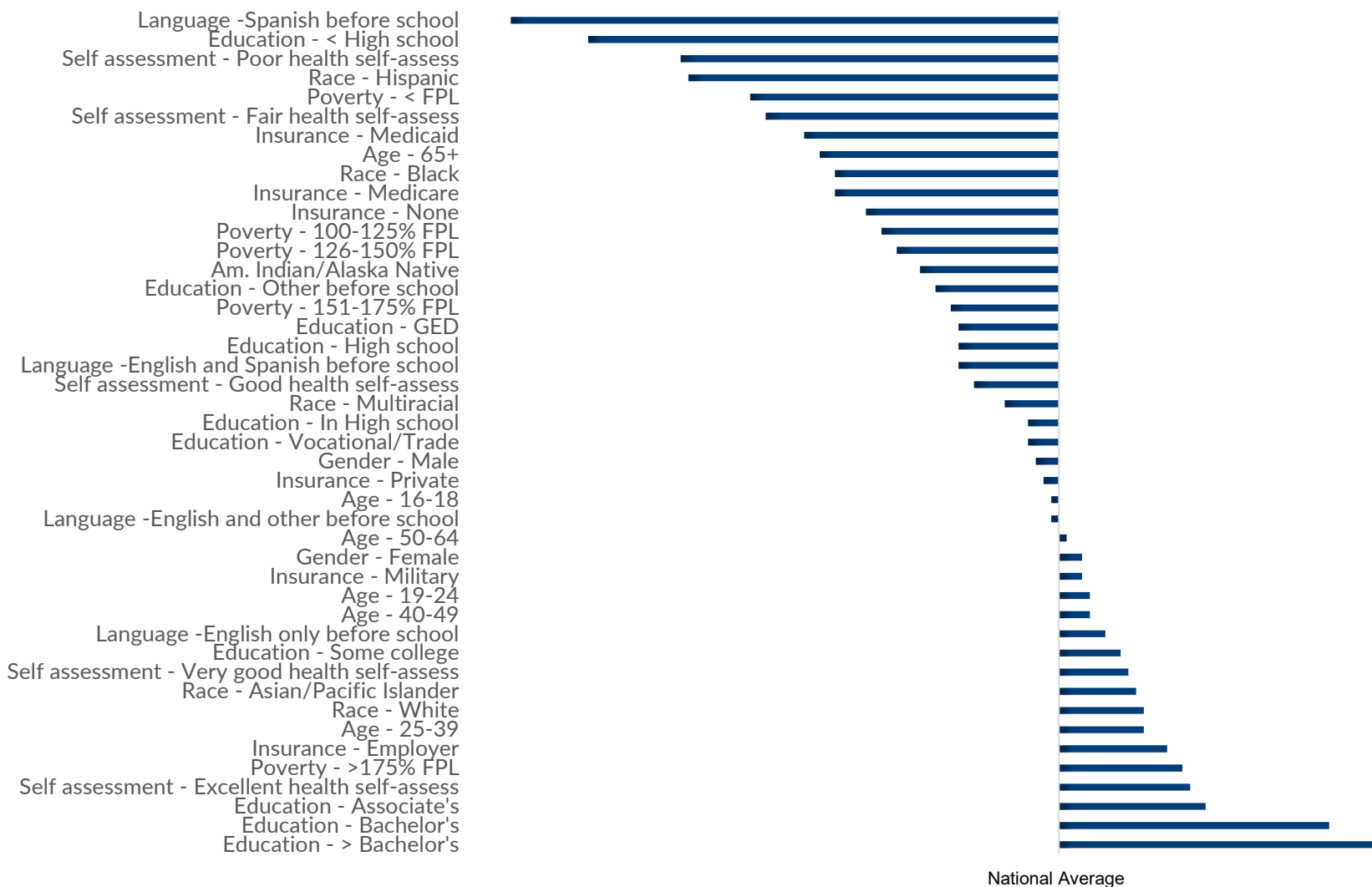
Source: NAAL (2003); Kutner et al. (2006)

Figure 1D. Percent of Health Literacy Level by Insurance



Source: NAAL (2003); Kutner et al. (2006)

Figure 2. Distribution of Health Literacy Level



Note: Estimated national average as 24.5.

Source: NAAL (2003); Kutner et al. (2006)

Efforts to Improve Health Literacy

Federal and Local Levels

Since 1980 the HHS Healthy People initiative, updated every 10 years, has set national objectives to improve the health and well-being of all Americans. Health-literacy improvement has been a part of the initiative since *Healthy People 2000* and is a central focus of the latest draft (HHS, 2010, 2021d; Tkacz et al., 2008). *Healthy People 2030* establishes six health-literacy objectives with the goal of encouraging health-care organizations to initiate strategies and develop resources for improving communication(see Appendix, Table B). The plan aims to:

- Increase the proportion of adults whose HCP checked their understanding using the teach-back or show-me confirmation method, in which providers ask people to teach-back in their own words or demonstrate the information they have been given (e.g., how they take their medicine).
- Provide system-level support for patient outreach and training to decrease the proportion of adults who report poor communication with their health providers.
- Increase the proportion of adults whose HCP involved the patient, according to their preference, in shared decision making.

In 2000, with executive order 13166 and issuance of the National CLAS Standards, the federal government established two major regulations to improve information access. According to President Clinton's executive order, all federal agencies must examine the needs of, and establish services for, persons with limited proficiency in English (HHS, 2021c). The HHS Office of Minority Health set up guidelines to promote culturally and linguistically appropriate services (CLAS): "The National CLAS Standards are a set of 15 action steps intended to advance health equity, improve quality, and help eliminate health care disparities by providing a blueprint for individuals and health and health care organizations to implement culturally and linguistically appropriate services" (HHS, 2021a).

In addition, three initiatives started in 2010 represent significant progress in health-literacy promotion at the federal level:

- Four sections of the **Affordable Care Act** directly mention health literacy. Two of them emphasize consideration of varying needs of HCPs and consumers, as well as diverse levels of health literacy (Somers and Mahadevan, 2010).
- The **Plain Writing Act, 2010**, requires federal agencies to use readily understandable, plain language in publications, including health-care communications.
- The **HHS National Action Plan to Improve Health Literacy**, echoing the Plain Writing Act, emphasizes the use of plain language by health professionals in communicating with lay persons. The plan includes practical goals (see Table 2). The Healthy People initiative sets national objectives, whereas the National Action Plan to Improve Health Literacy

“provides a blueprint for efforts to improve health literacy across all sectors involved in health information and services” (HHS, 2010).

Table 2. National Action Plan to Improve Health Literacy

No.	Goal
1	Develop and disseminate health and safety information that is accurate, accessible, and actionable
2	Promote changes in the health care system that improve health information, communication, informed decision-making, and access to health services
3	Incorporate accurate, standards-based, and developmentally appropriate health and science information and curricula in childcare 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

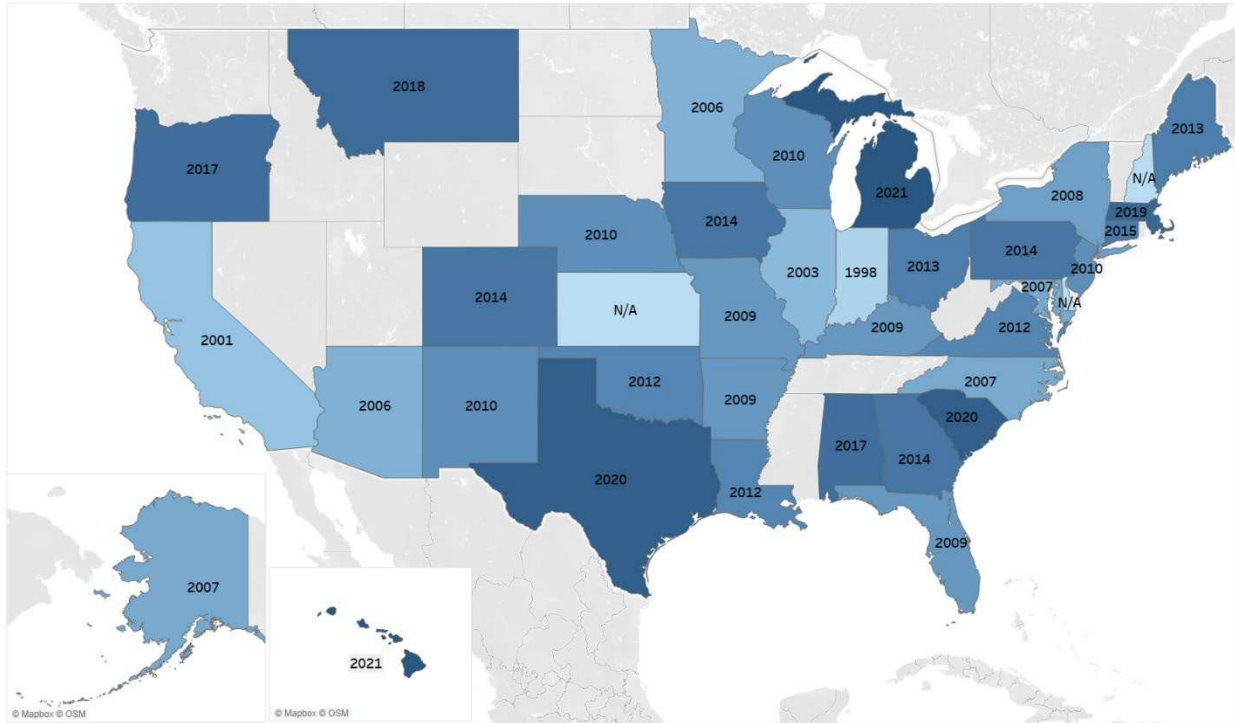
Source: CDC (2019a)

Following the National Action Plan to Improve Health Literacy, states increasingly see at least one organization targeting health literacy in their communities (see Figure 4; Appendix, Table C) (CDC 2019a, b; 2021a). More states are adopting the collaborative approach and building infrastructures to improve health literacy. State governments and agencies are developing programs at community or state levels to provide information, education, and resources on health literacy; host events for professionals in the field; and disseminate health-literacy curricula to schools and community.

Federal efforts have also focused on helping community organizations integrate health-literacy improvements. By assisting such groups, federal agencies can help them work directly with their communities to achieve the targets set out in the National Action Plan. To guide organizations in establishing Health Literacy Action Plans (HLAPs), the CDC has published a workbook template, “Making Health Literacy Real: The Beginnings of My Organization’s Plan for Action.” The template is a practical guide to making the National Action Plan and HLAPs more usable (CDC, 2021b, 2022). In March 2021, HHS announced the “Advancing Health Literacy to Enhance Equitable Community Responses to COVID-19” grant, which provides \$250 million in funding for two years for localities that partner with community-based organizations to improve the health literacy of racial and ethnic minority groups (HHS, 2021b).

The AHRQ has developed health-literacy improvement tools to guide HCPs. The tools are designed to ensure that the health-delivery system enhances patient-centered care by using the teach-back method; multilingual, simplified communication; and easy-to-understand language starting with diagnosis through admission, discharge, and follow-up care, including use of medications (AHRQ, 2020a; DeWalt et al., 2010, 2011).

Figure 4. US Health Literacy Activities by State



Source: Milken Institute (2022) ; See Table C, Appendix

Initiatives Targeting K-12 Students

Federal legislation currently governing K-12 education is the Every Student Succeeds Act (ESSA) of 2015, which mandates health and physical education as part of a student’s well-rounded school experience (Auld et al., 2020). The legislation allows states to measure school quality or success using additional or alternative metrics such as health education; it also provides increased funding for instruction in these subjects. In addition to ESSA, two major initiatives promote health literacy from K-12 through university level: the National Health Education Standards (NHES) and the Whole School, Whole Community, Whole Child (WSCC) model.

NHES, updated in 2004, is the recognized reference in health education for K-12 students to promote personal, family, and community health. The eight standards listed in Table 3 provide a framework for administrators, educators, and other stakeholders in developing a curriculum, identifying resources, and assessing progress in health literacy.

Table 3. National Health Education Standards

Standard	Description
1	Students will comprehend concepts related to health promotion and disease prevention to enhance health.

2	Students will analyze the influence of family, peers, culture, media, technology, and other factors on health behaviors.
3	Students will demonstrate the ability to access valid information, products, and services to enhance health.
4	Students will demonstrate the ability to use interpersonal communication skills to enhance health and avoid or reduce health risks.
5	Students will demonstrate the ability to use decision-making skills to enhance health.
6	Students will demonstrate the ability to use goal-setting skills to enhance health.
7	Students will demonstrate the ability to practice health-enhancing behaviors and avoid or reduce health risks.
8	Students will demonstrate the ability to advocate for personal, family, and community health.

Source: CDC (2020a)

The WSCC model, originally released in 2014, is the CDC’s framework for addressing health in schools (CDC, 2021c). The Coordinated Approach to Child Health (CATCH) model, based on WSCC, promotes physical activity and healthy food choices for children in preschool through middle school and their families. This student-centered model aligns the goals of public health and education and “emphasizes the role of the community in supporting the school, the connections between health and academic achievement and the importance of evidence-based school policies and practices.” It promotes the following 10 components to ensure that students are healthy, safe, engaged, supported, and challenged:

1. Physical education and physical activity
2. Nutrition environment and services
3. Health education
4. Social and emotional climate
5. Physical environment
6. Health services
7. Counseling, psychological, and social services
8. Employee wellness
9. Community involvement
10. Family engagement

Initiatives for Older Adults

Improving health literacy for older adults presents challenges different from those for younger populations. Among adults over age 60, 71 percent have been found to have difficulty using print materials, 80 percent had difficulty using documents (e.g., charts, forms), and 68 percent had low numeracy skills (CDC, 2020b). Besides the functional challenges in accessing traditional health information and understanding it, older adults’ ability to access information on the internet and other e-Health tools may be lower than in younger populations (CDC, 2009).

To improve health literacy among older adults, the CDC convened an expert panel on Improving Health Literacy for Older Adults in 2007 and published a report in 2009 (CDC, 2009). This panel was intended to identify health-literacy issues for this age group and provide appropriate, accessible information. The experts agreed on the following takeaways:

- Further studies are needed to identify older adults' difficulties finding and using health information.
- Health information must consider age-related changes in cognitive functioning and literacy.
- Plain-language principles must be applied uniformly to benefit public health.
- Messages should be bundled to avoid clustered/multiple information that older adults have trouble absorbing.
- Organizations should offer layered/structured information and multiple channels to reach audiences.
- The digital divide needs to be reduced by, for example, improving the quality of websites and adding e-health tools.
- Data collection should be expanded, focusing on populations with special needs (e.g., older immigrants who grew up outside the US).

The CDC also provides guidance and resources for health professionals and organizations to improve older adult health literacy by planning projects, identifying and overcoming challenges, increasing access to online information, and evaluating the effectiveness of projects (CDC, 2020b). These resources mainly focus on using plain language so that all readers, including older adults, can readily understand and effectively use the information.

Independent interventions have successfully used technology to improve health literacy for older adults. For instance, older veterans (average age of 67) at risk for cardiovascular disease who were provided with a computerized medication calendar showed improved health literacy, medication adherence, and clinical outcomes (Zullig et al., 2014).

Digital Health Literacy

The increasingly-diversified media landscape and the rise of readily-accessible social-media outlets via smartphone has made health information easily and constantly available. Further, both users and providers are taking advantage of internet-based health services and emerging technologies, including AI/machine learning, electronic communications, wearables, and apps.

Keeping abreast of the times, government agencies and health-care institutions such as the CDC and National Institutes of Health (NIH) use social-media platforms for sharing health information to complement the conventional approaches. Although public health interventions have traditionally relied on publications (written and alternative-format) and low-literacy initiatives,

the public health emergency of COVID-19 triggered increased use of targeted mass-media and social-media campaigns.

Mobile health (mHealth) technologies have emerged as a subset of eHealth and are helping to overcome structural barriers, especially for groups with limited access to care during the COVID-19 pandemic. Collecting and sharing health data through digital platforms allows for better monitoring of care and a higher quality of safe, appropriate health-service provision. Uses range from electronic health records (EHRs) to periodic engagement through personalized reminders and the flexibility of the platform language. More specifically:

- EHRs enable transparent communication before and after office visits, allowing providers to check patients' understanding of and adherence to clinical recommendations. They help ensure accuracy and reduce cognitive and administrative errors.
- Automatic reminders or messages via text or mobile app heighten awareness of the importance of regular checkups and target information based on user health profile.
- Web- and mobile-based apps for translation services can convey health information to non-English speaking patients in their native languages when live translation services are unavailable.
- User-friendly website design, increased use of visuals and plain language, and assistive technology can all render health information more accessible for people who have disabilities or difficulty with English.

Patients with higher health literacy are more likely to adopt information and communication technology and regard it as valuable and usable (Mackert et al., 2016). A systematic review of health literacy interventions found that the use of technology showed greater promise or more significant results than traditional interventions in a variety of conditions and populations (Jacobs et al., 2016).

Recognizing the advantages of digitized health information, *Healthy People 2020* expanded health literacy objectives to include health information technology in 2015. The result was the release of Health Literacy Online, a research-based guide for those looking to provide user-friendly health information and services (available at <https://health.gov/healthliteracyonline/>). Similarly, HHS, via AHRQ, has developed an easy-to-understand telehealth consent form that uses plain language to facilitate access to telemedicine. Finally, the Centers for Medicare & Medicaid Services (CMS) has developed a toolkit with plain-language manuals for clear communication. Healthcare.gov provides information to help navigate the US health insurance system.

These initiatives improve digital health literacy and eHealth—the understanding, interpretation, and use of health information from electronic sources—from two angles. They help individuals easily find health information and navigate health resources while also helping health organizations improve their delivery of digital information.

Challenges and Recommendations

Health literacy is evolving. It was first defined as an individual feature subject to interventions at the personal level. However, recent studies emphasize the importance of cultural, economic, environmental, and social factors. As a result, HHS revised the definition of health literacy for *Healthy People 2030*, stating that “[h]ealth literacy occurs when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions” (HHS, 2019).

The new definition has two main components (see A and B below). Ancker et al. (2020) focus on the interaction between these two components and add the notion of health information fluency as “the effective use of health information by those who need it”; such fluency relies on adequate personal and organizational health literacy.

A. Personal health literacy: “[T]he degree to which individuals can find, understand, and use information and services to inform health-related decisions and actions for themselves and others.”

B. Organizational health literacy: “[T]he 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” (HHS, 2021d).

Assessments of personal health literacy can use both objective and subjective measures. Objective measures in this context are performance-based, like a traditional test with participants scored according to their correct answers or how well they perform a task. Subjective measures are self-reported and rely on an individual’s assessment of difficulty understanding health information or the amount of help they need. Both performance-based and self-reported instruments are used in current clinical assessments. In contrast, measures for organizational literacy remain works in progress.

Adjusting existing tools and developing new ones are necessary to identify evolving needs and design effective, evidence-based interventions and initiatives to improve health literacy. Below, we identify the need for data and technology as two priorities in that process and offer recommendations for moving forward.

Data Drive Policies, Policies Drive Change

Addressing low health literacy requires policy change at both the individual and societal level. The 2003 NAAL remains the only population-wide health literacy assessment conducted in the US. Many countries use the European Health Literacy Survey (EU-HLS), the primary goal of which is to evaluate the health literacy level of a population or community and the evolution of such literacy in response to large-scale, specific policy interventions. The EU-HLS population-wide survey relies on a broader definition of health literacy and is conducted regularly in nationally representative samples from various countries, including non-EU nations (Appendix,

Table D; Duong et al., 2017). Use has been validated for each participating country since the initial round.

Recommendation 1: The US needs a systematic, recurrent population-wide health literacy assessment. Versions of a patient-centric or target-audience-centric survey should be validated for various languages spoken in the US and conducted via a medium that is easy to understand and use.

Adaptation of the EU-HLS to the US population would allow the collection of information about literacy levels among specific groups. Focusing on groups based on race, age, economic and social background, and other features would inform community-based policy and facilitate initiatives tailored to the needs of the communities or groups. However, unlike NAAL, the EU-HLS relies solely on self-reported assessment of one's abilities across different health-care domains (Appendix, Table D).

When it comes to measuring health literacy, efforts to assess individual understanding of health-related information must rely on simplified communication in educational sessions, the use of visual aids, and consultation focusing on populations with special needs, including needs related to language. As previously discussed, however, the NAAL and most clinical or diagnostic tools were developed for American English speakers. Several instruments are available in other languages, but measures are often translated from English and may not accurately assess health literacy.⁵

Although all literacy measures may ostensibly evaluate the same underlying concept, developing an instrument independently from its target group means losing cultural nuances. Those drawbacks limit assessments of minority populations' health literacy. This issue will only increase as US linguistic diversity grows. Currently, Hispanic immigrants, who largely come from Latin America and predominantly speak Spanish, comprise the largest immigrant population. By 2055, Asian immigrants, who bring a greater diversity of native languages, will be the largest immigrant group in the US (Lopez et al., 2015).

Recommendation 2: A companion program should focus on institutions' systematic and recurring organizational health literacy.

For organizational health literacy, the National Committee for Quality Assurance notes that the current measures rely on the Consumer Assessment of Healthcare Providers and Systems measures (AHRQ, 2021a) and have limited applicability (National Academies of Science, 2018). As an alternative, the AHRQ has “obtained consensus from experts on the usefulness, meaningfulness, feasibility, and face validity of 22 measures that can help organizations seeking to become more health literate” (AHRQ, 2020b). The next step is to require entities like health-care providers or payers to use these measures to monitor needs and improvements in

⁵ Some measures were developed and/or validated in another language, for example the TOFHLSA-S in Spanish and the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA), while other measures could not be validated in translation. Several works, such as Han et al. (2011) and Nurss et al. (1995), discuss these issues in more detail.

organizational health literacy (e.g. hospitals or insurance companies). These measures need to be complemented by benchmarks and goals, adding accountability to monitoring.

Technology: Keep It Simple

Recommendation 3: The sixth-grade reading level rule should apply to overall content to improve usability, readability, and accessibility of technology.

Technologies, essential in disseminating health information and promoting health literacy, may present new challenges to public health initiatives. Providing broad access to digital devices is a prerequisite for this digitalization of information. Yet, helping patients use them effectively is essential.

The COVID-19 pandemic and associated communication challenges highlight how misinformation can quickly spread. Social media are commonly used sources of information. They provide a user-friendly alternative to online health content and medical information from more traditional sources such as Wikipedia, the website most frequently consulted through search engines, where health information may be too complex for many readers (Kim et al., 2017; McInnes and Haglund, 2011). Unfortunately, simplification of information may come at the cost of reliability: a 2020 study found that 27.5 percent of YouTube's most-viewed English-language videos about COVID-19 conveyed nonfactual or misleading information (Li et al., 2020).

The pandemic and the shift toward eHealth disproportionately strengthen existing inequities between less digitally literate populations and those with greater knowledge and advantages (Lancet Healthy Longevity, 2021). Difficulty in effectively navigating online health information can prevent many people from taking advantage of telehealth opportunities or technologies that simplify medical communications and consultations, and support beneficial health behaviors (Neter and Brainin, 2012). AHRQ and HHS recommend simplifying all health-related communications by adhering to the sixth-grade reading level for online health-related content (Villaire and Mayer, 2009.) When clear, easy-to-understand information comes from officials and institutional sources, the need to seek out alternative sources of information is lessened.

Recommendation 4: Access to and use of technology can work hand-in-hand to improve health literacy; focusing on the patient will help tailor the information and share it.

Technology facilitates the interactions between patients, clinicians, and organizations. eHealth expands the delivery of health information by adding functions to select language options, short texts, simplified display, videos, dictionary links, and alternative text in web-based/mobile applications.

Health organizations have widely adopted EHRs to store and manage health-related information and communicate more effectively. Yet very little has been done to use these platforms to improve health literacy (Comer et al., 2018). EHRs could promote more productive engagement with patients based on their specific needs. The information stored in EHRs can help

systematically identify if a patient belongs to a vulnerable population regarding health literacy and develop tailored interventions. Using cumulative data, emerging technologies, such as platform-based cloud services and established infrastructure for 5G networks, can be combined with techniques such as data mining, AI, and machine learning to accelerate such individualization in information sharing. Finally, EHRs can easily be expanded to the community-level and customized for educational purposes, teaching people how to access, search for, and evaluate health information that is relevant to them (AHRQ, 2020c).

Facilitating Communities' Engagement

Recommendation 5: Community-based participatory research principles are fundamental to designing health-literacy interventions and programs.

The most effective interventions, especially for disadvantaged populations, share a crucial element: cultural appropriateness (Stormacq et al., 2019). Cultural appropriateness requires consideration of a community's values, beliefs, norms, and access to resources to ensure the success of any intervention in development. Socioeconomic conditions, local infrastructure, social capital, and family circumstances, to name a few factors, influence how a person or a community receives, comprehends, and uses health information.

Including cultural appropriateness ranges from making information visually appealing to its target audience, to using the audience's native language; from focusing on diseases that have a disproportionate impact on the targeted community, to accounting for local cultural values, beliefs, and availability of resources (Kreuter et al. 2003). The goal is to remove incongruence between an intervention and the target group's cultural norms and practices. The design of effective public health-literacy interventions depends on community involvement at every step of the process; use of Community-Based Participatory Research, an inclusive methodology, is valuable in building empowering and equitable community interventions.

Recommendation 6: Direct interaction with HCPs is a key channel for health communications; as a result, HCPs must have access to ongoing training that includes cultural competency and other health literacy-specific training.

Cultural appropriateness matters during interactions between HCPs and patients. Yet only 10 states require cultural competency training in continuing medical education (CME) programs as a part of their licensure requirements, although 11 are considering similar requirements (Federation of State Medical Boards, 2021; HHS, 2022c). No state currently requires specific training in health literacy; however, elective units on health literacy are becoming available.

Results of numerous studies indicate that, beyond physicians, all participants in the health-care system require health-literacy education (Baur, 2011; Polster, 2018; Singleton and Krause, 2010; Tkacz et al., 2008). Extending CLAS or health-literacy training to pharmacists, nurses, physician assistants and others in the health-care field can have an important effect.

Recommendation 7: Enlist the community to engage effectively with the target readership when sharing health information.

As well as drawing on pedagogical or behavioral-change theories, successful interventions generally combine more than one method of dissemination or point of contact. In other words, repeated exposure to, or engagement with, health information leads to better retention. Nontraditional venues such as public libraries, churches, and beauty parlors have been successfully used for distributing health information. Further, nonmedical environments can facilitate active engagement with information. An opportunity to discuss the information is helpful to understand and retain the key points; that is why the teach-back method is effective in clinical interactions.

Concluding remarks

All our recommendations are about meeting patients where they are. The call to establish periodic population assessments of US health literacy levels is necessary to understand the population's needs. The subsequent recommendations aim to increase health literacy by making the system work for patients, rather than changing any patient characteristics or abilities. Certainly, individual literacy and numeracy skills are important, and efforts to increase those should continue. Still, the stark health disparities seen in the US are the result of a health-care system that fails to work for everybody. By increasing the accessibility and usability of health information and even of health services, the recommendations in this report can hopefully reduce these disparities, allowing the health-care system to meet the needs of all people just as they are.

Appendix

Table A. Health Literacy Assessment Tools: Six Most Commonly Used

Tools	No. of items	Health literacy definition cited in the original article	Do items reflect every attribute of the definition?	Was this instrument developed for clinical use?
TOFHLA	36-37	None	N/A	Yes
REALM	7-66	None	N/A	Yes
NVS	6	"...the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan and Parker, 2000, p vi)	No	Yes
eHEALS	8	eHealth literacy comprises six core skills or literacies: traditional literacy, health literacy, information literacy, scientific literacy, media literacy, and computer literacy.	No	No
HLS-EU	47	As an outcome of health education and communication activities, health literacy represents the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health	Yes	No
Chew or BHLS	1-3	Health literacy is the ability to perform essential reading and numerical tasks required to function in the health-care environment (AMA 1999)	No; for example, no assessment or	Yes

			self-report of numeracy skills	
HLQ	44 in 9 scales	The World Health Organization (WHO) describes health literacy as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (Nutbeam, 1998, p 10)	Developed own construct map of health literacy as part of the measure development process	Yes and no

Source: Pleasant et al. (2019), Milken Institute (2022)

Table B. Six Healthy People 2030 Objectives in Health Literacy

Objectives	Baseline (Adult >=18)	Target
Increase the proportion of adults whose health care provider checked their understanding - HC/HIT-1.1	26.6 % (2017)	32.2%
Decrease the proportion of adults who report poor communication with their health care provider - HC/HIT-1.2	8.9% (2017)	8.0%
Increase the proportion of adults whose health care providers involved them in decisions as much as they wanted - HC/HIT-1.3	52.8% (2017)	62.7%
Increase the proportion of persons who report that their health care providers always listened carefully to them - HC/HIT-D10	Developmental status	
Increase the proportion of adults with limited English proficiency who say their providers explain things clearly - HC/HIT- D11	Developmental status	
Increase the health literacy of the population - HC/HIT- R01	Developmental status	

Source: HHS (2022c)

Table C. State-Level Activities on Health Literacy Promotion⁶

State	Name	Organization Type	Founded
Alabama	Alabama Health Literacy Initiative	Partnership with non-profit Alabama Health Action Coalition	2017
Alaska	The Anchorage Health Literacy Collaborative	A program of non-profit Alaska Literacy Program	2007 [♦]
Arizona	Arizona Health Literacy Coalition	Non-profit	2006 [~]
	Health Choice Arizona	A subsidiary of BlueCross BlueShield Arizona	1999 [♦]
Arkansas	Center for Health Literacy, the University of Arkansas for Medical Sciences	Academic center	2014 ⁷
	Partnership for Health Literacy in Arkansas	A section of the non-profit Arkansas Public Health Association	2009
California	Health Care Institute, University of California, Los Angeles [*]	Academic center	2001
	California Health Literacy Initiative [*]	Initiative of non-profit LiteracyWorks	2003 [♦]
Colorado	Colorado Health Literacy Coalition	Not listed or incorporated	2014
Connecticut	Connecticut State Library, Division of Library Development [*]	State library resource guide	2015
Delaware	Delaware Libraries [*]	State library resource guide	N/A
Florida	Florida Health Literacy Initiative	Initiative of the non-profit Florida Literacy Coalition and BlueCross BlueShield of Florida	2009

⁶ This list is not exhaustive; there are other organizations in many states that also work on Health Literacy. The organizations listed here are those listed by the CDC (2021a) or found through a cursory search.

[♦] For organizations whose founding date was not given on their website or found from another source, the year given is when the entity was incorporated according to state records or when its domain name was registered according to WHOIS.

⁷ UAMS Center for Health Literacy (2022).

^{*}Not included in CDC list of state activities (2021a).

Georgia	Georgia Alliance for Health Literacy	Non-profit	2014*
Hawaii	Health Literacy Research Hub: Hawai'i, University of Hawai'i at Mānoa*	Academic research guide	N/A
	Kuleana Health*	An initiative of non-profit Community First Hawai'i, the County of Hawai'i Department of Research and Development, and University of Hawai'i Hilo	2021
Illinois	Chicago Citywide Literacy Coalition*	Non-profit coalition of member organizations	2003
Indiana	International Center for Intercultural Communication, Indiana University	Academic center	1998
Iowa	Building Health Literate Organizations: A Guidebook to Achieving Organizational Change*	A resource from UnityPoint Health, a non-profit health system	2014
Kansas	A.R. Dykes Library, Medical Center, University of Kansas	Academic library guide	N/A
Kentucky	Health Literacy Kentucky	Affiliated with non-profit Kentucky Voices for Health	2009
Louisiana	Health Literacy Core, Louisiana Clinical & Translational Services*	NIH-funded center at Pennington Biomedical Research Center	2012 ⁸
Maine	Health Literacy Education and Training, MaineHealth*	Service of non-profit MaineHealth	2013*
Maryland	Horowitz Center for Health Literacy, University of Maryland	Academic center	2007
Massachusetts	Health Literacy Program, Lawrence Public Library	Public library program	2019 ⁹
Michigan	Michigan Health Literacy Collaborative	Working group	2021
	Kalamazoo Literacy Council*	Non-profit	1974
Minnesota	Minnesota Health Literacy Partnership	Program of the non-profit Literacy Minnesota (formerly Minnesota Literacy Council)	2006
Missouri	Health Literacy Media	Non-profit	2009*

⁸ NIH Reporter information for 5U54GM104940-06 6624.

⁹ Lawrence Public Library (2019).

Montana	Lifelong Learning – Health Literacy*	A resource of Montana State Library	2018
Nebraska	Nebraska Association of Local Health Directors*	Non-profit comprised of directors of local public health departments	2010
New Hampshire	Health Literacy Research Guide, University of New Hampshire*	Academic library research guide	N/A
New Jersey	Urban Healthcare Initiative Program*	Non-profit	2010
New Mexico	Health Literacy Office, University of New Mexico Health*	University health system department	2010 ¹⁰
New York	Community Health Network	Non-profit	2008
	S01407, establishing inter-agency task force on health literacy*	State Senate bill	2020-2021 (initially 2009-2010)
North Carolina	North Carolina Health Literacy, Health Sciences Library at the University of North Carolina at Chapel Hill	Academic library center	2007
Ohio	Ohio Health Literacy Partners	Non-profit	2013
Oklahoma	Oklahoma Health Equity Campaign	Collaborative group supported by state Department of Health	ca. 2012
Oregon	Health Literacy for Interprofessional Education e-toolkit, Pacific University Libraries	Academic library guide	2017 ¹¹
Pennsylvania	Pennsylvania Health Literacy Coalition	Affiliated with non-profit Health Care Improvement Foundation	2014

¹⁰ UNM Health Sciences (2022).

¹¹ Spatz (2017).

South Carolina	South Carolina Hospital Association Health Literacy Initiative	Initiative of non-profit SCHA	2020 ¹²
Tennessee	Health Literacy Education Module, University of Tennessee Health Science Center*	Academic library research guide	N/A
Texas	Health Literacy Texas	Non-profit	2020*
	SaferCare Texas, The University of North Texas Health Science Center at Fort Worth	Academic center	2016 ¹³
Virginia	Health Education and Literacy (HEAL) Program	An Initiative of Literacy for Life, a center of the College of William & Mary	2012 ¹⁴
Wisconsin	Wisconsin Health Literacy	Initiative of non-profit Wisconsin Literacy	2010

Source: CDC (2021a); Milken Institute research (2021).

¹² SCHA (2020).

¹³ Carlton (2016).

¹⁴ NRCAE (2020).

Table D. HLS-EU Health Literacy Matrix

	Access/obtain information relevant to health	Understand information relevant to health	Process/appraise information relevant to health	Apply/use information relevant to health
Healthcare	Ability to access information on medical and clinical issues	Ability to understand medical information and derive meaning	Ability to interpret and evaluate medical information	Ability to make informed decisions on medical issues
Disease prevention	Ability to access information on risk factors for health	Ability to understand information on risk factors and derive meaning	Ability to interpret and evaluate information on risk factors for health	Ability to make informed decisions on risk factors for health
Health promotion	Ability to update oneself on determinants of health in the social and physical environment	Ability to understand information on determinants of health in the social and physical environment and derive meaning	Ability to interpret and evaluate information on health determinants in the social and physical context	Ability to make informed decisions on health determinants in the social and physical environment

Source: Sørensen et al. (2013)

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