Health literacy in integrative medicine:

Key insights and strategies for supporting patient education

Note: The information provided in this report is based on a review of literature available at the time of publication. While the content is considered to be accurate at the time of publication, new or updated research released after the publication date may impact the accuracy of the information. Please use your discretion when using this resource.

Published: November 2022

Version 1.0

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Preface

As part of its mission to change how health is prescribed and help people get better, Fullscript developed this report as an extension to its white paper on Treatment Adherence in Integrative Medicine. The authors of that white paper identified health literacy as one of the key factors influencing treatment adherence. Thus, the Health Literacy Project was created to further investigate how integrative practitioners can better support patients with varying levels of health literacy.

Similar to Fullscript's work on treatment adherence and behavioral change, this white paper is also composed of a literature review and a patient survey. It provides an account of the methodology, as well as findings of the literature review and patient survey conducted by Fullscript's Integrative Medical Advisory team (IMAT) and Insights team. Unlike the treatment adherence and behavioral change reports, this white paper also includes interviews with health literacy academics, experts, and leaders.

A note on medical care terminology: For the purpose of this white paper, integrative medicine is defined as an approach where conventional and non-conventional (e.g., complementary, alternative, naturopathic, or functional) interventions are used together in a harmonized way. (NCCIH 2021) Of note, most health literacy research focuses on conventional care models. However, the findings shared throughout this white paper can be applied to integrative care models.

Acknowledgment

Fullscript would like to thank Dr. Michelle Simon, PhD, ND (president and CEO of the Institute for Natural Medicine), Dr. Robert Luby, MD (director of medical education initiatives at the Institute for Functional Medicine), and Dr. Tieraona Low Dog, MD (Fullscript advisor) for providing a clinical review of the white paper.

Disclosures

The authors of this report are employed by Fullscript as part of the IMAT and Insights team. They received no additional compensation for the production of this report and are not affiliated with any particular brands, products, or institutions. The authors aimed to provide an unbiased review of the literature in this area with the ultimate goal of providing practitioners with the knowledge and tools to help improve treatment adherence and patient outcomes by considering health literacy. They hope that this report supports the continued development of research in the area of treatment adherence and health literacy, particularly as it pertains to integrative medicine.

About Fullscript

Fullscript is an industry-leading health technology platform that facilitates virtual dispensing for practitioner-grade supplements and develops evidence-based clinical research and medical education content to contribute to the rapidly emerging field of integrative medicine.

Executive summary

In 2021, Fullscript published a white paper on Treatment Adherence in Integrative Medicine. This report highlighted that only 50% of patients adhere to their treatment plans beyond six months. In addition to behavioral change, low health literacy was identified as one of the key barriers to treatment adherence.

Although health literacy has had many definitions, it is currently defined as both:

Personal health literacy: "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: "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." (History of Health Literacy Definitions 2022)

National and international health literacy assessments have revealed that approximately 40 to 60% of American and Canadian adults have low health literacy. (Kutner et al. 2006)(Scott Murray et al. 2008) Although anyone can have low health literacy, the following historically marginalized populations are disproportionately affected:

- Individuals 65 years of age and older
- Individuals with disabilities
- Individuals with lower educational attainment
- Individuals with reduced proficiency in the dominant language
- Individuals from marginalized and minoritized racial/ethnic groups
- Individuals of lower socioeconomic status (Kutner et al. 2006)(Schillinger 2020)

Studies have shown that individuals with low health literacy are often dissatisfied with the quality of care they receive and are more likely to distrust their healthcare providers and the medical system. Consequently, utilization of preventive health services is lower within this population. (Berkman et al. 2011)(Miller 2016)(Paasche-Orlow and Wolf 2007) As a result, people with low health literacy have an increased risk of emergency care use, hospitalization, and all-cause mortality. (Berkman et al. 2011)(Hickey et al. 2018)(Miller 2016)

Poor practitioner communication is a commonly stated barrier to patient health literacy. Since practitioners often overestimate a patient's level of health literacy and routine health literacy assessments are discouraged, experts recommend that practitioners employ evidence-based health communication techniques with all patients. (Paasche-Orlow and Wolf 2008)(Sudore and Schillinger 2009) (Voigt-Barbarowicz and Brütt 2020)

Furthermore, health education materials are often too complex to understand and do not consider culture or educational needs, preferences, and barriers. (Brach et al. 2012) Consequently, individuals with low health literacy rarely benefit from these materials. (Moran et al. 2016) However, when health education considers the specific needs of individuals with low health literacy, all patients benefit. (Meppelink et al. 2015)

Despite being acknowledged as a key determinant of health, commitment to improving organizational health literacy is poor. (Brach et al. 2012) Consequently, there is an absence of policies, procedures, and protocols supporting health literacy practices in various clinical settings such as hospitals and private practices. Without policies and protocols to promote a health literacy-friendly environment, patients may be unable to successfully navigate the health center's telephone system or physical location, for example. (Charoghchian Khorasani et al. 2020)

Purpose

This white paper aims to educate integrative practitioners on health literacy and to provide them with strategies to better support their patients with low health literacy.

While personal health literacy focuses on **individual ability**, organizational health literacy focuses on 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. (History of Health Literacy Definitions 2022)

This report summarizes the literature on the topic of health literacy and adds primary research to the field through a survey conducted with patients working with integrative medicine practitioners.

Key findings of the literature review

- **Prevalence of low health literacy:** 40 to 60% of American and Canadian adults have low health literacy.
- **Populations more likely to have low health literacy:** Older adults, individuals with disabilities, individuals with reduced proficiency in the dominant language and education, individuals from marginalized and minoritized racial/ethnic groups, and individuals of lower socioeconomic status are more likely to have low health literacy.
- **Consequences of low health literacy:** Low health literacy results in a 14% greater risk of treatment non-adherence and 25% increased risk of all-cause mortality.
- **Health literacy assessment:** Experts recommend against routine health literacy assessments as they confer more harm than good.
- **Health literacy intervention:** Evidence-based health communication techniques should be used with all patients regardless of perceived level of health literacy.

Key findings of the patient user survey

- **Number of participants:** 911 individuals responded to the survey.
- **Health literacy rate:** 13% of participants self-identify as having low overall health knowledge (i.e., health literacy).
- **Health status:** Participants with "excellent" health were more likely to have rated their overall health knowledge (i.e., health literacy) as "very knowledgeable."
- **Top two barriers to health literacy:** The top two barriers are (1) not knowing **where** to find reliable health information and (2) not having enough **time** to look for health information.
- **Trust:** Participants trust health information from (1) their healthcare providers, (2) medical websites, and (3) search engines, in that order.
- **Educational preferences:** Most respondents prefer short to medium-length written educational materials.

Methodology

Literature review

An initial scoping review was conducted to gain a high-level understanding of what kind of literature currently exists on health literacy, how it is being discussed, current limitations, and future directions based on systematic reviews or other key studies or narrative reviews.

Example PubMed search results:

- Health literacy: 22,067 (636 systematic reviews (SRs) and 110 meta-analyses (MAs))
- Health communication: 174,960 (3,829 SRs and 827 MAs)
- Health information literacy: 12,399 (388 SRs and 63 MAs)

Key publications were reviewed, and themes were identified, which helped in the creation of a rough outline of topics to explore. More specific searches were then conducted using relevant keywords based on our proposed outline. Findings were drafted into a comprehensive literature review (written separately) and were used in developing the questions for the survey.

Patient survey

The purpose of the survey was to assess our patient users' specific educational barriers, needs, and preferences. Some key research questions included:

1. What is our patient user's baseline health literacy level?
2. What sources of health information are considered the most trustworthy?
3. What formats are preferred for learning?
4. What health topics are patients most interested in learning about?
5. What keeps patients motivated and engaged in learning about health-related topics?
6. What types of health education resources are patients receiving from their practitioners?

An email invitation to participate in a 28-question survey was sent to patient users (n=30,000) who had been invited to the platform, opened an account, and received a treatment recommendation within the last six months.

To acquire a representative sample, 69% of email invitations were sent to patients seeing naturopathic doctors (NDs), medical doctors (MDs), doctors of osteopathy (DOs), chiropractors (DCs), and nurse practitioners (NPs). The remaining 31% of email invitations were sent to patients of other practitioner modalities (e.g., nutritionists, dietitians, acupuncturists, health coaches). Patients were not required to have placed an order through the Fullscript platform to be eligible for participation.

Consent was implied through voluntary participation in the survey. The survey was open for eight days. Participation incentives included being entered in a draw to win a $200 USD gift card to Amazon.com (provided to the first-place winner) or five priority shipping credits on the Fullscript platform (provided to second- and third-place winners).

Data was collected and analyzed using the SurveyMonkey software. All responses were anonymous, and no personal or health-related data was collected. Using Google Sheets, several secondary stratification analyses were conducted to determine whether there were any associated links, for example, between age and self-perceived levels of health literacy.

We discuss the results of our survey throughout the report; however, here is a quick look at our key findings (Figure 1).

Figure 1. Findings from the patient-user survey

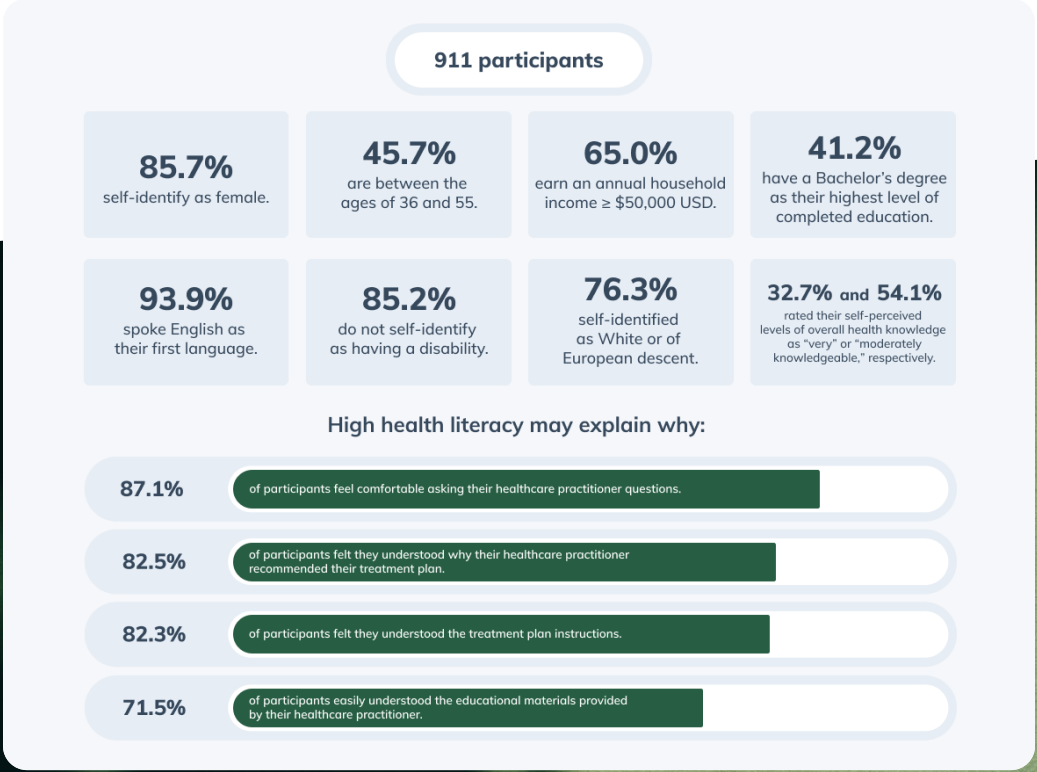
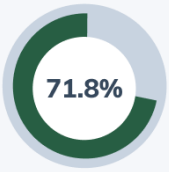
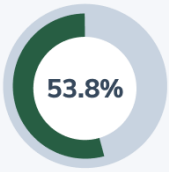


Figure 1. Findings from the patient-user survey (continued)

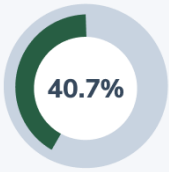
Participants indicated that their most common sources of health information are:



their healthcare provider



medical websites



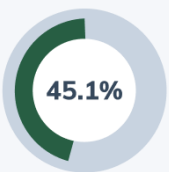
search engines

Barriers that prevent participants from searching for or finding health information:

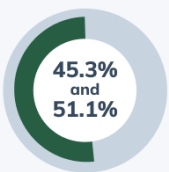
55.5%
of participants indicated that they do not know where to find reliable health information.

32.9%
of participants don't have enough time to look for health information.

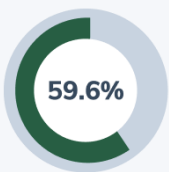
Educational needs and preferences:



of participants seek out health-related information or education a couple of times per week.



prefer short (takes 5 mins to read/watch/listen) to medium-length (takes 5–20 mins to read/watch/listen) educational content, respectively.



prefer written educational content.

Part 1

The current state of health literacy

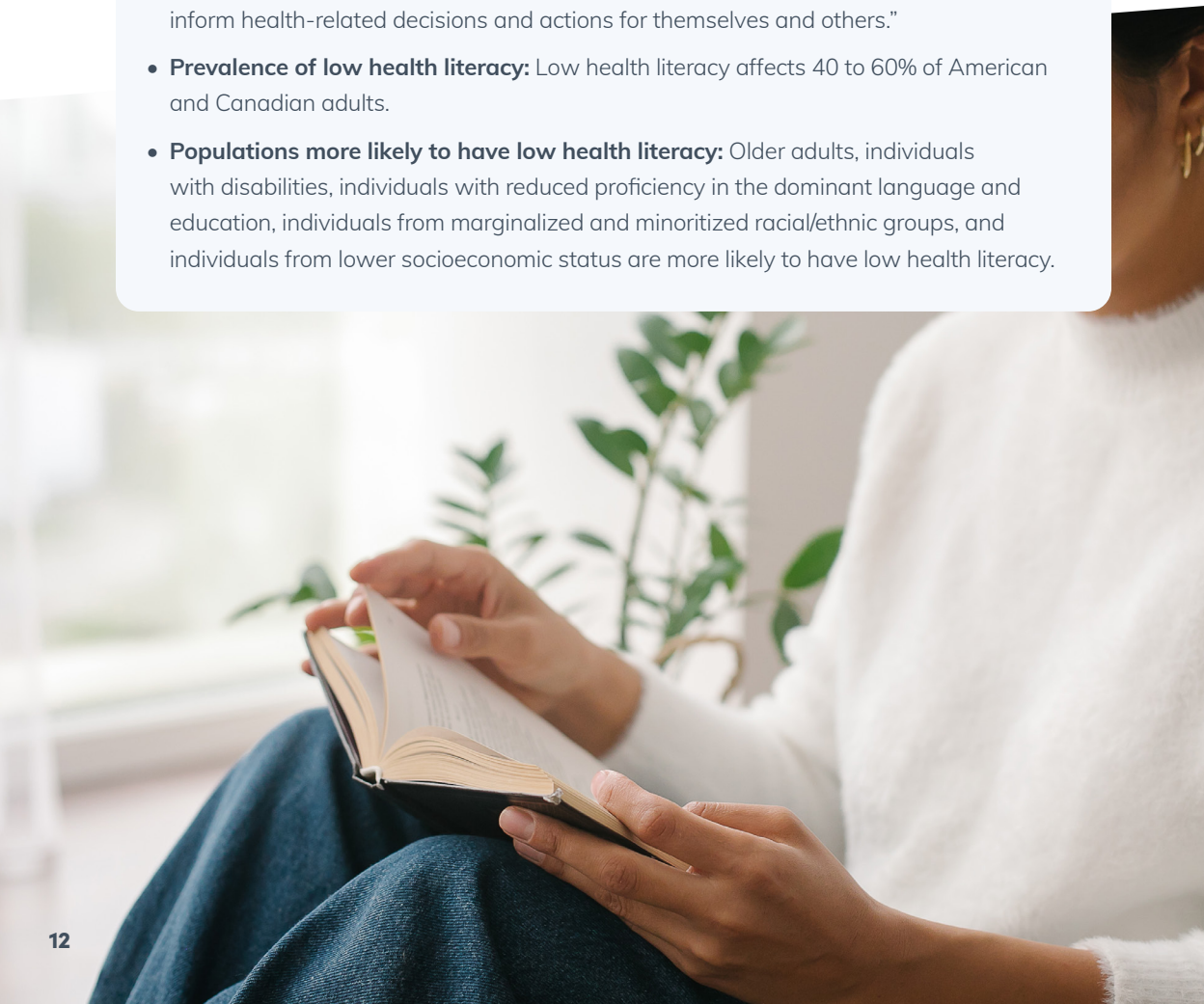
Why health literacy matters

Measuring health literacy

The current state of health literacy

Key takeaways

- **Personal health literacy** is defined as “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 defined as “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.”
- **Prevalence of low health literacy:** Low health literacy affects 40 to 60% of American and Canadian adults.
- **Populations more likely to have low health literacy:** Older adults, individuals with disabilities, individuals with reduced proficiency in the dominant language and education, individuals from marginalized and minoritized racial/ethnic groups, and individuals from lower socioeconomic status are more likely to have low health literacy.



What is health literacy?

The term "health literacy" was first introduced in the early 1970s. Since then, its definition has undergone many iterations, each emphasizing different key components of health literacy. (Sørensen et al. 2012)

For many years, health literacy focused solely on individual capacities. (Sørensen et al. 2012) For example, the Institute of Medicine (IOM), now the National Academy of Medicine, defined health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." (Elbashir et al. 2019)

Many argued the importance of moving beyond focusing solely on individual capacities and considering health literacy as an interaction between the healthcare system's demands and individual capacities. (Baker 2006)(Okan et al. 2018)(Sørensen et al. 2012)

The Secretary's Advisory Committee for the Healthy People 2030 initiative proposed a new definition, one that acknowledges that the responsibility for health literacy extends beyond the individual and includes the organizations and professionals who create and deliver health information and services. (History of Health Literacy Definitions 2022) They drafted the two new definitions shown below.

Personal health literacy

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

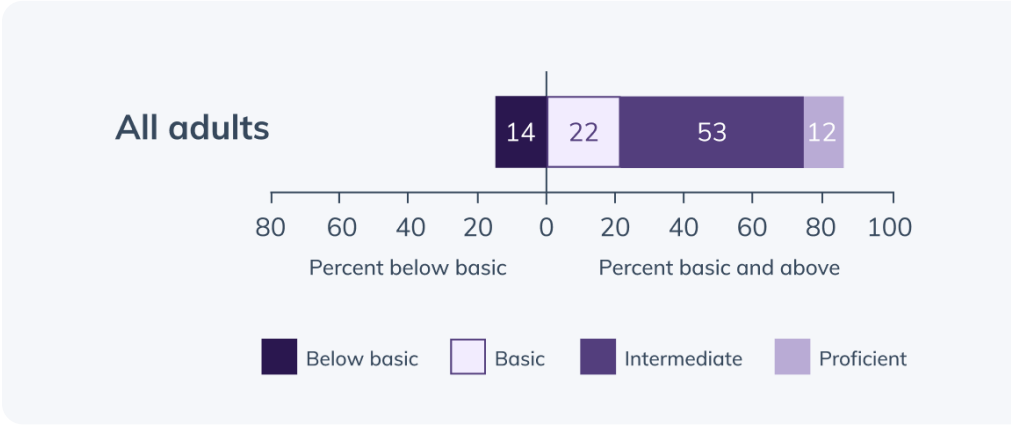
Organizational health literacy

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

How prevalent is low health literacy?

The 2006 National Assessment of Adult Literacy (NAAL) evaluated the English literacy and health literacy of over 19,000 American adults (ages 16 and older). This study found that **36%** of Americans have low health literacy (Figure 2). (Kutner et al. 2006)

Figure 2. Percentage of American adults in each health literacy level

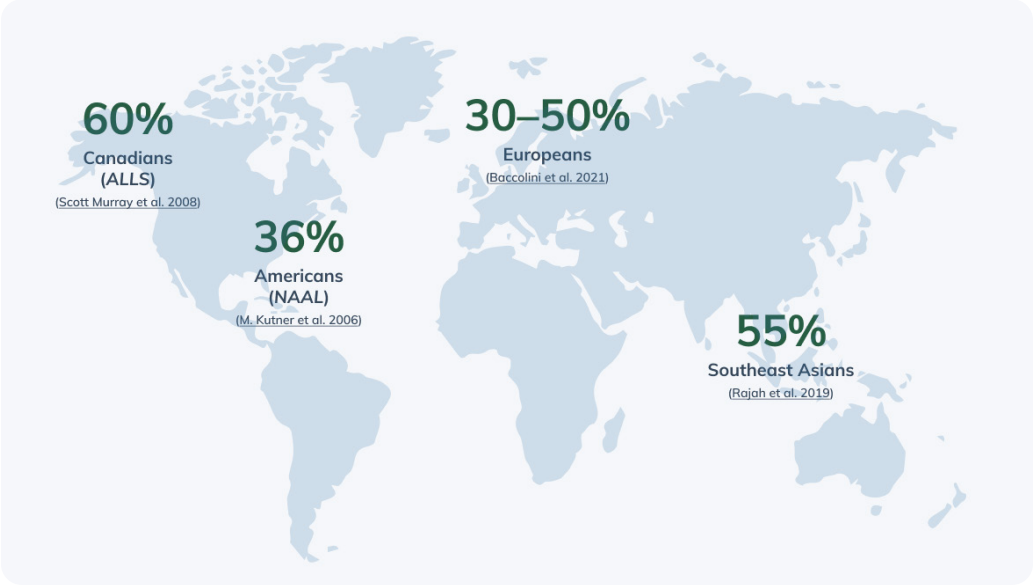


In the early 2000s, Canada and the United States both participated in The International Adult Literacy and Life Skills (ALLS) survey. In 2008, the Canadian Council on Learning published a report indicating that **60%** of Canadians have low health literacy. (Scott Murray et al. 2008)

All attempts at finding the United States' performance on this survey have failed. However, the authors of the Canadian report wrote that Canadians had higher health literacy levels than Americans. We can only assume that the ALLS survey revealed that over 60% of Americans have low health literacy.

Globally, a 2020 systematic review and meta-analysis found that nearly **one-third (33%) to one-half (50%)** of Europeans have low health literacy. (Baccolini et al. 2021) In Southeast Asian countries, the prevalence of limited health literacy varies significantly from 1.6 to 99.5%, with a mean of **55%** (Figure 3). (Rajah et al. 2019)

Figure 3. Prevalence of low health literacy

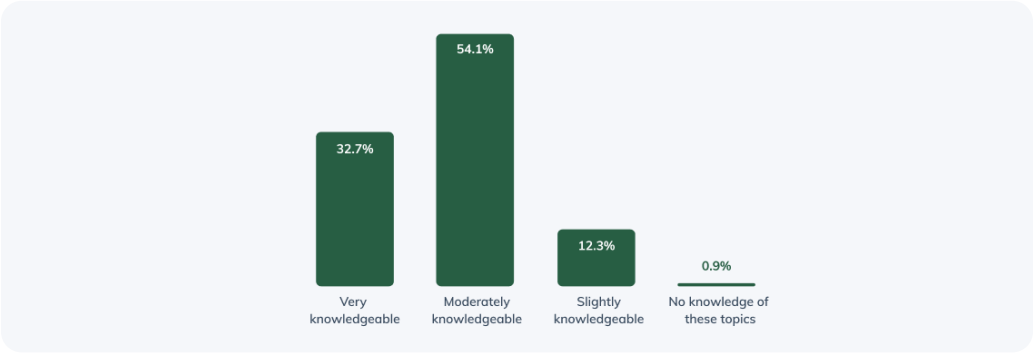


The European and Asian studies used established and well-known health literacy assessment tools like the Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional Health Literacy in Adults (TOFHLA), The Newest Vital Sign (NVS), and the Health Literacy Study (HLS - Asia and HLS - Europe). (Baccolini et al. 2021)(Kutner et al. 2006) (Rajah et al. 2019)(Scott Murray et al. 2008)

However, the National Assessment of Adult Literacy (the American study) and The International Adult Literacy and Life Skills (the Canadian study) surveys were not initially developed to assess health literacy. As a result, they did not use well-known health literacy assessment tools. Caution is therefore recommended when comparing the health literacy rates from these studies because their methodologies differ significantly.

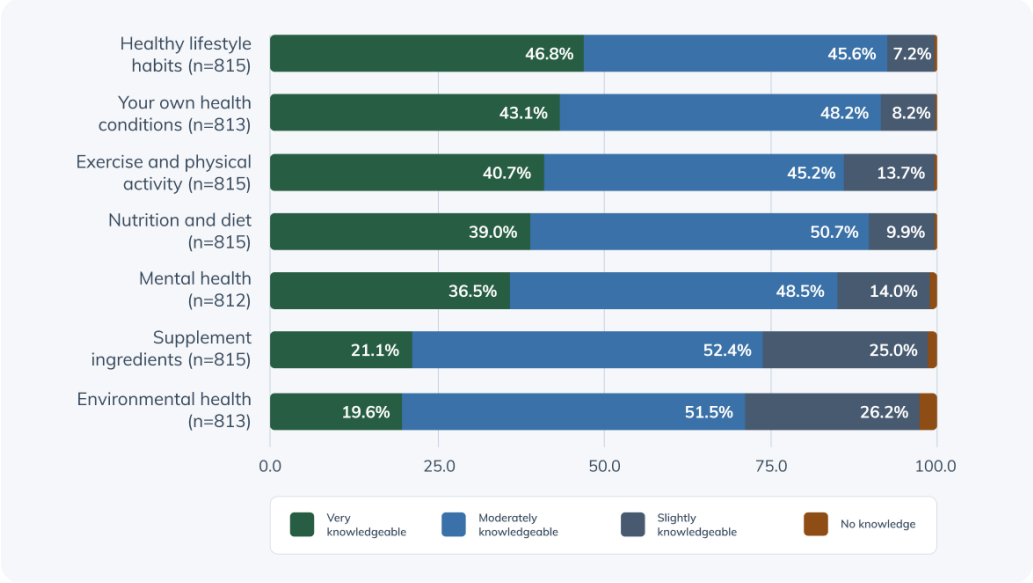
Interestingly, only **13%** of our survey participants rated their self-perceived levels of overall health knowledge as “slightly knowledgeable” or “no knowledge of these topics” (i.e., low health literacy) (Figure 4). This rate is far **below** the American (36 to 60%) and Canadian (60%) national averages. Our survey was subjective in nature which may have led to an overestimation of self-perceived levels of overall health knowledge. An objective health literacy assessment tool may have revealed similar results as the national and international studies.

Figure 4. Self-perceived level of overall health knowledge (n=813)



Additionally, the majority (> 45.2%) of participants rated their self-perceived levels of knowledge on specific health topics as “moderately knowledgeable.” However, fewer participants indicated being “very knowledgeable” on environmental health, supplement ingredients, and mental health, highlighting the need to educate patients on these topics (Figure 5).

Figure 5. Self-perceived level of health knowledge by health topic (n=816)



Who is at risk of low health literacy?

Although anyone can have low health literacy, historically marginalized populations are disproportionately affected. (Kutner et al. 2006)(Schillinger 2020)

Historically marginalized populations

- Individuals 65 years of age and older
- Individuals with disabilities
- Individuals with lower educational attainment
- Individuals with reduced proficiency in the dominant language
- Individuals from marginalized and minoritized racial/ethnic groups
- Individuals of lower socioeconomic status

Individuals aged 65+

The 2006 American and 2008 Canadian health literacy surveys identified individuals aged 65 years and older as having the lowest average health literacy scores compared to all other age groups. (Kutner et al. 2006) (Scott Murray et al. 2008)

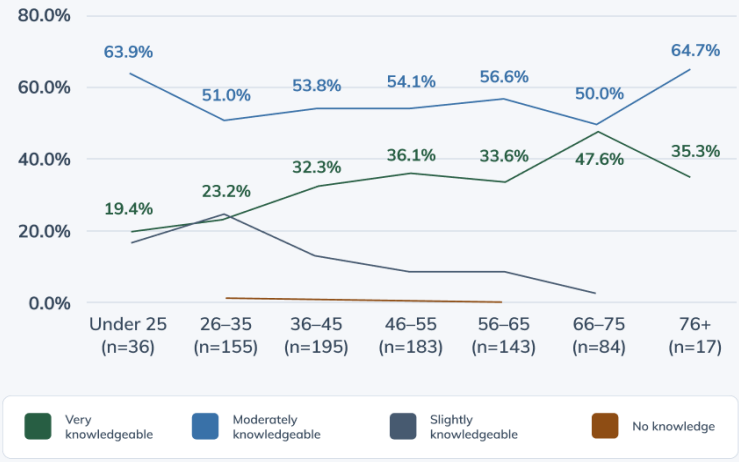
Age-related cognitive decline, impaired hearing, vision loss, and decreased reading fluency have been proposed as possible mechanisms for older adults' low health literacy rates. (Chesser et al. 2016)

These deficiencies can impact an individual's ability to understand and process health-related information, such as when to seek medical attention or take prescribed medications. (Chesser et al. 2016)

The data from our survey did not demonstrate a negative correlation between health literacy and age (Figure 6). The percentage of individuals selecting "very knowledgeable" as their self-perceived level of general health knowledge generally **increased** with age. In contrast, the percentage of individuals selecting "slightly knowledgeable" **decreased** with age, which is the opposite of what we expected.

We propose two possible theories as to why the association was not observed. First, health literacy was assessed subjectively, which may have resulted in an overestimation of high health literacy rates. Second, individuals who use integrative medicine may have higher health literacy rates than those who do not. (Gardiner et al. 2013) If this is true, individuals aged 65 and over who use integrative medicine may not have an increased risk of low health literacy.

Figure 6. Self-perceived level of overall health knowledge and age



Individuals with disabilities

Adequate health literacy is the culmination of various skills. Fluent reading, writing, and numeracy skills, as well as listening and verbal communication, are considered vital in the development of health literacy. As a result, anything that interferes with these skills can negatively impact health literacy.

For example, sensory impairments such as hearing and vision loss can prevent individuals from accessing and implementing health-related information. Communication and language barriers and limited access to deaf-tailored health information have been identified as the underlying cause of low health literacy among deaf individuals. (Naseribooriabadi et al. 2017)

In a qualitative analysis, women with visual impairments describe how assumptions that they are on government assistance and/or intellectually disabled made it challenging to communicate with their healthcare providers in a way that promoted their health literacy. (Harrison et al. 2010)

Due to these communication barriers, patients with vision loss may turn to the internet to gain further information. However, the lack of accessible health websites and the cost associated with specialized equipment such as screen readers can render this near impossible. (Harrison et al. 2010)

In 2002, only 19% of health websites were accessible to those with visual impairments. (Harrison et al. 2010)

The lack of accessible content can significantly impact one's ability to process health information and make health-related decisions. (Harrison et al. 2010)

Our survey did not demonstrate a correlation between health literacy and disability status. However, only approximately 11% (n=98) of participants self-identified as having a disability. The survey may not have been accessible for individuals with certain disabilities, such as visual impairment, which may have impacted these results.

As previously mentioned, health literacy was assessed subjectively, which may have resulted in an overestimation of high health literacy rates. Additionally, individuals with disabilities who use integrative medicine may generally have higher health literacy rates than those who do not. (Gardiner et al. 2013)

Individuals with lower educational attainment

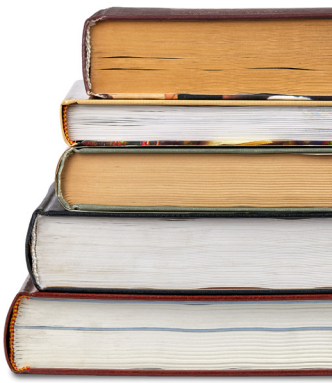
Low health literacy is often observed in those with lower educational attainment. (Kutner et al. 2006) This observation may be the result of the decreased literacy skills often seen in this population (Park and Kyei 2011) and the fact that many health-related tasks and activities use print materials that are often poorly designed and/or use complex vocabulary. (Scott Murray et al. 2008)

However, there are conflicting data. First, health literacy rates vary significantly between individuals with a high school education due to funding inequalities between school districts. These inequalities may leave certain "students with fewer and lower-quality books, curriculum materials, laboratories, and computers; significantly larger class sizes; and less qualified and experienced teachers." (Smedley et al. 2001)

Second, some studies have found low health literacy skills in highly educated individuals. The Dutch Adult Literacy and Life Skills Survey (ALL) found that a significant proportion of highly educated respondents had low levels of health literacy. Although highly correlated, these findings suggest that health literacy is not equivalent to the level of education. (van der Heide et al. 2013)

Daily reading, either for work or leisure, can help maintain and even improve health-literacy rates, regardless of educational attainment.
(Scott Murray et al. 2008)
(van der Heide et al. 2013)

The results from our survey demonstrate a positive correlation between health literacy and educational attainment. Although most participants (36 to 71%) across all educational attainment groups rated their overall health knowledge as "moderately knowledgeable," a higher percentage of individuals with PhDs (63.9%) rated their general level of health knowledge as "very knowledgeable."



Individuals with decreased proficiency in the dominant language

Linguistic differences are the main barrier to patient-practitioner communication, especially if the patient's first language or language spoken at home is not the prevalent language spoken in the healthcare setting. The 2006 NAAL identified Americans who spoke only Spanish before starting school as having the lowest health literacy averages of any other language group. (Kutner et al. 2006)

A recent Canadian retrospective population-based study found that allophones who received more than 50% of their care from a healthcare providers who spoke their primary language had:

- 26% lower risk of adverse events
- 77% shorter hospital stays
- 46% decreased risk of in-hospital death (Seale et al. 2022)

Allophone: a person who has a first language that is not English, French, or an Indigenous language

A second study highlighted that patient education typically consists of written materials such as handouts that patients take home to read. In most cases, the provided written educational materials are not well suited for individuals with limited literacy skills or proficiency in the dominant language. (Poureslami et al. 2007)

Approximately 94% (n=854) of our survey participants indicated that their first language is English. As a result, the sample size for the other languages, which included French (n=4), Spanish (n=17), and others (n=34), was too small to draw any meaningful conclusions. The fact that the survey was only available in English may have discouraged users with low English proficiency/non-English speakers from participating.

Individuals from marginalized and minoritized racial/ethnic groups

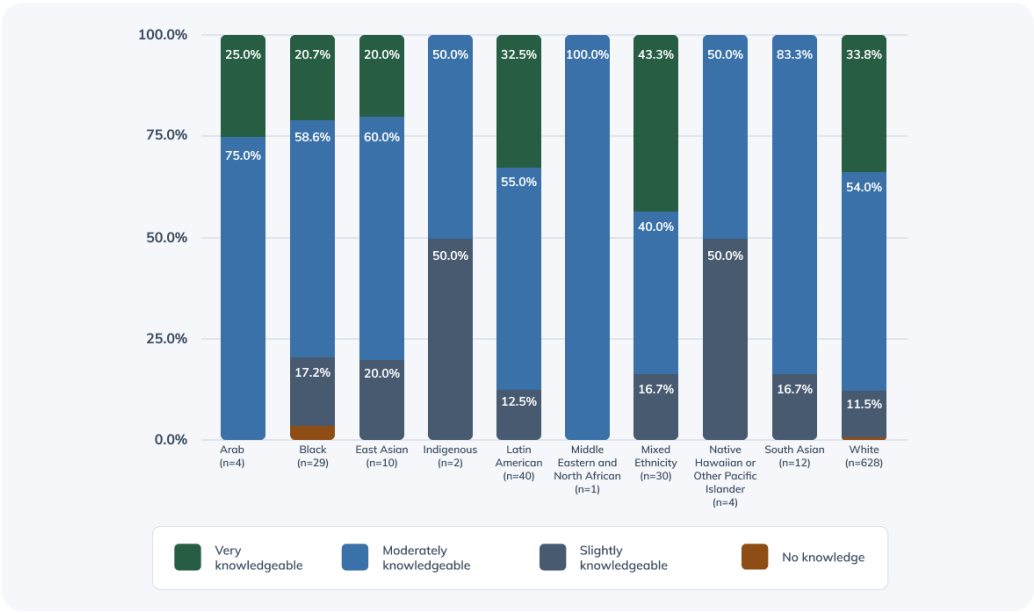
The 2006 NAAL identified American Hispanic adults as having the lowest health literacy averages compared to any other racial/ethnic minority group. Black, Indigenous, and multiracial individuals were also identified as having lower health literacy rates than Asian/Pacific Islanders and White adults. (Kutner et al. 2006)

Studies have found that race remains strongly associated with health literacy even after adjusting for the level of education. (Chaudhry et al. 2011)

Years of discriminatory policies and practices that have systematically limited marginalized and minoritized racial/ethnic groups' access to resources to develop their health literacy skills may explain this correlation. Authors Muvuka et al. (2020) explain that "systemic factors such as limited educational opportunities, racism, health system mistrust, and a lack of culturally tailored health information and services are health literacy barriers" for individuals from marginalized and minoritized racial/ethnic groups.

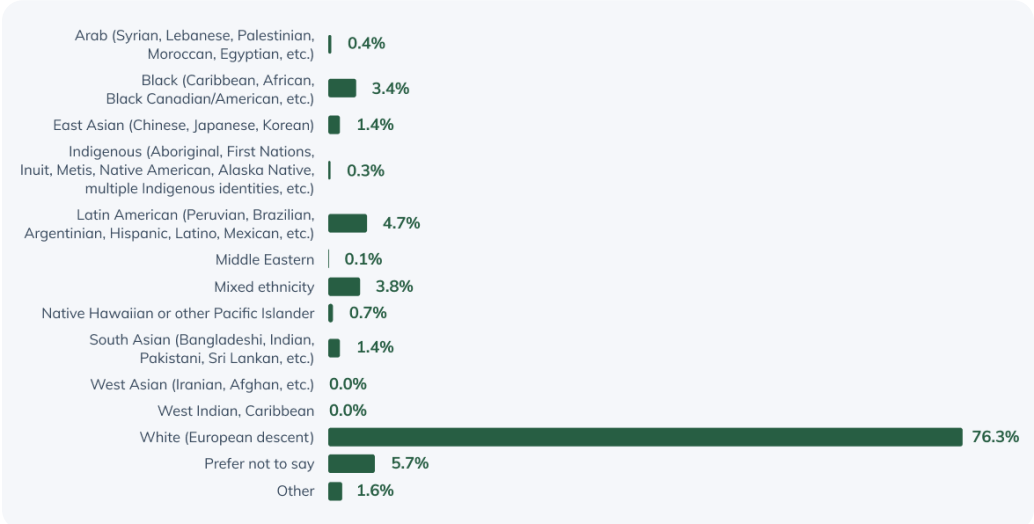
Despite the well-established link between race/ethnicity and health literacy, our survey results did not demonstrate a correlation between the two. Figure 7 demonstrates that regardless of race/ethnicity, most participants indicated having "**moderate health knowledge**" (except individuals of mixed race/ethnicity). A slightly higher percentage of individuals of mixed race/ethnicity (~43%) indicated having "**high health knowledge**." 50% of Indigenous participants, Native Hawaiians, and other Pacific Islanders indicated having "**slight health knowledge**."

Figure 7. Self-perceived level of overall health knowledge and race/ethnicity



Approximately 76% of participants self-identified as White or of European descent. The sample sizes for the remaining races/ethnicities were quite small, which may have impacted these findings (Figure 8).

Figure 8. Racial/ethnic breakdown of survey participants



Individuals of lower socioeconomic status

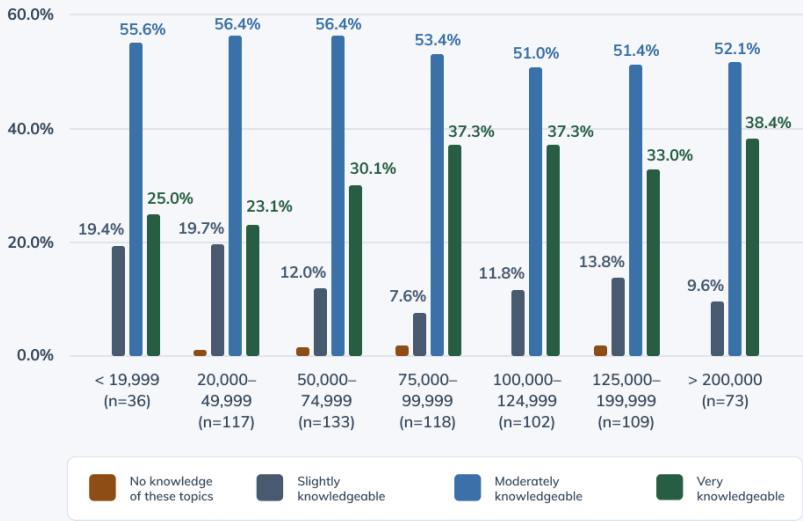
Low health literacy disproportionately impacts individuals of lower socioeconomic status. (Kutner et al. 2006)(Li and Guo 2021) (Svendsen et al. 2020)

> **The reason behind this social gradient is not well understood.** (Svendsen et al. 2020)

However, authors Li and Guo (2021) propose a theoretical framework in their paper where race/ethnicity, occupation, financial status, and educational attainment all make up an individual's socioeconomic status, which then impacts health literacy skills.

In our survey, when we stratified self-perceived levels of overall health knowledge by annual household income, the percentage of individuals rating their health knowledge as "moderately knowledgeable" remained stable across all income groups. However, the percentage of participants rating their overall health knowledge as "very knowledgeable" increased as annual household income increased (Figure 9).

Figure 9. Self-perceived level of overall health knowledge and annual household income



Why health literacy matters

Key takeaways

Low health literacy is associated with:

- ↓ information-seeking
- ↓ trust in healthcare practitioners and the medical system
- ↓ question-asking during clinical appointments
- ↑ delays in or avoidance of seeking medical attention
- ↑ risk of non-adherence
- ↑ risk of multiple comorbid conditions
- ↑ risk of emergency care use and hospitalization
- ↑ risk of all-cause mortality (death)

Low health literacy impedes actively seeking health information

Seeking, understanding, and using health-related information are vital for improving health literacy and health outcomes. Unsurprisingly, studies have shown that low health literacy can impede actively seeking health information. (Saab et al. 2018) In other words, individuals with low health literacy, especially older adults, show decreased motivation for seeking health information. (Kim and Utz 2018)

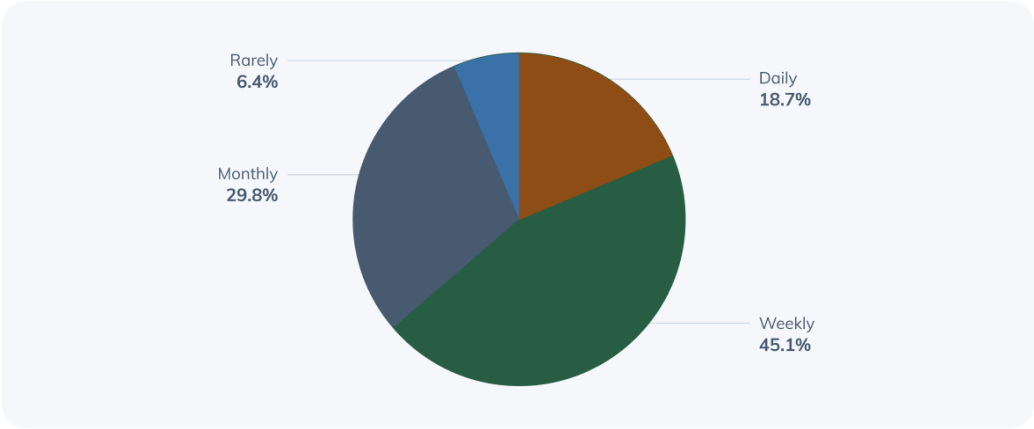
Lee et al. (2021) propose that individuals with high health literacy may feel more comfortable seeking out information, navigating the internet, and interpreting health information.

Access to the internet has been found to significantly impact information-seeking behaviors and health status, regardless of educational attainment. (Feinberg et al. 2016) However, there is some debate regarding whether individuals with low health literacy have decreased access to digital devices. (Bailey et al. 2015)(Manganello et al. 2017)

To date, it remains unclear if the observed reduction in health information-seeking behaviors in individuals with low health literacy is due to reduced access to digital devices, lack of motivation, or decreased comfort in seeking out information, navigating the internet, and/or interpreting health information.

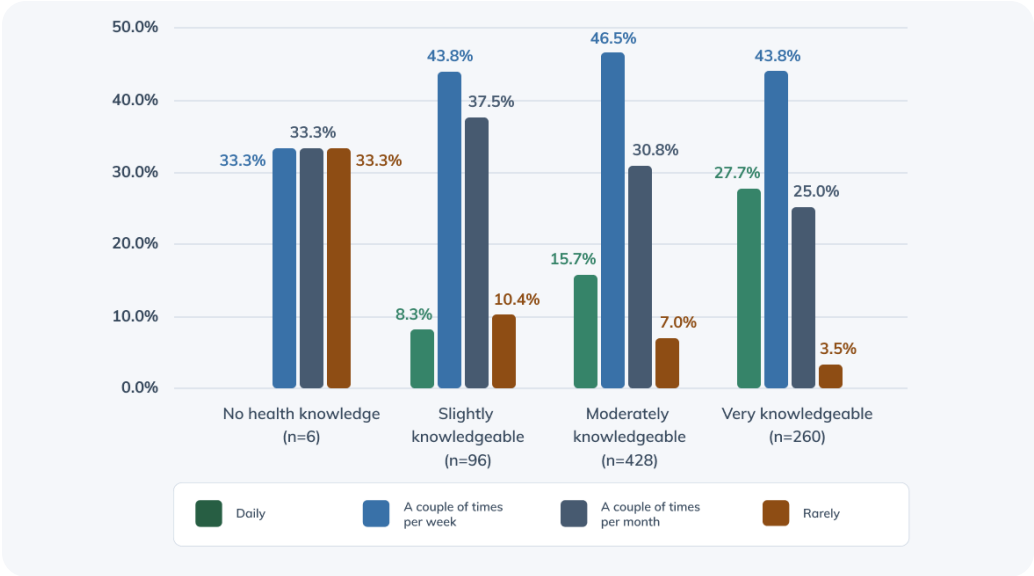
Our survey showed that almost half (45%) and one-third (30%) of participants seek health information either a couple of times per week or a couple of times per month, respectively. Approximately 20% of participants seek health information on a daily basis (Figure 10).

Figure 10. Frequency of seeking out health information (n=793)



When we stratified these results with self-perceived levels of general health knowledge (i.e., health literacy), we noticed that as health literacy increased, the percentage of individuals seeking out health information on a **"daily" basis increased** and the percentage of individuals seeking out health information on a **"monthly" basis or "rarely" decreased** (Figure 11).

Figure 11. Self-perceived level of overall health knowledge and frequency of seeking out health information



Patients with low health literacy have decreased trust in their healthcare practitioners

When it comes to sourcing health information, studies have shown that patients typically get their health information from their primary care providers, nurses, medical websites, online search engines, specialist doctors, and friends, in that order. (Chen et al. 2018)

Our survey showed similar results, with the top four-rated sources of health information being "my healthcare provider," "medical websites," "search engines," and "friends, family, and coworkers," in that order.

However, studies have also shown that sources and trust in health information differ significantly according to health literacy level. (Chen et al. 2018) Individuals with low health literacy were more likely to source health information from television and radio programs, social media, blogs, celebrity web pages, and health-related apps on smartphones. (Chen et al. 2018)(Manganello et al. 2017) "Mistrust interferes with health literacy development as it affects interaction with the healthcare system, access to health-related resources, and health-related decision-making." (Muvuaka et al. 2020)

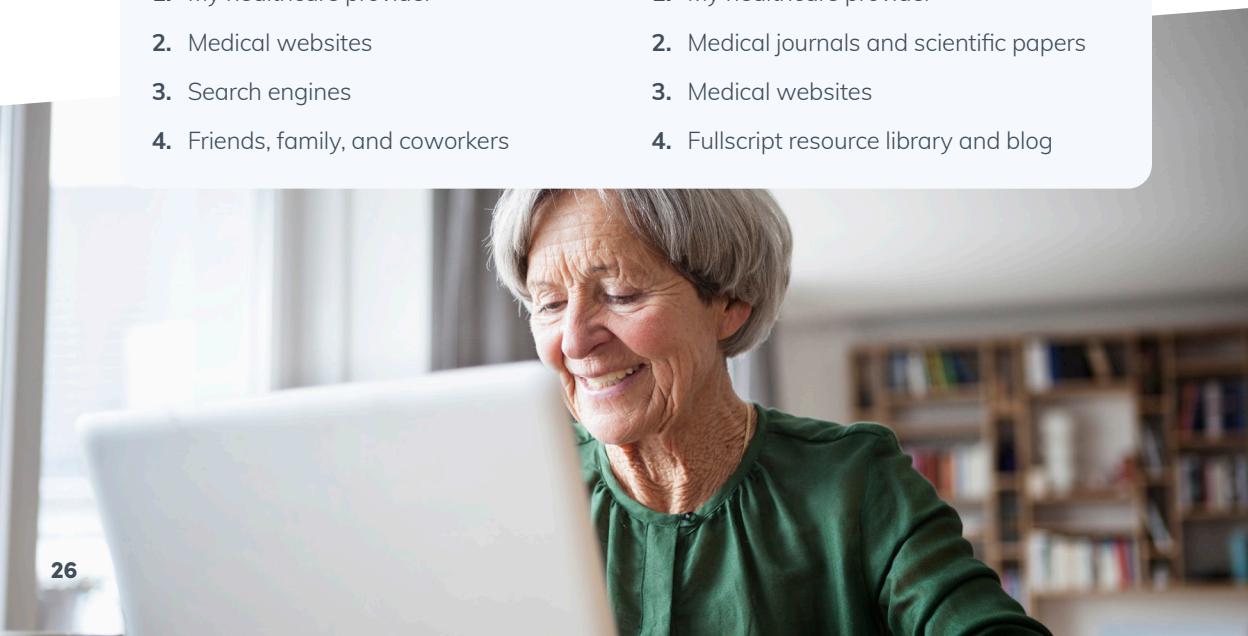
The following are the top four most common and most trusted sources of health information reported by our survey participants.

Most common sources of health information:

1. My healthcare provider
2. Medical websites
3. Search engines
4. Friends, family, and coworkers

Most trusted sources of health information:

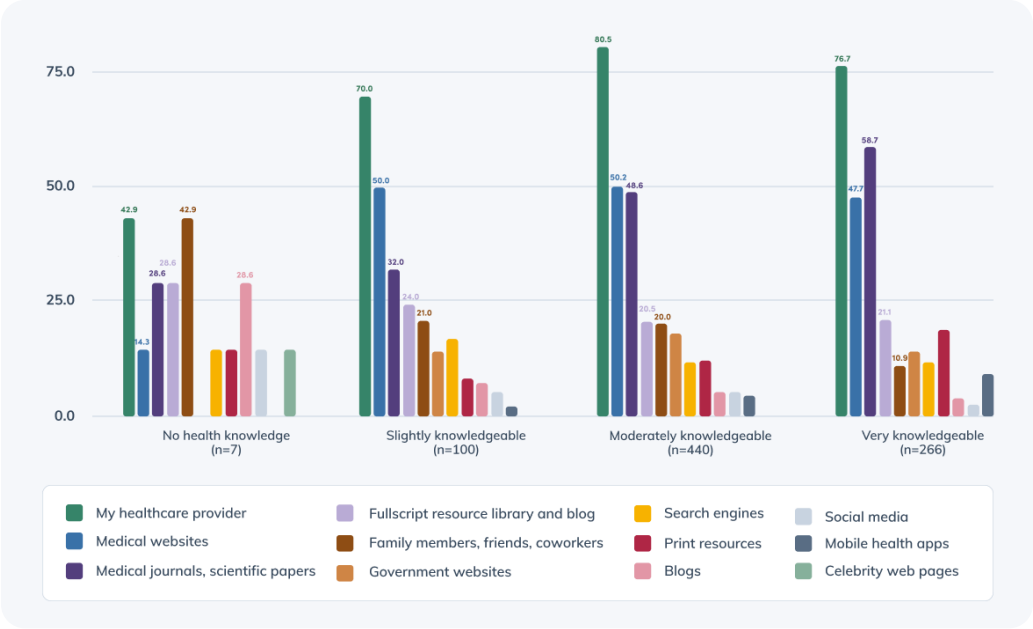
1. My healthcare provider
2. Medical journals and scientific papers
3. Medical websites
4. Fullscript resource library and blog



When we stratified the most trusted sources of health information by self-perceived levels of health knowledge, we found that the top three sources of trusted health information for the knowledge groups “slightly,” “moderately,” and “very” were all the same: “my healthcare provider,” “medical websites,” and “medical journals or scientific papers.”

The top sources of health information for the knowledge group “no health knowledge” differed significantly. Individuals trusted health information received from their “healthcare provider” just as much as the information received from their “family, friends, and coworkers.” Additionally, individuals were just as likely to trust information from “blogs,” “medical journals and scientific papers,” and the “Fullscript resource library and blog.” The small sample size (n=7) may have influenced the data. It is unknown if a larger sample size would have revealed similar results (Figure 12).

Figure 12. Self-perceived level of overall health knowledge and most trusted sources of health information



If these findings are accurate, they suggest that individuals with low health literacy struggle with differentiating between trustworthy (e.g., healthcare provider, medical journals, and scientific papers) and possibly untrustworthy (e.g., blogs, family, friends, and coworkers) sources of information.

Low health literacy influences question-asking

In addition to increased provider distrust, individuals with low health literacy generally ask fewer questions than patients with high health literacy (five ± four questions versus nine ± seven questions) during their clinical appointments. (Menendez et al. 2017)

Specifically, they ask fewer questions about key aspects of their medical care. Interestingly, in one study, when surgeons asked their patients if they had any questions, 79% of patients asked questions. Unfortunately, only 29% of surgeons made this inquiry to their patients. (Menendez et al. 2017)

Patient shame and fear of having their limited health literacy exposed could be one reason why patients with low health literacy ask fewer questions and require additional encouragement from practitioners. (Menendez et al. 2017)

The authors also observed a racial difference in question-asking behaviors where individuals from marginalized and minoritized racial/ethnic groups asked fewer questions than White individuals. They suggest that due to decreased healthcare provider trust and "social power," individuals from marginalized and minoritized racial/ethnic groups may have traditional role expectations from their healthcare provider, reducing active involvement in the clinical encounter. (Menendez et al. 2017)

Approximately 96% of our survey participants indicated that they either "strongly" or "somewhat agreed" that they feel comfortable asking their healthcare provider questions about their health and treatment plan. Further analysis demonstrated that as self-perceived levels of overall health knowledge increased, so did the percentage of participants "strongly agreeing" with the statement.

Specifically, 77% of participants from the "slightly knowledgeable" group "strongly agreed" that they feel comfortable asking their healthcare provider questions compared to 87.4% and 89.1% of participants from the "moderately" and "very knowledgeable" groups (respectively).

Low health literacy influences healthcare utilization

Low health literacy impacts how patients access and utilize care. For example, in a systematic review on health literacy and female reproductive health, the authors found that females with low health literacy were more likely to engage in avoidance behaviors such as reduced screening for sexually transmitted infections (STIs), delayed initiation of prenatal care, and decreased follow-ups after being diagnosed with abnormal cervical cells. (Kilfoyle et al. 2016)

Individuals with low health literacy may delay seeking medical attention for any of the following reasons:

- They do not understand the importance of preventive care.
- They are unfamiliar with the signs and symptoms of diseases.
- They feel uncomfortable interacting with the medical system and fear their limited literacy will be exposed.
- They are unable to navigate the complexities of the healthcare system and facilities.
- They are typically dissatisfied with the quality of care they receive.
- They distrust their healthcare providers.

(Paasche-Orlow and Wolf 2007)

Low health literacy influences self-efficacy and treatment adherence

Studies have shown that individuals with low health literacy lack adequate self-management. Specifically, individuals with low health literacy experience increased challenges with understanding their condition and symptoms, knowing how to monitor their condition and use monitoring devices correctly, interpreting their results, and knowing what to do with that information. (Paasche-Orlow and Wolf 2007)

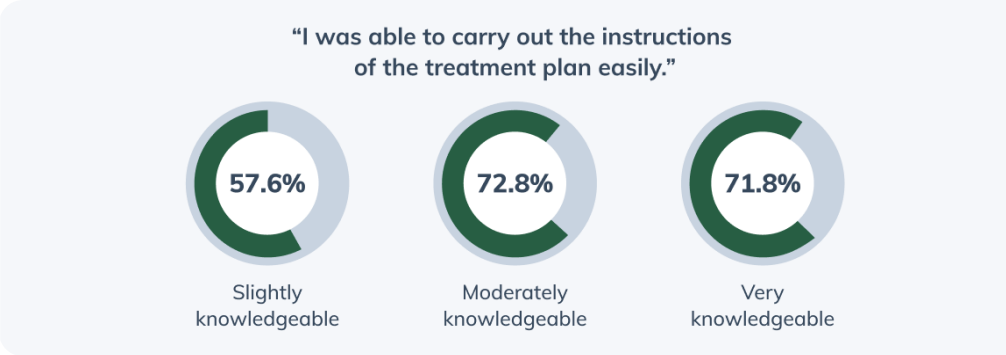
Self-management is defined as daily decision-making and activities that patients engage in to live with and manage their health conditions.

Medication-taking skills, which are a component of self-management, are also decreased in those with lower levels of health literacy. (Berkman et al. 2011) One 2006 study found that individuals with low health literacy were able to read the medication label instructions correctly; however, only one-third could accurately demonstrate the total number of pills needed daily. (Davis et al. 2006)

A meta-analysis found a 14% greater risk of non-adherence among patients with lower health literacy. Non-adherence was greater with lifestyle-type recommendations, suggesting that behavioral changes may demand greater health literacy skills than starting a medication. (Miller 2016) This finding of greater treatment non-adherence in those with lower health literacy may be due to the poorer self-efficacy skills observed within this population.

In our survey, we asked our participants to think back to their most recent treatment plan or interaction with their practitioner. We noticed that individuals with higher self-perceived levels of health knowledge (i.e., moderately and very knowledgeable) were more likely to "strongly agree" that they were able to easily carry out the instructions of their treatment plan than individuals with lower self-perceived levels of health knowledge (i.e. slightly knowledgeable) (Figure 13).

Figure 13. Self-perceived level of overall health knowledge and treatment adherence



Although not a direct measure of treatment adherence, these results suggest that health literacy may impact treatment adherence.

Low health literacy increases emergency care use, hospitalizations, and death

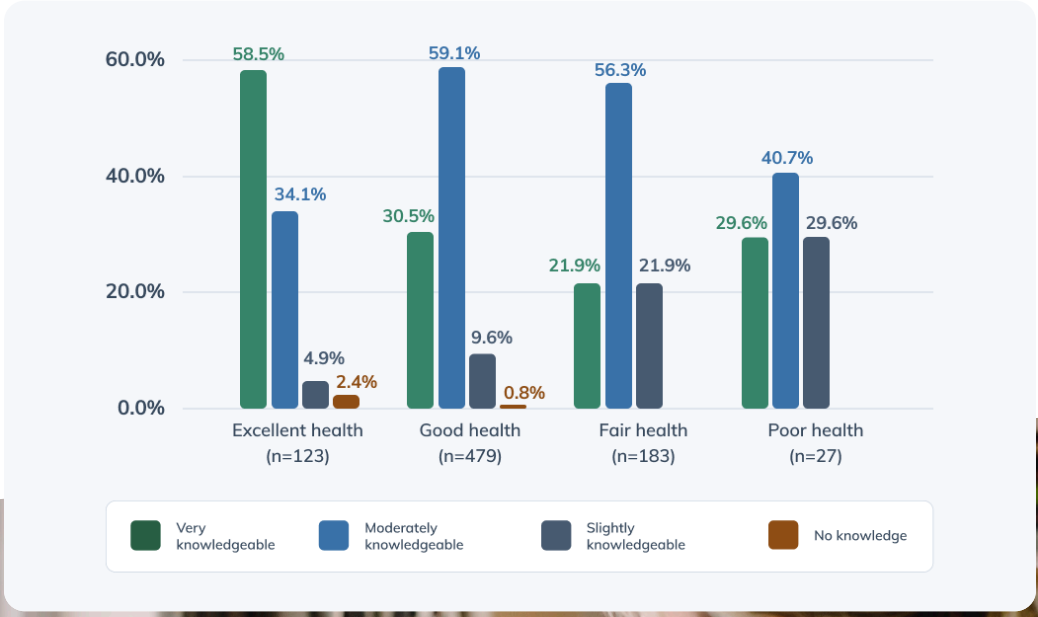
Individuals with low health literacy have poorer health outcomes. For example, studies have shown an association between low health literacy and the presence of multiple comorbidities. (Hickey et al. 2018) Furthermore, individuals with low health literacy have an increased risk for emergency care use and hospitalization. (Berkman et al. 2011)(Hickey et al. 2018)(Miller 2016)

Consequently, studies estimate that the cost of low health literacy to the American healthcare system is between 3 and 10% of total healthcare spending. Studies looking at the additional cost of low health literacy on the patient level estimate that $143 to $7,798 is spent annually for every patient with low health literacy. (Eichler et al. 2009) The implementation of health literacy interventions may help negate this increased cost. For example, one study observed a 10.8% decrease in annual per capita expenditure after implementing a web-based health literacy intervention with hospital employees. (Greene et al. 2019)

Most importantly, decreased health information-seeking behaviors, trust in healthcare practitioners, question-asking, self-efficacy, treatment adherence, and utilization of healthcare services increase the risk of death. Specifically, low health literacy has been associated with a 25% increased risk of mortality (pooled all-cause mortality and disease-specific mortality). (Fan et al. 2021) Older adults with low health literacy have a 27 to 75% increased risk of all-cause mortality. (Berkman et al. 2011)

In our survey, participants who rated their health as "**excellent**" were more likely to rate their overall health knowledge as "**very knowledgeable**." Individuals who rated their health as either "**good**," "**fair**," or "**poor**" were more likely to rate their overall health knowledge as "**moderately knowledgeable**" (Figure 14).

Figure 14. Self-perceived level of overall health knowledge and health status



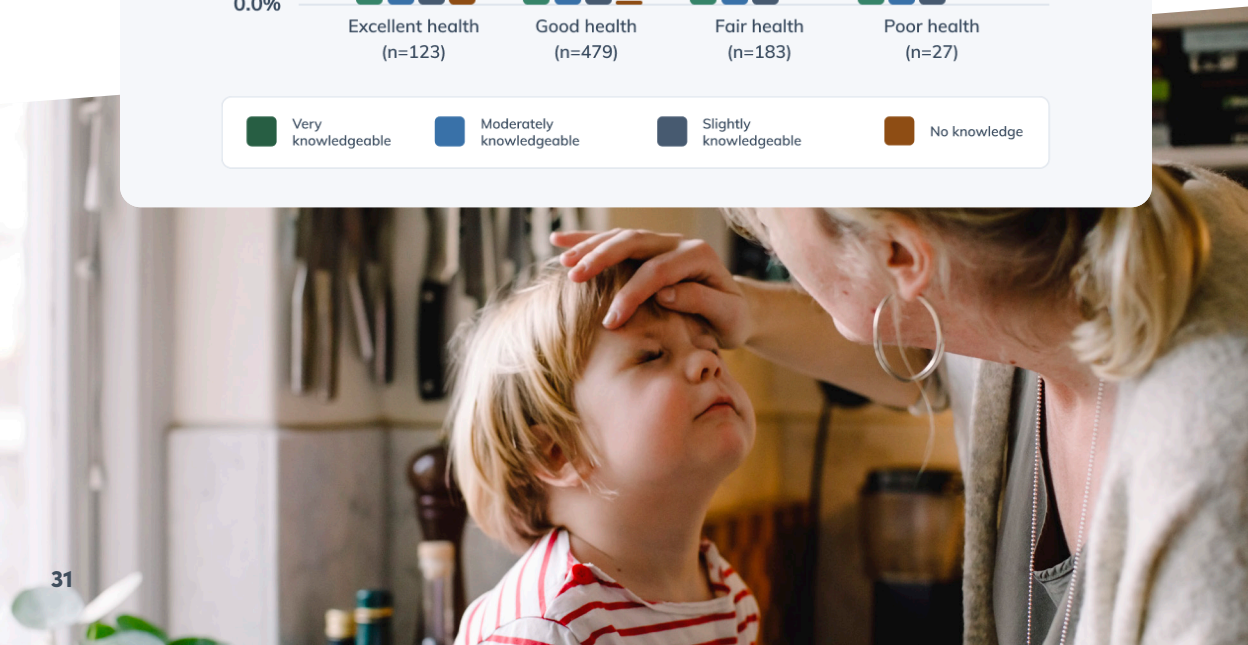


Figure 15 summarizes how social determinants of health, healthcare providers, educational materials, and organizations influence health literacy, behaviors, and beliefs, which then impact health outcomes.

Figure 15. The causal pathway between health literacy and health outcomes

Measuring health literacy

Key takeaways

- Health literacy experts recommend against health literacy assessments as they confer more harm than good.
- Evidence-based health communication techniques should be used with all patients regardless of perceived levels of health literacy.

A brief history of health literacy assessment tools

Throughout the years, health literacy has been defined in many ways, each definition highlighting a different problematic area of health literacy. However, without a universal and consistent definition in this field of research, disagreement regarding how health literacy should be measured is inevitable. (Baker 2006)

If health literacy is a constellation of personal skills, measuring an individual's reading ability, text comprehension, and numeracy would be appropriate. However, measuring individual capacity would be insufficient if health literacy also depends on the relationship between individual capacity and the healthcare system. (Baker 2006)

With that being said, most of the instruments developed to measure health literacy are based on individual capacities, such as finding, understanding, evaluating, communicating, and using health-related information in health-related decision-making. (Altin et al. 2014)

A 2014 systematic review identified an extensive reliance on pre-existing instruments (which have many weaknesses) in developing new health literacy assessment tools. Almost one-third of the instruments reviewed were based on existing functional literacy screeners like the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA). They argue that the development of new and original instruments is required to advance the field of health literacy research. (Altin et al. 2014)

Furthermore, various health literacy tools are translated into multiple languages. For example, the European Health Literacy Survey Questionnaire (HLS-EU-Q) was translated from English into six other languages. The investigators proposed that translating existing health literacy assessments eliminates the constraints of language. (Liu et al. 2018)

However, simply translating assessment tools may ignore cultural and institutional differences between, for example, English-speaking and non-English-speaking countries. (Altin et al. 2014)

While many argue for the development of original assessment tools, (Altin et al. 2014) others recommend against screening patients for low health literacy. These investigators suggest that health literacy assessment tools confer more harm than benefit to patients. (Paasche-Orlow and Wolf 2008)

For example, a 2017 systematic review demonstrated that patients feel shame and embarrassment when undergoing health literacy assessments and exposing their limited literacy skills to their healthcare provider. (Rajah et al. 2018)

Patients with limited health literacy may not be open to routine assessment of their health literacy skills and may not want such details recorded in their medical files.

Additionally, literacy tests have historically been used to discriminate against individuals from marginalized and minoritized racial/ethnic groups. Specifically, in the southern United States, literacy tests were used to prevent African Americans from registering to vote. (Literacy Tests 2017)

Routine health literacy assessment could potentially further isolate patients who already face significant barriers accessing healthcare. (Paasche-Orlow and Wolf 2008)

A second argument against routine testing is that health literacy is a dynamic and comprehensive construct; as a result, it is not compatible with tests. (Altin et al. 2014)

In other words, an individual's level of health literacy may vary depending upon the medical condition being discussed or treated, the healthcare provider, and the healthcare system. (Baker 2006)

Due to the common overestimation of patients' level of health literacy by healthcare providers, (Voigt-Barbarowicz and Brütt 2020) researchers recommend using evidence-based health communication techniques with all patients regardless of perceived levels of health literacy. (Sudore and Schillinger 2009)

Three reasons why routine health literacy assessments are not recommended

Health literacy assessments can make patients feel ashamed and embarrassed.

Literacy tests have historically been used to discriminate against racial and ethnic minority groups. Consequently, routine health literacy assessment could potentially further isolate patients who already face significant barriers accessing healthcare.

Health literacy is dynamic and may vary depending factors such as the medical condition being discussed or treated, the healthcare provider, and the healthcare system.

Should we routinely assess patients for low health literacy?

As mentioned above, researchers currently recommend **against** routine health literacy assessments due to the risk of harming patients and the ever-changing nature of health literacy.

However, if health literacy assessments are desired, the Health Literacy Skills Instrument – Short Form (HLSI-10) may be preferred for the following reasons:

- It is available in English and Spanish.
- It assesses four domains of health literacy.
- It is free to use.

Most importantly, the assessment can also be completed independently at home, which may reduce harm (i.e., causing feelings of shame and embarrassment within the patient).

Five health literacy tools are summarized in the appendix if you would like to learn more.

Part 2

Improving practitioner communication skills

Improving health education

Improving organizational health literacy

Improving practitioner communication skills

Key takeaways

- Address linguistic and communication differences.
- Use clear, everyday language.
- Encourage question-asking.
- Use the teach-back method.

Individuals with low health literacy often have low literacy skills. As a result, they often rely solely on verbal communication for instructions. (Brega et al. 2015) This is especially problematic as healthcare providers often struggle to communicate complex medical information to patients with low health literacy. (Roodbeen et al. 2020)

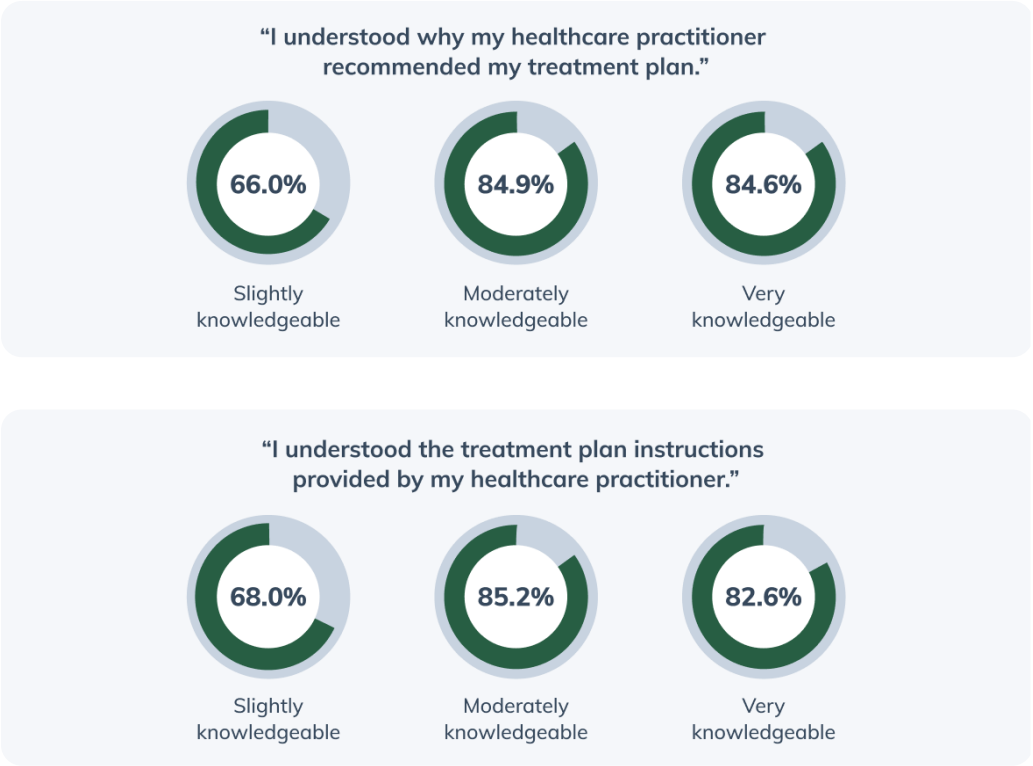
When we asked our survey participants to think back to their most recent treatment plan or interaction with their healthcare practitioner:

96.1% said they either "strongly" or "somewhat agreed" and **1.4%** either "strongly" or "somewhat disagreed" with the statement: "I understood why my healthcare provider recommended my treatment plan."

96% said they either "strongly" or "somewhat agreed" and **1.1%** either "strongly" or "somewhat disagreed" with the statement: "I understood the treatment plan instructions provided by my healthcare provider."

When we compared the data from this question with self-perceived levels of health literacy, we noted a positive correlation. In other words, participants with higher self-rated health literacy (i.e., moderately and very knowledgeable) were more likely than participants with lower self-rated health literacy (i.e., slightly knowledgeable) to "strongly agree" with these two statements (Figure 16).

Figure 16. Self-perceived level of overall health knowledge and patient ability to understand treatment plan recommendations and instructions



Health literacy research suggests that effective healthcare provider communication benefits **all** patients regardless of health literacy level. Consequently, we would have expected to see similar percentages across all health literacy groups if healthcare providers practiced effective communication.

However, the sample size for the "slightly knowledgeable" group (n=100) was smaller than the "moderately" (n=438) and "very knowledgeable" (n=266) groups. A larger sample size may have revealed similar results as the high-health literacy groups (i.e., moderately and very knowledgeable).

The following are guidelines that can help practitioners practice effective communication. It is essential to remember that the key to successful communication with all patients, regardless of health literacy level, is **establishing a trusting patient-provider relationship**. (Poureslami et al. 2007)

Address linguistic and communication differences

Linguistic differences between the patient and practitioner can complicate communication, impair health literacy, and increase the risk of adverse events, longer hospital stays, and in-hospital deaths. (Brega et al. 2015) (Seale et al. 2022)

The 2006 NAAL demonstrated that linguistic differences disproportionately impact Spanish-speaking Americans. (Kutner et al. 2006)

To mitigate this barrier, it is important to ask all new patients what language they prefer to speak and read. (Brega et al. 2015)

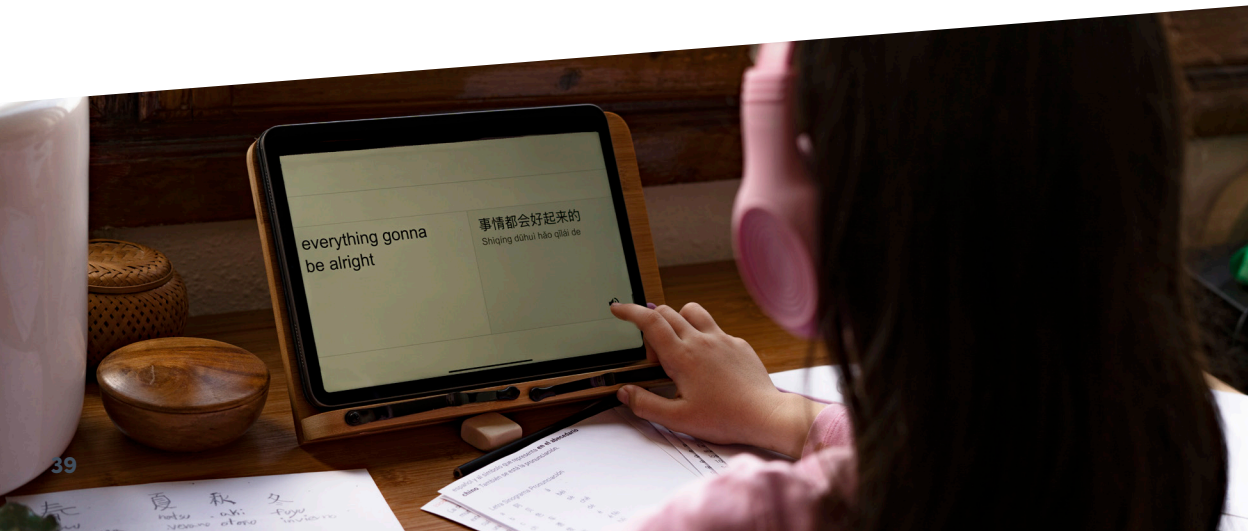
For patients with low English proficiency, "I Speak" cards can help identify the language spoken.

Linguistic preferences should then be noted in the patient's medical record for future reference. From an administrative standpoint, all language assistance needs and how they are being met should be recorded weekly. This information can help clinicians and clinics plan in advance for interpreter services and ensure the availability of linguistically appropriate educational materials. (Brega et al. 2015)

Multilingual easy-to-read patient education:

MedlinePlus by the National Institutes of Health

Additionally, individuals with intellectual and/or sensory disabilities (vision and hearing) are further disadvantaged as healthcare providers are rarely trained on how to communicate understandable health-related information to these different populations. (Geukes et al. 2019)(Naseribooriabadi et al. 2017)



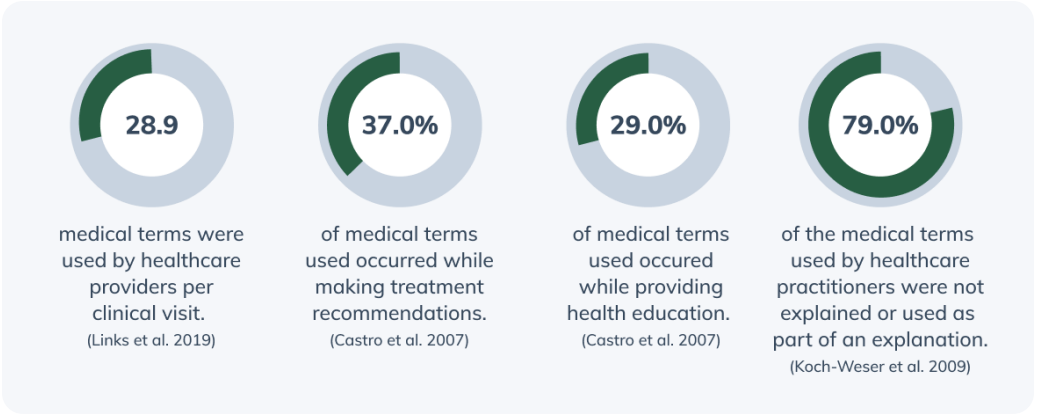
(Smeltzer et al. 2017) (Sudore and Schillinger 2009)

Each quarter, review the following:

- ☐ How are language assistance and communication needs being met?
- ☐ Are language assistance and communication needs being recorded in the medical records?
- ☐ What are the most common languages used by patients?
- ☐ Are educational materials available in the languages most frequently used by patients?
- ☐ Are qualified individuals providing language assistance (e.g., bilingual clinicians or staff members whose proficiency has been confirmed; staff trained as American Sign Language (ASL) interpreters; on-site trained medical interpreters; or telephone or video medical interpreter services)? (Brega et al. 2015)

Use clear, everyday language

Poor practitioner communication is a commonly stated barrier to patient health literacy.



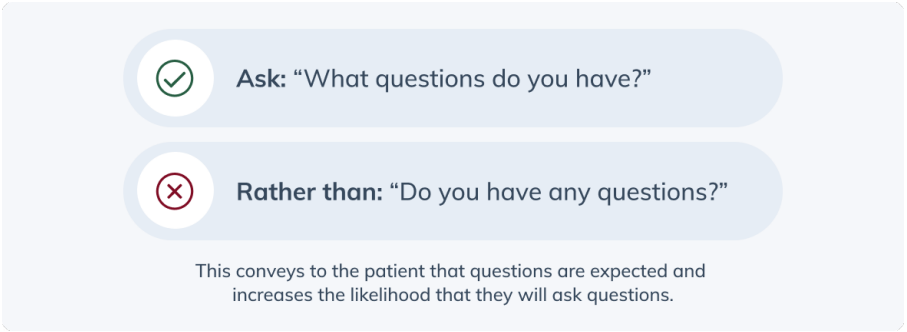
These poor communication practices prevent patients from using their health literacy skills during their consultations and impede the exchange of information. (Edwards et al. 2012)

It is vital for practitioners to:

- ☐ Use everyday, non-medical language.
- ☐ Speak clearly at a moderate pace.
- ☐ Use the patient's own words—for example, the words they use to describe their condition—to facilitate understanding and reduce confusion.
- ☐ Limit key points discussed to three or less to reduce overwhelm. (Sudore and Schillinger 2009)

Encourage question-asking

Studies have found that individuals with low health literacy ask fewer questions during their medical visits than individuals with high health literacy. (Menendez et al. 2017) It is, therefore, vital to invite patient participation by encouraging questions and asking open-ended questions. (Menendez et al. 2017) (Sudore and Schillinger 2009)



Use the teach-back method

It has been proposed that poor practitioner communication skills could be responsible for the following phenomenon:

40.0–80.0%	of information provided by healthcare practitioners is forgotten immediately by patients.
50.0%	of the remembered information is incorrect.

(Kessels 2003)

The teach-back method can help practitioners confirm patient understanding by having the patients repeat or demonstrate the information or technique taught by the practitioner. Researchers recommend destigmatizing the interaction by placing the onus of clear communication on the clinician. (Sudore and Schillinger 2009)

Healthcare practitioners can preface the teach-back method by saying: "I've just said a lot of things. To make sure **I did a good job and explained things clearly**, can you describe to me…?" (Sudore and Schillinger 2009)

The Always Use Teach-Back! Toolkit provides practitioners tools and resources to help them implement the teach-back method into their practices. (Brega et al. 2015)

Track your progress

Prior to implementing the recommendations mentioned above, complete the following communication assessments:

- Self-assessment form: Following a patient visit, take a few moments to reflect on your communication skills.
- Peer feedback form: Ask a colleague to assess your communication skills. Remember to explain to patients that the accessor will be evaluating your communication skills, not theirs.
- Patient feedback form: Ask patients to provide feedback about their appointment.

One month after starting the implementation process of these recommendations, complete another round of self-assessment and peer and patient feedback. Notice if there are any changes.

Reassess every quarter or at a cadence that works best for you. (Brega et al. 2015)

Improving health education:

How to create and effectively use health literacy-friendly educational materials

Key takeaways

1. Get to know your patient population.
2. Identify your patients' educational barriers, needs, and preferences.
3. Draft health literacy-friendly educational materials.
4. Test your educational materials and ask for patient feedback.
5. Use educational materials effectively.
6. Manage educational materials.

The pressures of today's healthcare system make it difficult for practitioners to spend extra time with their patients. As a result, there is an increased reliance on written take-home educational materials. (Poureslami et al. 2007) For example, among Fullscript's patient users, over half (> 66%) reported receiving educational materials from their healthcare practitioner either "somewhat often" or "often."

Unfortunately, educational materials are often inappropriate for patients with low health literacy. As a result, this population rarely benefits from educational interventions compared to individuals with greater health literacy. (Moran et al. 2016)

Conversely, when health education considers the specific needs of individuals with low health literacy, not only do they benefit, but individuals with high health literacy benefit as well. The reason being is that easy-to-read and understand educational materials are beneficial for all patients regardless of health literacy level. (Meppelink et al. 2015) Below, we've outlined key considerations for creating, sourcing, and effectively using patient educational materials that benefit all patients regardless of their health literacy level.

1. Get to know your patient population

In order to create or provide health literacy-friendly and culturally appropriate educational materials, you must first understand who makes up your patient population. In other words, what are their key characteristics?

Consider gathering the following demographic information of your patient population:

- Age
- Annual household income/ socioeconomic status
- Disability status
- Gender
- Highest level of education
- Physical location
- Preferred language of communication
- Race/ethnicity

In addition to demographic information, inquire about culture. Studies have shown that cultural differences between patients and practitioners can impair effective communication, which is essential for successful healthcare encounters and health outcomes.

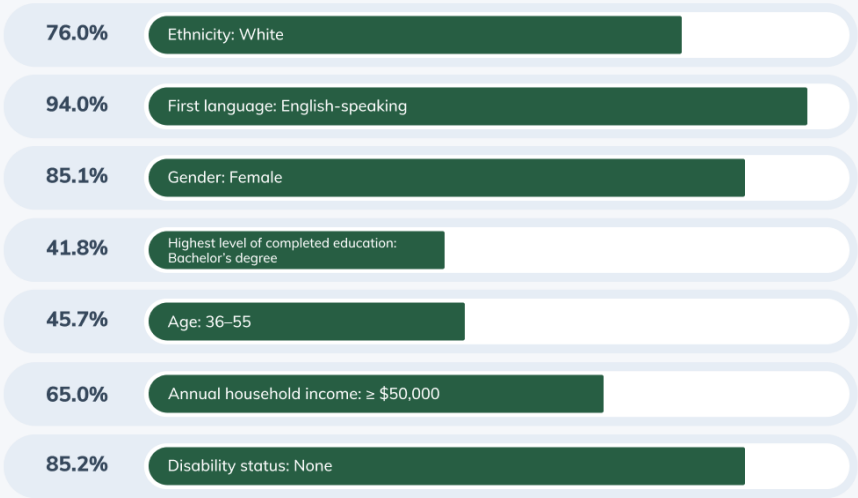
Religious and cultural beliefs and ethnic customs can influence how patients understand health concepts, how they take care of themselves, how they make health-related decisions, and how they understand and act upon health information relayed by their healthcare providers. (Brega et al. 2015) (Shaw et al. 2009) Health literacy interventions that fail to consider cultural beliefs are unlikely to meet the needs of those struggling with low health literacy.

Asking patients respectfully about their health-related beliefs, customs, and values can help practitioners better understand and care for their patients. Practitioners can approach the subject by asking patients the following open-ended questions:

- "Tell me about your cultural beliefs or religious practices that would help me take better care of you."
- "What dietary restrictions should we consider as we develop your food plan?" (Brega et al. 2015)

Of note, culture extends beyond race, ethnicity, and religious practices. For example, individuals may have cultural practices relating to their gender identity, sexual orientation, disability status, and health condition.

Understanding the importance of knowing our patient user base to create relevant and culturally appropriate educational materials, we included demographic questions within our survey. These questions revealed the following data:



Resources for cultural awareness:

Culture, Language, and Health Literacy

EthnoMed

LGBTQ2SIA+ glossary

Think Cultural Health

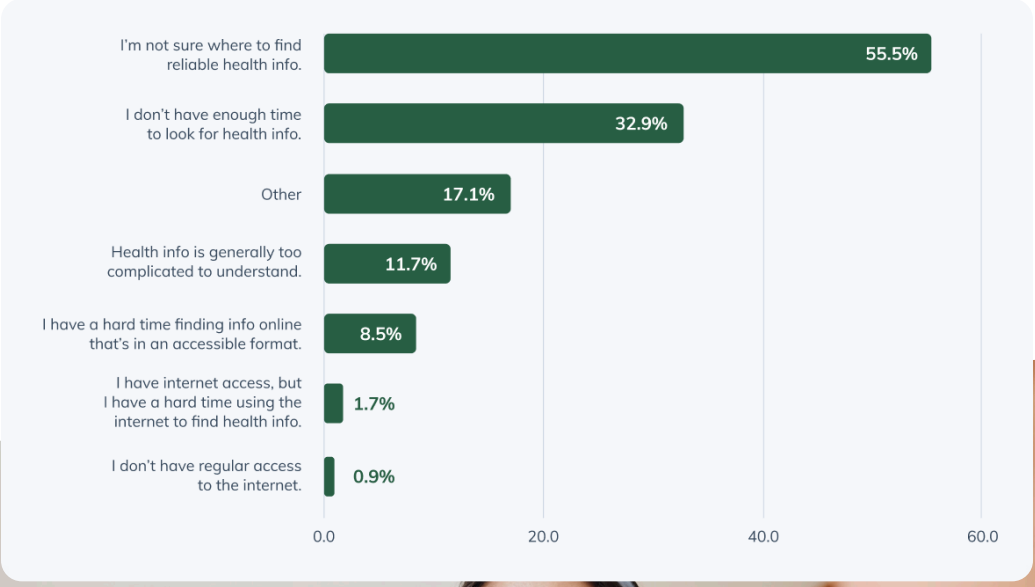
2. Identify your patients' educational barriers, needs, and preferences

In addition to demographic information, it is also important to inquire about your patient populations' educational barriers, needs, and preferences.

What educational barriers does your patient population face?

Health literacy research has identified many educational barriers that can hinder a person's ability to find, understand, and use health information to inform health-related decisions and actions for themselves and others. Below are common barriers cited in the literature; however, it is not an exhaustive list. The barriers are organized from most common to least common according to the results from our survey. Figure 17 illustrates the results from our patient user survey.

Figure 17. Barriers that prevent searching or finding health information (n=750)



A. Reliable, high-quality online health information is hard to find

One of the biggest concerns regarding online health information is quality. Various systematic reviews analyzing the available online information on specific health topics have found that many websites provide poor-quality information. (Daraz et al. 2019) (Hirsch et al. 2017)(Raptis et al. 2019)

Additionally, finding high-quality websites in a sea of low-quality websites can be extremely difficult, especially for patients with low health literacy. (Raptis et al. 2019)

The number one health literacy barrier identified by our survey participants was "I'm not sure where to find reliable health information" (55.5%) (Figure 17). Interestingly, only 12.5% of participants had previously indicated that they "somewhat disagree" or "strongly disagree" that reliable health information is easy to find.

These conflicting findings may be the result of how both questions were phrased and structured. For example, when asked how strongly they agree with the statement: "I can easily find reliable health information online," participants could only select one option out of five. However, when asked "What barriers prevent you from searching for or finding health information?", participants could select as many options as needed.

These differences may have led participants to interpret these questions differently. Perhaps they felt that health information is readily available; however, they do not feel confident in determining the reliability of said health information.

Of note, when stratified "How strongly do you agree with the following statement?: I can easily find reliable health information online" with self-perceived levels of health knowledge (i.e., health literacy), we noticed that the percentage of participants who "strongly agreed" increased as health literacy increased.

B. There is not enough time

Time scarcity is a commonly cited barrier to behavioral change like physical activity and healthy eating/meal planning. (Venn and Strazdins 2017) Unfortunately, there appears to be a lack of studies investigating time scarcity as a barrier to developing health literacy skills such as searching for online health information.

Our survey identified "lack of time" as the second most common barrier to searching or finding health information (Figure 17). Further studies examining time scarcity as a barrier to developing personal health literacy skills are warranted.

C. Other barriers

Approximately 17% of participants selected "other," making it the third most common barrier to searching or finding health information (Figure 17). Participants who selected this option provided the following barriers:

- Not being able to trust the information or the source of information
- Experiencing condition-specific barriers (i.e., brain fog)
- Becoming overwhelmed by the amount of information
- Not feeling motivated to deep dive and triple-check information found online
- Not having free access to medical journals
- Not being able to find reliable studies

D. Educational materials are too complex to read

Numerous studies have found discrepancies between patient health literacy levels and the reading level of patient education materials. (Behmer Hansen et al. 2020)(Hunter et al. 2012)(Imoisili et al. 2017)(Ryan et al. 2014)

Signs, public health information, medical instructions, and important medical documents such as informed consent forms often include complex technical terminology that makes them difficult to read and use. (Toolkit for Making Written Material Clear and Effective 2020)

Surprisingly, over half of the participants (> 66%) in our patient-user survey, regardless of their self-rated level of health knowledge (i.e., health literacy), "strongly agreed" that educational materials provided by their healthcare practitioners are easy to understand.

When asked directly what barriers prevent them from searching or finding health information, only 11.7% selected "health information is generally too complicated to understand" as a barrier, making it the fourth most common barrier (Figure 16).

E. Accessible online health information is hard to find

A 2021 exploratory cross-country study evaluated the accessibility of multiple public health websites in 25 countries. The author found that most websites had critical accessibility barriers. Out of the 25 websites evaluated, only one (Italy) had less than five accessibility errors. Health Canada's English and French web pages each had 29 accessibility errors, while the United States' Department of Health and Human Services web page had 53 accessibility errors. (Alajarmeh 2022)

The inaccessibility of online health content is a significant barrier to individuals with disabilities and interferes significantly with their ability to find, understand, and use online health information.

These limitations are not unique to online information. Paper educational materials, which are generally free, can be costly to individuals with visual impairments as they may need to hire a reader, scan the documents to a computer, or use a screen reader to access the information provided. (Harrison et al. 2010)

Approximately 9% of our survey participants indicated that finding health information in an accessible format prevented them from searching or finding health information. The survey itself may not have been accessible for individuals with disabilities, which may have led to an underestimation of the significance of this barrier.

F. Decreased access to digital devices and/or the internet

The use of online health information has increased in popularity over the years. Historically, research has shown **lower access to and use of** digital technologies by individuals from marginalized and minoritized racial/ethnic groups, individuals of lower socioeconomic status, older adults, (Bailey et al. 2015) and individuals with disabilities. However, some studies have found no link between health literacy levels and access to and use of digital devices. (Manganello et al. 2017)

A possible explanation for the discrepancy between these findings could be the dramatic increase in internet use over the years. In 2000, approximately 52% of American adults used the internet, which increased to 88% in 2016. (Chen et al. 2018)

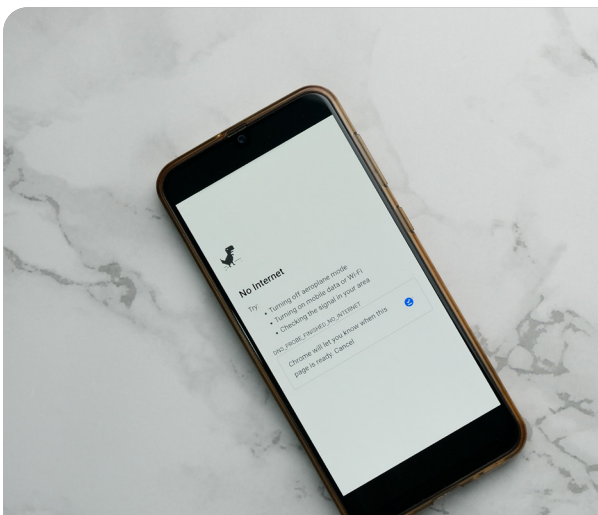
Only 2.6% of survey participants indicated that they either don't have regular access to the internet or have a hard time using the internet to find health information (Figure 17). Decreased access to digital devices and/or the internet appear to be unlikely barriers to searching or finding health information for this population.

What are your patient population's educational needs and preferences?

Information about educational needs and preferences will allow you to further customize educational materials to your patient population's specific health literacy needs, thus potentially improving health outcomes.

Questions to consider include:

- What delivery format do they prefer?
- What length of health information do they prefer?
- What language do they prefer?
- Do they require accessible content?
- Do they prefer digital or hard copy resources?



Our survey demonstrated that:

45.3% and 51.1% of participants prefer short- (take 5 minutes or less to read) and medium-length (take between 5 and 20 minutes to read) educational content (respectively).

59.6% of participants prefer written health content.

66.6%, 64.1%, 48.0% and 47.6% of participants prefer to learn about supplement ingredients, nutrition and diet, lifestyle, and health conditions (respectively).

3. Create health literacy-friendly educational materials

Once you know your patient population's demographic information and educational barriers, needs, and preferences, you can start creating your educational materials. When creating or sourcing educational materials, consider the following key criteria outlined in the CDC's guide, Simply put: A guide for creating easy-to-understand materials.

Communicate your message clearly

- ☐ Give the most important information first.
- ☐ Use clear, everyday language.
- ☐ Limit the number of messages to three or four per document or section of your document.
- ☐ Use an active voice and a positive tone.
- ☐ Use analogies familiar to your audience.
- ☐ Avoid unnecessary abbreviations and acronyms.
- ☐ Keep sentences (8–10 words) and paragraphs (3–5 sentences) short.

Use easy-to-read fonts

- ☐ Main text: 12–14 points
- ☐ Headings: ≥ two points larger than the main text
- ☐ Use sans serif fonts for digital resources.
- ☐ Avoid using ALL CAPS.
- ☐ Use **bold** to emphasize words. Avoid *italics* and underlining.

Optimize design and layout

- ☐ Use dark lettering on a light background.
- ☐ Breakdown lists (3–7 items per list).
- ☐ Use white space to enhance readability.
- ☐ Avoid justified margins.

Use images/photographs/ illustrations effectively

Images should:

- ☐ Enhance your message rather than simply decorate your educational material
- ☐ Show your audience what to do or take, not what not to do
- ☐ Be culturally appropriate (e.g., race/ethnicity, age, gender, disability)
- ☐ Be labeled with brief descriptions that include your key message
- ☐ Present one message only

4. Test your educational materials and ask for patient feedback

If possible, all educational materials should be evaluated using state-of-the-art assessment tools (e.g., readability formulas and understandability assessments) and patient feedback.

Use readability formulas

Readability formulas focus on the length of words and sentences and estimate how difficult the text is to read (e.g., The Fry formula, SMOG, and Flesh Reading Ease). (Brega et al. 2015) Consider using these formulas as part of the initial assessment of your educational materials. However, these formulas do not provide feedback or instruction on how to improve the text, nor do they consider many of the criteria mentioned above, such as layout, culture, and the effective use of images.

Use understandability assessments

Understandability assessments examine factors aside from readability that can influence comprehension, such as word choice, organization of information, and formatting.

- Patient Education Materials Assessment Tool (PEMAT) and PEMAT Tool for Audiovisual Materials (PEMAT-A/V): provide information regarding how easy materials are to understand and act upon
- Suitability Assessment of Materials (SAM): assesses the suitability and cultural appropriateness of materials
- CDC's Clear Communication Index: assesses the clarity and ease of use of written information (Brega et al. 2015)

Seek out patient feedback

Involve your patients in evaluating forms and educational materials that you've either developed yourself or sourced externally. When following up with patients, consider asking them any of the following questions:

- "Are any parts clear and easy to understand? Which?"
- "What did you find confusing?"
- "Which parts or words are hard to understand?"
- "Is there anything offensive?"
- "What is helpful and what isn't? How?"
- "Does it suggest that you take any action? Is it clear what to do?" (Get Patient Feedback: Tool #17 2020)

You can also consider asking your patients for their help by having them complete a short assessment form, such as this patient feedback form, regarding a specific educational material.

5. Use educational materials effectively in clinical practice

Patients with limited health literacy often have low literacy skills. As a result, merely providing patients with handouts may not be sufficient. In this section, the focus will be placed on how to effectively use educational materials from a clinical perspective.

Do not rely solely on educational materials

It is important not to rely solely on educational materials or assume that patients will read the provided handouts or visit the suggested online resources. Educational materials should always supplement, not replace, verbal instructions or education. (AHRQ: Ten Attributes of Health Litera...)

Review educational materials with patients

Review handouts with the patient during the clinical appointment by circling or highlighting relevant and essential information. Use the teach-back method to confirm understanding. (Brega et al. 2015)

For educational resources consumed outside appointments like videos, podcasts, and websites, always follow up with the patient to verify understanding and answer questions. Furthermore, referring back to these resources can emphasize the importance of the educational material. Note that these resources may need to be given to the patient on more than one occasion. (Brega et al. 2015)

6. Manage educational materials

If your clinic or organization creates, manages, or provides educational materials, it is essential to monitor and organize regularly shared educational handouts, whether physical or electronic.

Each quarter, review the following:

- ☐ Did you run out of any of your physical educational materials (e.g., printed handouts and guides)?
- ☐ How many educational materials were assessed? Of the assessed materials, how many were considered poor, how many were revised, and how many were replaced?
- ☐ Are the handouts available through your electronic health record (EHR) up-to-date?
- ☐ Are the hyperlinks for digital educational resources functional?
- ☐ Were staff members able to consistently find the recommended educational materials either physically or digitally?
- ☐ Is the system for managing educational materials performing better or worse than the previous quarter? (Brega et al. 2015)

Consider using this Educational resources: Audit tracking sheet to help stay on track.

Although we chose to focus on educational resources, many of these principles can be applied to a variety of written materials such as intake and consent forms, treatment plans, websites, informational kiosks, and signs.

Getting started

The various steps required to create health literacy-friendly educational materials may feel overwhelming, especially for solo practitioners and small practices. We suggest starting with choosing one educational material, perhaps your most popular handout, and going through the checklist provided in "Create health literacy-friendly educational materials." The next time you provide this updated version of your handout, ask your patient for feedback at their follow-up appointment.

With your first revised handout completed, you may want to create a tracking sheet and audit schedule (see Educational resources: Audit tracking sheet). The cadence at which you audit your educational and written materials (e.g., website, consent forms) is highly dependent on your workload. You may want to start auditing one educational material per quarter, and as you become familiar with the process, increase the audit rate to once per month.

Over time, you may also want to consider gathering the sociodemographic information of your patient population in order to provide more culturally relevant educational materials. Additionally, you may also want to inquire about your patient populations' educational needs, preferences, and barriers.

If you use an electronic health record, you may be able to gather your patient's sociodemographic information from there. Sending out a survey is a great way to gather information about your patient's sociodemographics, cultural health beliefs, and educational needs, preferences, and barriers (see sections 1 and 2). You could also include questions about their cultural health beliefs and educational needs, preferences, and barriers in your intake forms or ask them as part of your initial intake.

Formal assessment tools like readability formulas (e.g., Flesch Reading Ease, and Fry Formula, SMOG), understandability assessments (e.g., PEMAT, PEMAT-A/V, SAM, Clear Communication Index), and formal patient feedback (e.g., patient feedback form) can be integrated over time into your auditing process.

Improving organizational health literacy

Key takeaways

A health-literate healthcare organization:

- Has leadership that makes health literacy integral to its mission, structure, and operations
- Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement
- Prepares the workforce to be health-literate and monitors progress
- Includes populations served in the design, implementation, and evaluation of health information and services
- Meets the needs of patients with low health literacy while avoiding stigmatization
- Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact
- Provides easy access to health information and services and navigation assistance
- Designs and distributes print, audiovisual, and social media content that is easy to understand and act on
- Addresses health literacy in high-risk situations
- Communicates clearly what health plans cover and what individuals will have to pay for services

Despite being acknowledged as a key determinant of health, commitment to improving organizational health literacy is poor. Irrespective of size, all organizations—from conventional medical systems like hospitals to multi-interdisciplinary, integrative, complementary, and alternative medical clinics—are responsible for equitably enabling "individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others." (Brach et al. 2012)

However, due to poor leadership commitment (i.e., board members and clinic owners) to health literacy and health literacy-friendly environments, there is an absence of policies, procedures, and protocols supporting health literacy practices. (Charoghchian Khorasani et al. 2020)

Consequently, patients may be unable to successfully navigate the clinic's website, book an online appointment, sign in to their virtual appointment, or locate the physical location. They may experience difficulties effectively communicating with their healthcare providers and/or clinic staff, as well as accessing their patient portal, treatment plans, and recommended educational materials.

When health literacy is not prioritized within an organization, practitioners and staff are unlikely to engage in health literacy training, further impacting patient health literacy and health outcomes. (Charoghchian Khorasani et al. 2020)

In 2012, the Institute of Medicine (IOM), now the National Academy of Medicine, published a white paper titled "Ten Attributes of Health Literate Health Care Organizations." This paper discusses what healthcare organizations can do to improve organizational health literacy. Although improving organizational health literacy is beneficial for all patients, it's especially beneficial for patients with limited health literacy. (Brach et al. 2012)

Attributes of a health-literate healthcare organization

1. Has leadership that makes health literacy integral to its mission, structure, and operations

A health-literate organization goes beyond simply initiating a few projects aimed at addressing health literacy; it infuses health literacy throughout the organization and embraces it as a key organizational value. Leadership buy-in is crucial to ensuring the successful implementation and maintenance of organizational health literacy goals. (Brach et al. 2012)

2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement

Health-literate healthcare organizations use health literacy to inform their strategic and operational planning and integrate it into all their activities. (Brach et al. 2012)

3. Prepares the workforce to be health-literate and monitors progress

Organization-wide health literacy training can help establish a culture where everyone contributes to the unified goal of promoting successful communication. Healthcare practitioners (e.g., community health workers, integrative healthcare practitioners, medical assistants, nurses, pharmacists, and physicians), staff (e.g., administrative assistants and billing clerks), and organizational executives should all be aware of the issues that individuals with low health literacy face and how they can mitigate these barriers. (Brach et al. 2012)

4. Includes populations served in the design, implementation, and evaluation of health information and services

Unfortunately, community members are rarely consulted during the development and design of informational resources and services. When planning programs and materials addressing health literacy, it is especially important to consider the voices and perspectives of individuals with low health literacy. A participatory approach to design can result in products better suited to meet the needs of this population. (Brach et al. 2012)

5. Meets the needs of patients with low health literacy while avoiding stigmatization

Health-literate healthcare organizations simplify all communications as much as possible, verify comprehension, and never assume which patients understand or require additional support. Furthermore, they do not rely solely on written materials to communicate crucial information because they know that individuals with limited health literacy often have low literacy skills. They understand the importance of treating all patients equally to prevent feelings of embarrassment and shame. (Brach et al. 2012)

6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact

Health-literate healthcare organizations understand that clear communication is essential at all levels of contact (e.g., explaining bills, giving directions, scheduling an appointment), not only during clinical interactions. (Brach et al. 2012)

7. Provides easy access to health information and services and navigation assistance

Navigation of the traditional healthcare system imposes high health literacy demands on patients. Health-literate healthcare organizations go beyond improving signage, using architectural design and staff to help patients find their way. They steer patients towards accurate, easy-to-understand, and actionable health information, and insist on using user-friendly products (e.g., patient portal). (Brach et al. 2012)

8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on

Health-literate healthcare organizations recognize that most educational materials are too technical or complex for the majority of patients, especially patients with limited health literacy. As a result, these organizations strive to create and/or make available appropriate educational materials for their target audiences. (Brach et al. 2012)

9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines

Certain situations and topics (e.g., surgery, transition care, administration of pharmaceuticals with potentially severe adverse effects, and end-of-life care) demand greater understanding from patients. Health-literate healthcare organizations understand the importance of identifying these situations and developing safeguards, standards, and processes to ensure patients fully understand the communicated information. (Brach et al. 2012)

10. Communicates clearly what health plans cover and what individuals will have to pay for services

Too often, patients are expected to make healthcare decisions without first knowing the out-of-pocket cost. Health-literate healthcare organizations understand the importance of clearly communicating coverage and costs of medicines and services to patients. (Brach et al. 2012)

Part 3

Interviews with health literacy experts

Becoming a health literate organization

Interviews with health literacy experts

Ms. Alison Caballero, MPH, CHES

Ms. Caballero, MPH, is a nationally certified health education specialist with over 20 years of experience and is currently the director of the Center for Health Literacy and an associate professor at the University of Arkansas for Medical Sciences (UMAS).

Under her leadership, the Center for Health Literacy aims to improve health by making health information easier to understand.

Her team provides various services such as health communications training, plain language assessment and editing, Spanish translation, health education materials development, and field testing.

Welcome, Ms. Caballero. You've been working at the Center for Health Literacy for the last five years. What have you learned about health literacy during your time at the center?

Before working with the Center for Health Literacy, I was aware that messages in all formats needed to be free from jargon so everyone could understand them, and I understood that some organizations desired or required a specific reading level for their materials.

But the nuanced skill set that my colleagues and I have developed in "plain language writing" only occurred during my tenure with the Center for Health Literacy. Only through daily immersion in plain language writing, editing, and a plethora of formative feedback from formal assessment tools, colleagues, and field testing participants have I been able to gain such depth in this technical writing style.

And on the note of field testing, I must acknowledge the community members who help us review materials, as I cannot think of a single field testing session during which I've not learned something from them.

I have also learned that the collective "we" —the health professions—still have a lot to learn. Unfortunately, health literacy competencies are not routinely integrated into formal training programs in public health or health professions.

Even in our academic health system, where the Center for Health Literacy has done tremendous work to raise awareness about the importance of health literacy, and where great strides have been made to integrate health literacy into the longitudinal Interprofessional Education curriculum, comprehensive curricular integration of all-important health literacy competencies across training programs remains a work in progress.

Among other services, your team conducts plain language assessments of educational materials. What are the most common writing mistakes encountered by your team when conducting these assessments?

Opportunities to improve readability are almost always present. Many health materials are written by those with expert training in their disciplines, and we tend to see longer sentences and longer words than desirable.

Then, going a layer deeper toward optimizing potential for understanding, we also see jargon—not just the obvious scientific and medical jargon but also industry jargon (e.g., insurance terms). We do need to evaluate health terms with caution, as there are instances in which readers need to learn new terms, such as names of their diagnoses and medications. However, these terms must be defined using plain language.

Beyond word choice, we often see opportunities to improve how information is organized. I have been part of the initial development of many health education documents. The number of professionals involved, quantity of important messages, and the revision process itself can leave the content less organized than desired, making it difficult for learners to find important information.

A final plain language attribute I will mention is providing adequate detail for the learner to take action. I share this example to illustrate this point: My team was reviewing an after-visit summary for a health system. In a section labeled "What to do next," the instructions read: "Follow up with primary care in two weeks." In a community field testing session, we asked what that phrase meant to them in terms of the learner's required actions. One participant said it meant that in two weeks, they needed to call their primary care doctor and make an appointment. Another argued that they needed to make that call now in hopes of securing an appointment to take place in two weeks. A third suggested that no action was required for the patient since the hospital usually makes follow-up appointments on their behalf. A fourth then questioned whether "primary care doctor" meant the usual family practice physician or the main specialty doctor who had attended the recent hospital stay. Clearly, the instructions were not actionable.

This last type of improvement we make to many materials doesn't fall under the umbrella of plain language editing but rather has to do with content selection using health behavior theory. Many materials we review include the "what," "when," and "how," but often we need to help our learners understand the "why." Decisions and actions about adopting health behaviors are complex, with many contributing factors. Often, we need to help learners more accurately perceive their risk of susceptibility to a health problem or its severity. Or, we may need to provide information that helps them recognize the benefits of a recommended health behavior or address perceived barriers to taking action. We turn to published health behavior theories to help guide this portion of our work.

What top recommendation(s) do you give health communicators (e.g., providers, educators) wanting to improve their educational content/communications (e.g., writing, speaking, etc.)?

We encourage communicators to consider two big ideas when developing content. First, use health behavior theory to help you get the most relevant information on the page (or video or talk). Tailoring content in a way that helps shape knowledge, attitudes, and intentions toward desired behavior can help you stay focused on key messages.

Then, write or speak using plain language. This is a broad topic and one that we love to train health communicators to do. It includes everything from logically organizing the content to choosing words and sentence structures with care to incorporating graphics and tools that facilitate understanding and action.

With written tools prepared in advance, I would suggest formal evaluation. Tools like readability formulas and the Patient Education Materials Assessment Tool can provide objective evaluation, and community field testing can engage the most important part of the development team—the end users.

Once content has been carefully crafted with theory and plain language, we urge you to consider who is the best message deliverer, and it is not always the team who developed the message! When delivering content verbally, always use teach-back to confirm understanding. This is a specific method that involves explicitly inviting the learner to teach back what they learned so that you can correct any misunderstandings and reinforce messages as needed.

How can healthcare organizations/ practitioners better support individuals with low health literacy?

We should avoid making assumptions about anyone's health literacy. Implicit bias can spring from many factors, such as known or perceived educational level, appearance, or hometown, and this can lead us to over- or underestimate health literacy skills.

Only about 12 out of 100 adults in the United States have proficient health literacy skills. I like to think I'm one of those 12, but am quite certain that if I were to present at an emergency department with a parent or spouse, learning barriers in the healthcare environment would alter my ability to learn. Examples of those barriers include pain, stress, fear, anxiety, sedation, and other influences of medications. So, we encourage taking a "universal precautions" approach and making your best effort to speak to everyone in plain language and to confirm understanding using teach-back. Plain language benefits everyone.

That said, it is a worthwhile endeavor to improve organizational health literacy for the benefit of all those you serve. At an organizational level, a formal assessment can help determine the current state and identify opportunities to build on strengths or address challenges.

There are several tools available online to help with such assessments. If your organization's leaders are not yet committed to a full organizational assessment, you may consider your organization's current strategic objectives and explore how improving communication can support those. For example, if your organization is working to reduce complications from sepsis, you can evaluate patient-facing materials to ensure they are optimally readable, understandable, and actionable.

In your opinion, what resources could healthcare providers and organizations offer patients to help develop their health literacy skills?

Building health literacy skills could start in public education. While most educational systems have learning objectives for health education (e.g., how to choose nutritious foods or the importance of helmet use), objectives focused on health literacy may be lacking. Examples of skills that could be introduced early and reinforced longitudinally include identifying authoritative sources of health information, discerning the quality of social media posts, evaluating the quality of research findings, and becoming confident communicators during healthcare visits.

For those working in public health and healthcare, consider these opportunities to build personal health literacy skills. Community health education seminars could focus on how to prepare for doctors visits, and patient portals could include worksheets to help patients practice that skill. Another approach might be to shadow a patient through their journey with your organization and identify common situations that leave patients confused or lacking confidence in the next steps. That journey begins with exploring your organization's services (perhaps online or by telephone) and extends well beyond the exam room (to billing communications, for example). This type of assessment might help you identify opportunities to provide brief educational interventions focused on the communication skills your learners need most.

How does improving health education by attending to health literacy impact behavioral change?

Behavior change theory tells us that there are numerous antecedents to behavioral choice. Examples include knowledge, attitudes, subjective norms, and self-efficacy. Health education programming is a deliberate effort to change these or other factors that influence individuals, and information exchange is a likely prerequisite for all of them.

For example, if you aim to decrease barriers to influenza vaccine uptake and your community names cost as a perceived barrier, you would want to provide information about where and how to access free or low-cost vaccines. If those details are omitted, illogically placed, not in plain language, or delivered by someone other than a trusted health communicator, the success of your message is at risk.

Plain language benefits everyone, so providing health education messaging that is readable, understandable, and actionable can help level the playing field and enhance equitable access to your messages. In addition, clear communication could help to build trust between professionals and the public and thus present additional opportunities to address inequities.

More studies are needed to better understand the value of health literacy interventions, advance our collective learning in this area, and stimulate broad commitment to this work.

Thank you, Ms. Caballero, for your time.

Dr. Amie Steel, PhD, ND, MPH

Dr. Amie Steel, PhD, ND, MPH, is a naturopath and health service researcher from the Australian Research Centre in Complementary and Integrative Medicine at the University of Technology Sydney

She applies her mixed methodological expertise to complementary medicine research, among other topics, and has authored and co-authored many scientific papers throughout her career.

Welcome, Dr. Steel. From your list of publications, it's clear that you are an accomplished researcher. Interestingly, since the start of your career, you have investigated the role that complementary medicine plays in various healthcare sectors. Tell us about your story; what led you to study/research complementary medicine?

I had trained as a naturopath and was in clinical practice but felt drawn to undertake further study. I enrolled in a Masters of Public Health and was inspired by the global thinking that public health engendered, but also excited by the alignment between the public health viewpoint and naturopathic philosophies and principles.

I decided to use my public health training to better understand the role and contribution of traditional medicine professions such as naturopathy within contemporary health systems. I believe that the community, the health system, and traditional medicine professions have a lot to gain by critically examining traditional medicine practices, outcomes, and the interface with the wider health system and patient use of health services.

Tell us a little about the work you're currently doing?

I have a broad suite of research that includes examining the role naturopathy and other traditional medicine professions play in improving health in the community, beyond their use of treatments and practices such as herbal medicine and nutritional supplements.

At present, I am particularly interested in how naturopathic practitioners educate their patients to make better health choices and how they listen to their patients to better understand their health needs.

What has your research revealed about health literacy or health education?

My research shows that naturopathic practitioners may be playing an underappreciated role in health promotion, including improving health literacy in the wider community. This is an important aspect of healthcare that governments are trying to address—particularly in this age of chronic illness—and we need better evidence to show the contribution that naturopathic practitioners are making, so we can communicate that to governments and work to ensure better integration of naturopathic care into the health system.

In your opinion, what role does complementary medicine play in health education?

This is a two-fold question—in some ways, complementary medicine emphasizes the need for better health literacy and wider-scoped health education for the community, particularly given so much complementary medicine use is consumer-driven.

On the other hand, traditional (i.e., complementary, alternative, or integrative medicine) practitioners have a key and underutilized role in providing such education to the community and other health professionals. We have the highest level of training in the medicines and practices that patients may be using, and as such we have an important role in educating the public about the safety and effectiveness of commonly used complementary medicine.

We also have a holistic understanding of health and wellness that can be shared with patients, the public, and other health professionals to help strengthen health policy and service delivery more generally.

What top recommendations would you give to a practitioner who wishes to become a health knowledge mobilizer?

The practice of knowledge mobilization is an interesting one, and clinicians are likely already health knowledge mobilizers. However, there are likely skills and practices from other areas of knowledge mobilization that clinicians can learn from.

For example, clinicians are often not trained in developing effective patient handouts. As such, some of the resources that may be used in clinical practice, and given to patients, may not be as impactful as they otherwise could be. But such skills are easily acquired, as there are a lot of guides about preparing resources, such as patient handouts, that have been developed for public health and health promotion practitioners that clinicians can easily access and use.

From another perspective, naturopathic practitioners and other traditional medicine clinicians have the opportunity and responsibility to document clinical practice approaches and outcomes that draw on and value patient knowledge and wisdom and share these with the wider clinical and research community. The best vehicle to do this is by publishing case reports in peer-reviewed journals.

This is important because knowledge mobilization is not only about educating the community, but also about sharing clinical experience and patient wisdom with other health providers and policymakers. All knowledge has value and needs to be mobilized so it can be accessed by those without it.

What do you think is the biggest impact of health education/improving health literacy on health equity and behavioral change?

We first have to start with a clear understanding of the audience if we want to significantly impact health education and improve health literacy. Considering the social determinants of health is critical when providing health education, and any activities aimed at improving health literacy need to be developed with a clear awareness of the starting point of the target population, including their health knowledge, social supports, financial resources, and motivations for health change.

This is why areas of health promotion are adopting practices developed through marketing and advertising, but using it for the benefit of community health. This approach is called "social marketing," and it treats a health intervention or behavior change as a "product" and engages with the target population to ensure it is packaged and presented in a format that resonates with them.

However, we also need to be aware that there are often larger forces at play affecting an individual's health behavior, and for this reason, we will not achieve the full benefits of health education and improved health literacy without also affecting change in policies that create structural barriers to an individual's ability to make positive health choices, such as socioeconomic, ethnicity, gendered influences.

Thank you, Dr. Steel, for your time.

Dr. Holly Lucille, ND, RN

Dr. Holly Lucille, ND, RN, is a naturopathic doctor with a private practice in Los Angeles. She is an experienced lecturer and has made numerous appearances on national media programs and radio shows.

Dr. Lucille is currently a senior medical advisor at Fullscript and the chair of the Institute for Natural Medicine. Among her many accomplishments, she was awarded the SCNM Legacy Award for her "contribution to the advancement and development of the field of naturopathic medicine."

Welcome, Dr. Lucille, ND. You are a very accomplished clinician and educator. You maintain not only a clinical practice, but you also use various social media platforms to empower individuals with health knowledge. Why is educating people so important to you?

As the daughter of two pharmacists, the "take this medication" approach never sat well with me. I love to cook and I could cook you a wonderful fish dinner. But if I taught you how to cook, how much more empowered would you feel, and how much more cost-effective would your life be. To me, knowledge is power, and self-knowledge is a superpower.

What drives my passion for teaching is being able to empower people with knowledge so that they can take ownership of their health. Recommending patients to change their diet and lifestyle, and treating root causes with evidence-based doses of botanicals or supplements, sometimes multiple throughout the day, is not always easy.

As healthcare practitioners, we need to educate and empower our patients to take responsibility for their health because, at the end of the day, they are the ones who decide whether or not they will follow our recommendations.

Does health education improve treatment adherence?

First off, I want to point out that there is a difference between compliance and adherence. Compliance is unidirectional, where the practitioner tells the patient what to do. Adherence, on the other hand, is more sticky—it's a faithful attachment to something.

I always ask my patients, "How can we make our work more sticky?" For example, "With dietary changes, do you want a weekly check-in, would you like to use a digital device to track your food, or would you like educational handouts with additional information?".

Everybody is different, everybody behaves differently, everybody learns differently, and everybody's lifestyle is different. You have to find the sweet spot for that person to help them remain adherent.

What top recommendation(s) would you give to a practitioner who wishes to implement more teaching in their clinical visits?

I always say, "I can't work without you." I make sure that people understand that our visits are going to be very different from any other visit they have ever had. I also show empathy and compassion, and I tell patients, "Listen, I am going to ask a lot from you, but I do think that the payoff is going to be worth it." That has been super important for me.

It's important that we focus on the individual in front of us even when we use protocols to help guide our treatment plans. Also, create analogies and ask patients a lot of questions. Get them in the game. Ask them questions even if you already know the answer. Make sure that they stay engaged with you to build that partnership.

Our research has shown that individuals with low health literacy ask their healthcare provider fewer questions. How do you encourage patients to ask questions?

Be super gentle, and reassure patients that there is no wrong answer. Even for me, the more I know, the more I realize I don't know. I was a registered nurse before going to medical school and I am constantly learning.

What common health barriers have you encountered in your clinical practice?

Health is such a personal thing. From a patient perspective, a common barrier is that we don't want to give up certain things like coffee or happy hour, for example. We don't want to lean in and look inside.

For practitioners, a barrier would be not knowing your audience. You can feel so good about what you did in that visit, but if the patient doesn't have the capacity or the knowledge, or if they don't have the motivation to go and execute the strategy, then it's going to blow back on you, the practitioner.

Thank you, Dr. Lucille, for your time. Any final words you would like to share?

Yes, as practitioners, we need to understand that patient health education is a need. We also have to ask ourselves how we can become better teachers for our patients. In addition, I think it's equally important that we teach our practitioners as much as our patients.

Dr. Paula Gardiner, MD, MPH

Dr. Paula Gardiner, MD, MPH, is an Associate Professor in the Department of Family Medicine at Boston University School of Medicine. She has joined the Center for Mindfulness and Compassion at Cambridge Health Alliance as the primary care implementation research director. Her passion is studying and teaching clinicians how to facilitate and implement group medical visits.

Dr. Gardiner is currently researching the adaptive role of Integrative Medicine Group Visits (IMGV), which combines mindfulness-based stress reduction and medical group visits, in supporting health behavior change and reducing pain and stress.

Welcome, Dr. Gardiner. Your current research project on the adaptive role of integrative medicine within group medical visits sounds very interesting. What got you interested in studying, teaching, and facilitating group medical visits?

I did my family medicine residency at the Boston Medical Center. The medical center serves a low-income, racially and ethnically diverse population. For example, when I worked there in the late 2010s, the medical center had about 7,000 refugee visits with over 114 languages spoken at any time. I became very interested in the idea of bringing integrative medicine to these patients.

Then while I was doing my Master's in Public Health at Harvard, I became really interested in health literacy because I was trying to figure out how to educate the members of this community about integrative medicine.

The group medical visits came out of this need to educate people about a new way they can care for themselves that is not medication-based.

At the time, we were doing one-on-one visits, which were very time-intensive. We found that if we gathered many patients at once, we would only need to give the patient health talk once. More importantly, the group members could then support each other in trying these integrative modalities. For example, imagine a group acupuncture session with a room full of acupuncture-naive patients. Having one patient say, "I've had acupuncture before, and the needles don't hurt," is the best way to encourage the others to try acupuncture. Because the community supports trying new things, it creates a collective literacy.

In your opinion, what common health literacy barrier do immigrants and refugees face when interacting with the Western medical system?

There is a significant culture clash between immigrants/refugees and the Western medical system. According to the WHO, 70% of the world's population uses plant-based medicine. So we have people coming into the United States bringing with them their traditional medicines. For example, in Haiti, it's Voodoo; in the Dominican Republic, it's Santeria; in India, it's Ayurveda; and in China, there is Traditional Chinese Medicine.

These individuals from diverse cultural backgrounds are now having to interact with the Western medical system. Not only is this system incredibly difficult to navigate (even for a highly health-literate individual), but there are also many new terms that make it difficult for people to understand and make health-related decisions.

Let me give you an example. Let's say a female patient immigrated to the United States from India. She has a spiritual tradition and has eaten a vegetarian diet throughout her life. She also grew up using Ayurveda plant-based medicines and lifestyle medicines. During her appointment with her doctor, they propose screening her breasts for breast cancer with a mammogram and prescribing her a pill for her high blood pressure. She is confused by these recommendations, especially the blood pressure medication, since her diet, now turned to a typical American diet, and weight gain are likely the causes. As you can see, not only is there a clash in culture but also a clash in values.

Can you tell us more about how culture influences health literacy?

Of course, let me give you an example. When we started a mindfulness-based stress reduction medical group visit, we decided to use the existing curriculum, which is a very well-known systematic meditation curriculum. However, the group members, mainly African American and Spanish-speaking patients of low income, did not find the curriculum helpful to use outside the classroom. The reason is fairly complicated, but essentially it didn't speak to them.

For example, the meditations and body scans were all 45-minutes long. Many of the patients didn't have 45-minutes to sit down and meditate. Some frequently moved between homeless shelters, and others didn't have a quiet space. Basically, it didn't work with the group's culture.

We ended up taking the curriculum through a series of patient advisory groups. These groups advised us on how to phrase certain things and what kinds of pictures to use. Essentially, the patient advisory groups created the curriculum. So now, when you look at the curriculum, all the images are images of people of color, and the language is very specific and meaningful to their culture.

The next thing we decided to do was translate some of these materials into Spanish. You might think, "Well, that sounds relatively easy; it will be the same thing but in Spanish." It wasn't easy. At one point, I was sitting around a table with individuals from four different Spanish-speaking countries, all of whom had a different word for "bean," as in "eat more beans."

Members of the dominant culture must let go of our perception that we know the right way to communicate in other cultures. It's all about cultural humility.

In what way do group medical visits increase health knowledge/literacy?

Group visits are all about health education and literacy. For example, let's say we are having a group session on vitamin D. The first thing we do is have an open discussion and have participants share what they know about vitamin D. The provider, who is facilitating the group, can then add or correct any misconceptions shared during the discussion.

For this specific group session, we typically have everyone's vitamin D levels tested beforehand. During the session, all the participants receive their vitamin D lab value, which promotes further discussion into what the numbers mean, what vitamin D deficiency means, and how we treat it. The conversation of treatment may have patients question whether they truly need to supplement or if they can get all their vitamin D needs from their diet and/or the sun. So part of what the groups do is they take real-life information and try to dispel the myths but bring out the health topics that are meaningful to the group.

Another example is in one of our diabetes groups. We talked about the sugar content of soda. We had clear soda bottles and we poured tablespoons of sugar into the soda bottle so that patients could see how much sugar is in soda. This helped the group members understand why they should avoid drinking soda. However, I remember there was a patient with a very high A1C, and I couldn't convince them to stop drinking soda. But with the support and accountability of the group, they finally did.

Generally, adherence is much higher when peers share their knowledge and experiences. Because of this, I will get a peer to share their experiences in the group whenever possible. If something is incorrect or medically unsafe, I step in, but otherwise, my job is to facilitate.

The group visits also allow you to address different types of learners (e.g., auditory, visual, and kinetic), which helps with health literacy. One issue with Western allopathic medicine is that it depends on someone being an auditory learner. But that's not how people remember to do things or change behavior.

In our group visits each week, we do something kinetic. Last week, I did a cooking demonstration to help address constipation. We discussed what the participants do when they feel constipated and what medications they take. But then we went into the kitchen and made a prune compote with rhubarb and dried fruit. Patients got to learn how to make their own medicine.

The other thing we see is patient activation or self-advocacy. Due to the complexities of the American medical system, there are many barriers to care. And for many chronic care patients, interacting with the medical system can be very traumatizing.

The groups allow patients to talk about their experiences and build advocacy and capacity skills to help them navigate the medical system. This could be as simple as practicing writing a list of what to talk to the doctor about.

There is also a lot of resource sharing, such as locations of shelters, restaurants that offer free lunch, community centers that have free yoga, and farmer's markets that accept SNAP (Supplemental Nutrition Assistance Program). That is all health literacy. Together, the group members start addressing the social determinants of health by lifting each other up.

What feedback have you received from patients participating in Integrative Medicine Group Visits?

The participants have shared many things, but I think the most important is that the group matters most. It's not the provider or the education but the peer group.

There seems to be something unique that happens during a group visit, like a special sauce. It's pretty amazing when you see participants take in the information shared in the group and then change their behavior, such as walking three times per week or giving up meat or something else that the group is working on.

What top recommendation(s) would you give a practitioner who wishes to implement more teaching in their clinical visits?

The first thing is to have a patient education source that works for your patient population. For example, I use the Veterans' Affairs Whole Health Education Handouts and the CDC (Centers for Disease Control and Prevention) to make my handouts. Then you want to customize your education so that patients can relate culturally to the information. Of course, we may not know our patients' culture, so we have to ask them. Once you draft up a patient information sheet, like the anti-inflammatory diet, ask patients if they can give you feedback on the handout, what they liked and what they didn't like. And they will.

Don't be afraid of failure or not having it perfect. Mock it up and get feedback; mock it up and get feedback again. The handout is going to speak differently to different patients. This process leads to two things: (1) your patients' health knowledge increases, and (2) you become a better teacher.

The second thing to consider is language preferences. It's very meaningful to patients when you can offer them educational resources in their native language. If translation is not possible, refer your patients to reliable online resources. For example, Medline Plus has health information in Spanish.

The third thing that is important to consider is experiential learning. For example, if you are prescribing a patient an inhaler or a spacer for their inhaler, have those things available in your office and show patients how to use them.

Thank you, Dr. Gardiner, for your time. Any final words you would like to share?

First, what has been most helpful to me is learning not to be afraid of failure. Second, I've learned to question where my dominant culture may be getting in the way of either under- or over-anticipating what my patients can or cannot do. Lastly, I hope readers understand that simply printing out a patient information sheet and handing it to your patient does not help them develop adequate health literacy skills.

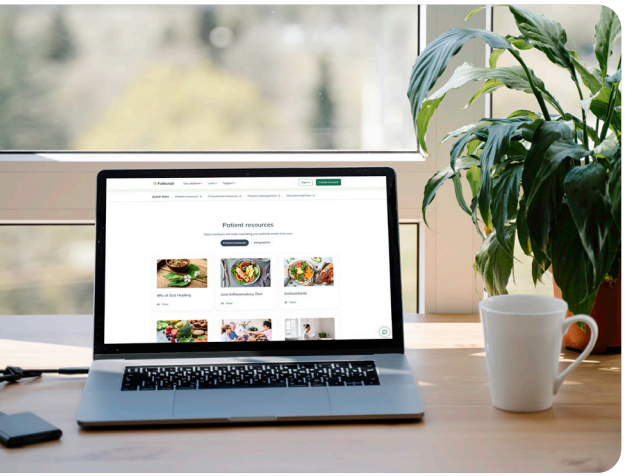
Becoming a health-literate organization

Improving organizational and personal health literacy at Fullscript

Fullscript's in-app Resource Library

Fullscript's Resource Library is an ever-expanding collection of high-quality, professionally designed resources—simplifying patient education and allowing you to focus on providing the best patient care.

Within the Fullscript platform, practitioners can find a collection of guides, handouts, and graphics on topics ranging from nutrition and lifestyle to supplements and health conditions. Each resource included in the library was developed using the most recent scientific evidence and was medically reviewed by a practitioner on Fullscript's Integrative Medical Advisory team.



Key features of Fullscript's in-app Resource Library

- ✓ **Evidence-based**: All resources available in the Resource Library are developed using the latest evidence-based information and are routinely updated to reflect changes based on changes to scientific literature. Rest assured that all information is based on evidence from peer-reviewed, reputable sources.
- ✓ **Medically reviewed**: Fullscript's resources are fact-checked and vetted by practitioners on Fullscript's Integrative Medical Advisory team before publication. Fullscript's practitioners review content to ensure that all information is accurate, up-to-date, and clinically relevant.
- ✓ **Professionally designed**: Fullscript's resources are designed by an in-house team for consistency and a better patient experience.

Benefits of providing educational resources

- ✓ **Improves health literacy**: Providing evidence-based health information to patients has been shown to improve their health literacy. (Taibanguay et al. 2019)
- ✓ **Enhances treatment adherence**: Patient education can significantly enhance treatment adherence and encourage patients to make necessary lifestyle modifications. (National Action Plan to Improve Health Literacy 2022)(Taibanguay et al. 2019)
- ✓ **Improves quality of care and health outcomes**: Education can empower patients to become more engaged in their care and the development of their treatment plans. When patients are more engaged, they're more likely to experience better health outcomes. (Fereidouni et al. 2019)(Patient Engagement 2021)

To learn more about the benefits of sharing educational resources with patients, as well as how Fullscript's Resource Library can help, visit the Fullscript blog.

How Fullscript is improving health literacy in integrative and functional medicine

Fullscript's readability and accessibility project

Fullscript's objective is to make health education accessible to all patients by creating content with the following factors in mind. These factors influence the access and impact of health education.

- **Readability**: appropriate reading level and language, accessible to individuals with disabilities
- **Predictability**: consistent user experience across all content and communications
- **Relatability**: diverse, inclusive, and culturally appropriate

As part of Fullscript's ongoing efforts, we've taken numerous measures to assess the quality and readability of our content, identify areas for improvement, and make modifications to improve accessibility.

In early 2022, Fullscript contracted the Center for Health Literacy at the University of Arkansas for Medical Sciences (UAMS) to conduct a comprehensive assessment of the readability and other plain language qualities that promote equitable accessibility of our patient-centered educational materials and other content. Fullscript then conducted field tests and gathered feedback on comprehension and reader experience for both original content and content edited for accessibility.

The UAMS Center for Health Literacy's director, Alison Caballero, MPH, CHES®, described her experience of working with Fullscript. "This is an exciting time for the health literacy field as health-related organizations are rapidly increasing their awareness of the important role clear health communication plays in reaching their objectives. **Working with Fullscript was a big motivator for my team as it provided evidence that the work we and others are doing to promote plain language is effective.** Fullscript approached us with a clear understanding of how attention to plain language could advance patient engagement and contribute to growth of their business, and our mutual passion for this work made our collaboration both impactful and fun."

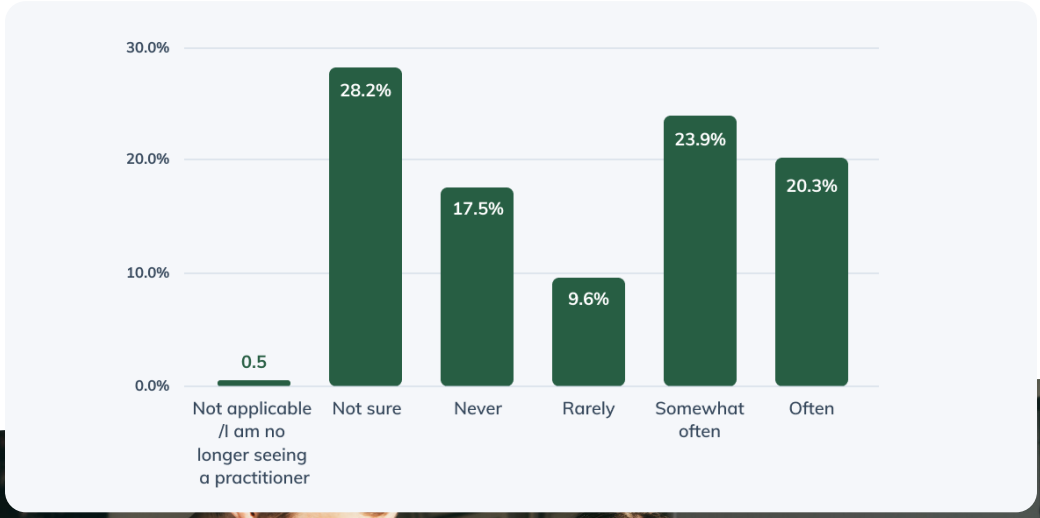
Using the insights gathered from these projects, Fullscript is currently developing a set of guidelines to improve the readability and accessibility of our content for patients.

Insights from Fullscript's patient user survey

In April 2022, Fullscript's Integrative Medical Advisory team sent out a 28-question survey to 30,000 patient users who had been invited to the platform, opened an account, and received a treatment recommendation within the last six months from their healthcare provider.

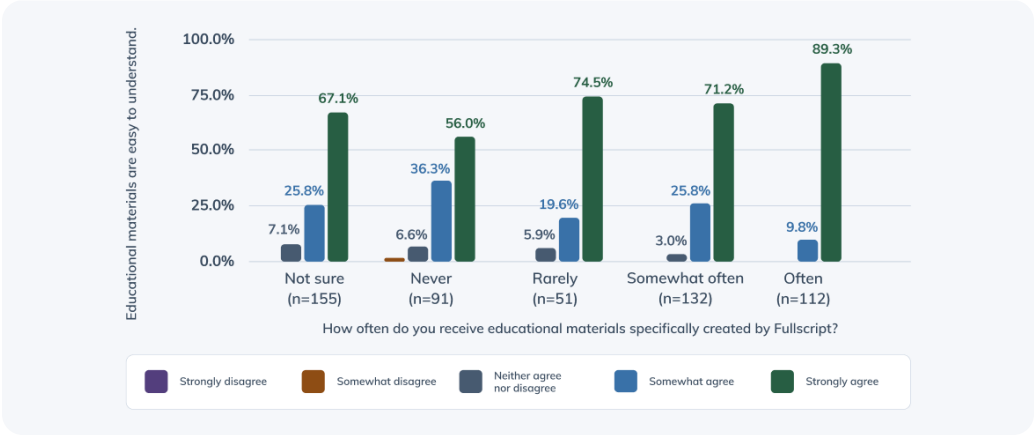
Our survey (n=911) revealed that approximately 44% of participants reported receiving Fullscript-created educational materials from their healthcare providers either "somewhat often" or "often" (Figure 18).

Figure 18. Percentage of participants receiving Fullscript-created educational material from their healthcare provider (n=553)



Participants who reported “often” receiving Fullscript-created educational materials were more likely than any other group to indicate that educational materials are easy to understand. This data suggests that Fullscript-created educational materials are easily understood by patients (Figure 19).

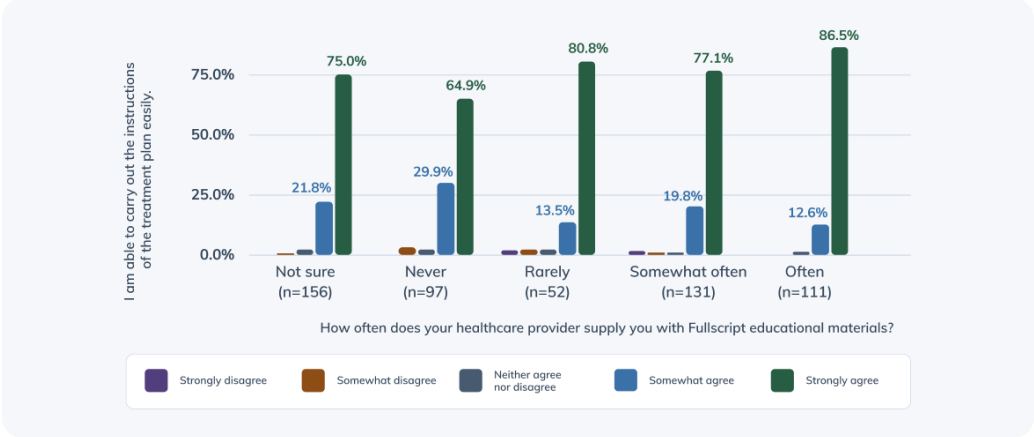
Figure 19. Fullscript-created educational materials and comprehension



The majority of participants (~71%) “strongly agreed” with the statement, “I was able to carry out the instructions of the treatment plan easily.” However, respondents who “often” receive Fullscript-created educational materials were more likely (~87%) to “strongly agree” with this statement than participants who “never” receive Fullscript-created educational materials (~65%) (Figure 20).

Respondents who “often” receive Fullscript-created educational materials were also less likely (~13%) to only “somewhat agree” with this statement than respondents who “never” receive Fullscript-created educational materials (~30%).

Figure 20. Fullscript-created educational materials and ability to carry out treatment plans (adherence)



As discovered in the Treatment Adherence Project, 15 to 30% of patients are non-adherent to new treatment plans, and ~50% of patients with chronic disease are non-adherent to treatment plans. (Bailey et al. 2021) Additionally, individuals with low health literacy have a 14% greater risk of non-adherence. (Miller 2016)

Although not a direct measure, the results from our survey suggest that Fullscript-created educational materials may help patients carry out the instructions of their treatment plan, thus improving overall treatment adherence and patient outcomes.

Helping people get better

Patient education can improve patient quality of life and treatment adherence and even lower all-cause mortality. (Juillière et al. 2003) (Myhill et al. 2017)(Taibanguay et al. 2019)

However, studies have found that not all patients equally benefit from these educational interventions. (Moran et al. 2016)

At Fullscript, our mission is to help people get better. Over the past two years, we have assessed the readability and accessibility of our educational materials. We've also conducted a literature review on health literacy and surveyed our patient users to better understand their educational needs, preferences, and barriers.

By prioritizing health literacy, we hope to equitably enable all patients to find, understand, and use information to make health-related decisions.

Research study strengths and limitations

In the development of this white paper, several strengths and limitations were noted.

Strengths

- There was a strong response to the survey with a total of 911 responses, providing more than 500 for each question.
- The development of survey questions was well-informed by performing an initial literature review to understand key topics to address.
- We have provided several practical ways healthcare practitioners, healthcare organizations, and health content producers can support patients with low health literacy.
- In order to provide a well-rounded research paper on health literacy, we have included interviews with health literacy academics, experts, and leaders.

Limitations

- For reasons of feasibility, the literature review was not explicitly conducted in a systematic manner. However, the authors made efforts to provide well-rounded information on a variety of health literacy topics, with a focus on systematic reviews, meta-analyses, and large randomized controlled trials.
- Despite a strong (yet relatively homogenous) absolute n-value (n=911), there was a relatively low response rate as the survey was sent via email to an audience of 30,000 patient users.
- Stratification analyses were helpful for teasing out some relationships but not for others (e.g., cases where n-values become too small to be considered reliable).
- The survey was only available in English, which may have discouraged low proficiency/non-English speakers from participating.
- The survey may not have been accessible, which may explain why only a small percentage (11%) of participants self-identified as having a disability.
- Health literacy was assessed subjectively, which may have resulted in an overestimation of high health literacy rates.
- Knowledge categories (e.g., slightly knowledgeable, moderately knowledgeable, very knowledgeable) were not defined in the survey. As a result, they were subject to individual interpretation, which likely influenced the survey results.

- As discussed, health literacy is a complex concept to measure. We attempted to measure our patient user's health literacy level by asking about their (1) self-perceived levels of overall health knowledge, (2) level of knowledge of individual health topics, (3) information-seeking behaviors, and (4) ability to find and understand health information. However, this is not a holistic approach to evaluating personal and organizational health literacy.
- Although we briefly inquired about organizational health literacy (e.g., whether or not they receive easy-to-understand educational materials from their healthcare providers), the survey focused primarily on personal health literacy.
- Some of the questions relied on patient memory, which may have impacted the results.

Conclusions

Low health literacy is a global health issue affecting 40 to 60% of North American adults. Individuals with low health literacy are more likely to distrust their healthcare providers and are less likely to utilize preventative health services. Consequently, they have a higher risk of emergency care use, hospitalization, and all-cause mortality than individuals with high health literacy.

Cultural and linguistic differences between the patient and practitioner, as well as complex and poorly designed educational materials and poor leadership commitment to health literacy, impair the development of patient health literacy skills and negatively impact health outcomes.

In order to improve health literacy rates and patient outcomes, these barriers must be addressed by all organizations and professionals who create and deliver health information and services.

Appendix

A summary of five health literacy assessment tools

To date, 217 health literacy assessment tools are listed on the Health Literacy Tool Shed website. (Health Literacy Skills Instrument 2021) Below is a summary of five health literacy assessment tools.

Rapid Estimate of Adult Literacy in Medicine – Short Form (REALM-SF)

Advantages

- Free to use
- Used extensively in research
- One-minute administration time

Disadvantages

- Can over- and underestimate health literacy
- Favors White over Black Americans
- Measures one domain
- Only available in English

The Rapid Estimate of Adult Literacy in Medicine (REALM), published in 1991, is one of the most widely used health literacy assessment tools in adults. (Baker 2006) (Dumenci et al. 2013) Originally developed to measure the level of literacy in patients, it was quickly adopted by health literacy researchers because it required very little time to complete. (Dumenci et al. 2013)(Shea et al. 2004) Due to its popularity, the REALM has also been used extensively in the development of "new" assessment tools. (Altin et al. 2014)

The Rapid Estimate of Adult Literacy in Medicine - Short Form (REALM-SF), published in 2007, measures the pronunciation of seven medical terms commonly found in patient education materials (Figure 21). (Health Literacy Measurement Tools (Revised) 2019) (Health Literacy Skills Instrument 2021) A patient's score is determined by the number of correctly pronounced medical words.

The score is then converted to one of five reading grades: third grade and below, fourth to sixth grade, seventh to eighth grade, and ninth grade and above. Patients with a grade less than ninth grade may have difficulty understanding patient education materials. Note that REALM scores are estimates of literacy, not school grade equivalencies. (Dumenci et al. 2013)

The authors of a 2013 systematic review argued that the REALM should not be used to determine a patient's level of health literacy. "Rather, the REALM should be used to make inferences about [a person's ability] to read and pronounce health-related terms." (Dumenci et al. 2013)

Additionally, the REALM can over- or underestimate reading ability compared to the abbreviated version of the Test of Functional Health Literacy in Adults (S-TOFHLA) (see below for additional details on the S-TOFHLA). They argue that "some patients are able to read individual words on the REALM and pronounce them correctly but do poorly when their actual reading comprehension is assessed with the S-TOFHLA." Conversely, some individuals may struggle to pronounce the REALM words, which are devoid of context, but perform better with S-TOFHLA words since they have context to assist them. (Baker et al. 1999)

Lastly, the investigators of a 2004 prospective cohort found that multiple REALM test items favored White Americans over Black Americans. The authors proposed three possible explanations: (1) the results are an anomaly and are unlikely to be found again in repeated studies; (2) the results are due to measurement error, in that not all educational experiences are equal; or (3) specific patient characteristics associated with REALM performance were not taken into account or measured. (Shea et al. 2004)

Figure 21. REALM-SF score sheet (Health Literacy Measurement Tools (Revised) 2019)

Patient ID #: _____ **Date:** _____ **Examiner initials:** _____

Behavior	
Exercise	
Menopause	
Rectal	
Antibotics	
Anemia	
Jaundice	
Total score	

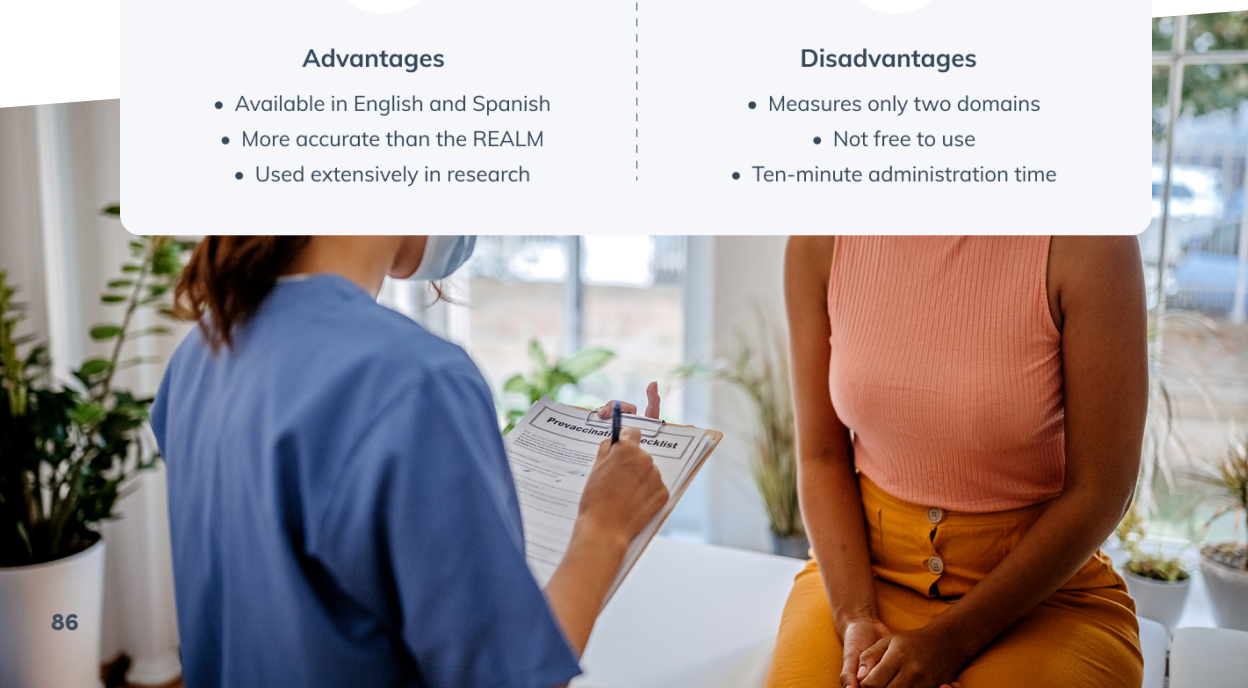
The abbreviated version of the Test of Functional Health Literacy in Adults (S-TOFHLA)

Advantages

- Available in English and Spanish
- More accurate than the REALM
- Used extensively in research

Disadvantages

- Measures only two domains
- Not free to use
- Ten-minute administration time



The Test of Functional Health Literacy in Adults (TOFHLA) was created in 1995 in response to the critiques of the REALM's sole focus on print literacy. (Rosenbaum et al. 2018) Like the REALM, the TOFHLA is also one of the most widely used health literacy assessment tools in research (Baker 2006)(Dumenci et al. 2013) and has also been used extensively in the development of "new" health literacy assessment tools. (Altin et al. 2014)

The abbreviated S-TOFHLA, published in 1999, is comprised of two components: reading comprehension and numeracy. The reading comprehension section consists of two health-related passages where the reader must select the grammatically and contextually correct word from four possible choices.

The numeracy section consists of four items designed to assess a patient's ability to understand prescription labels, monitor blood sugar, keep clinic appointments, and obtain financial assistance. (Health Literacy Skills Instrument 2021)(Parker et al. 1995)

The Newest Vital Sign (NVS)

Advantages

- Available in English and Spanish
- Free to use
- More sensitive than TOFHLA
- Three-minute administration time

Disadvantages

- May overestimate limited health literacy
- Measures only two domains
- The psychometric properties of the Spanish version are not as good as the English version.

The NVS, published in 2005, is a six-item test that measures the ability to read and apply information from an ice cream nutrition label (Figure 22). (Health Literacy Skills Instrument 2021)(Weiss et al. 2005) The NVS is based on the TOFHLA and appears to be more sensitive than the TOFHLA to marginal health literacy. However, specificity may result in the overestimation of limited health literacy.

Individuals who score above four are very likely to have adequate health literacy. Scores under four indicate a possibility of limited health literacy. Individuals who score below two have a greater than 50% chance of having low health literacy skills. The psychometric properties of the Spanish version, although adequate, were not as good as the English version. (Weiss et al. 2005)

Figure 22. NVS assessment questionnaire (Weiss et al. 2005)

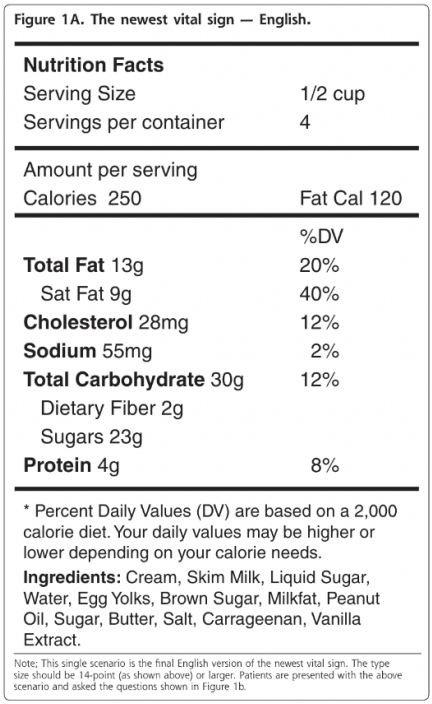


Figure 1A. The newest vital sign — English.

Nutrition Facts

Serving Size	1/2 cup
Servings per container	4
Amount per serving	
Calories 250	Fat Cal 120
	%DV
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

* Percent Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Note: This single scenario is the final English version of the newest vital sign. The type size should be 14-point (as shown above) or larger. Patients are presented with the above scenario and asked the questions shown in Figure 1b.

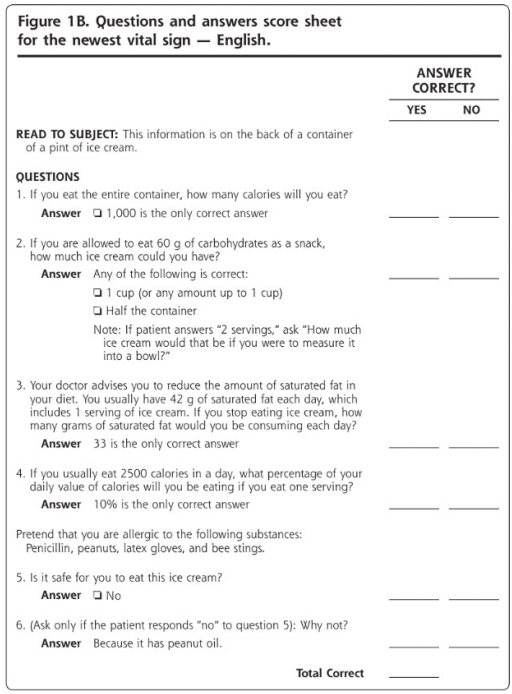


Figure 1B. Questions and answers score sheet for the newest vital sign — English.

	ANSWER CORRECT? YES	NO
READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.		
QUESTIONS		
1. If you eat the entire container, how many calories will you eat? **Answer** ❑ 1,000 is the only correct answer	____	____
2. If you are allowed to eat 60 g of carbohydrates as a snack, how much ice cream could you have? **Answer** Any of the following is correct: ❑ 1 cup (or any amount up to 1 cup) ❑ Half the container Note: If patient answers "2 servings," ask "How much ice cream would that be if you were to measure it into a bowl?"	____	____
3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes 1 serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day? **Answer** 33 is the only correct answer	____	____
4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving? **Answer** 10% is the only correct answer	____	____
Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.		
5. Is it safe for you to eat this ice cream? **Answer** ❑ No	____	____
6. (Ask only if the patient responds "no" to question 5): Why not? **Answer** Because it has peanut oil.	____	____
Total Correct	____	

Short Assessment of Health Literacy – Spanish and English (SAHL-S&E)

Advantages

- Available in English and Spanish
- Ability to assess and compare health literacy levels between English and Spanish speakers
- Free to use
- 2.5-minute administration time

Disadvantages

- Cannot differentiate between high levels of health literacy
- Measures only two domains
- Uses standard "dictionary" terms and idiomatic expressions

The SAHL-S&E was developed by AHRQ-funded researchers and was first published in 2010. (Health Literacy Measurement Tools (Revised) 2019)(Health Literacy Skills Instrument 2021) The SAHL-S&E consists of 18 items and assesses pronunciation and information-seeking skills. (Health Literacy Skills Instrument 2021)

During the assessment, patients are presented with a health-related test term as well as one word that has a related meaning to the test term and one distractor word that is unrelated to the test term. For example, patients must first read out loud the test term, "kidney," and then select the correct related term, either "urine" or "fever" (Figure 23). (Health Literacy Measurement Tools (Revised) 2019)

One important limitation of the SAHL-S&E is that the instrument was developed using standard "dictionary" terms for both the English and Spanish versions. Additionally, the tool uses idiomatic expressions that may not be familiar to different English- and Spanish-speaking subpopulations (e.g., "nerves" meaning "anxious," and "blocked" meaning "constipated"). One advantage is that the SAHL-S&E offers a reliable way to assess and compare health literacy levels between Spanish and English speakers. (Lee et al. 2010)

Figure 23. SAHL-E assessment questionnaire
(Health Literacy Measurement Tools (Revised) 2019)

Stem	Key or distracter		Don't know
1. kidney	__urine	__fever	__don't know
2. occupation	__work	__education	__don't know
3. medication	__instrument	__treatment	__don't know
4. nutrition	__healthy	__soda	__don't know
5. miscarriage	__loss	__marriage	__don't know
6. infection	__plant	__virus	__don't know
7. alcoholism	__addiction	__recreation	__don't know
8. pregnancy	__birth	__childhood	__don't know
9. seizure	__dizzy	__calm	__don't know
10. dose	__sleep	__amount	__don't know
11. hormones	__growth	__harmony	__don't know
12. abnormal	__different	__similar	__don't know
13. directed	__instruction	__decision	__don't know
14. nerves	__bored	__anxiety	__don't know
15. constipation	__blocked	__loose	__don't know
16. diagnosis	__evaluation	__recovery	__don't know
17. hemorrhoids	__veins	__heart	__don't know
18. syphilis	__contraception	__condom	__don't know

Health Literacy Skills Instrument – Short Form (HLSI-10)

Advantages

- Available in English and Spanish
- Assess four domains
- Free to use

Disadvantages

- Five-minute administration time

The health literacy skills instrument (HLSI) was created in 2010 in response to a demand for more comprehensive health literacy assessment tools. (Health Literacy Skills Instrument 2021)(Rosenbaum et al. 2018) HLSI-10 was created in 2012 to enhance the feasibility of measuring health literacy in the clinical setting and reduce respondent burden. (Bann et al. 2012)(Health Literacy Skills Instrument 2021)

Unlike most health literacy assessment tools which measure one or two domains, the HLSI-10 measures four domains of health literacy: print literacy (reading and writing), numeracy, oral literacy skills (listening), and information-seeking (navigation of internet and facilities) (Figure 24). (Health Literacy Skills Instrument 2021)(Rosenbaum et al. 2018)

It is worth highlighting that the HLSI is one of the few assessment tools that focuses on health-related information disseminated via various media (e.g., the internet). (Rosenbaum et al. 2018) Additionally, the HLSI-10 can be self-administered using a computer which may enhance patient comfort and reduce shame and embarrassment during the assessment. (Health Literacy Skills Instrument 2021) (Health Literacy Skills Instrument (HLSI) 2016)

Figure 24. HLSI-10 assessment questionnaire (McCormack 2011)

Print-prose	
Cholesterol	Which set of low-density lipoprotein (LDL) and high-density lipoprotein (HDL) levels is best?
Stroke	Which of the following is not a sign of a stroke?
Print-document	
Hospital map	Which of the following entrance is closest to the elevator?
Medicine record	In the example listed in the first row of the table, when should the medicine be taken?
Portion control	A person is cooking dinner for himself and he wants to include one serving from the meat and beans group. What should he choose?
Print-quantitative	
Nutrition label	If a person is on a 2,500 calorie diet, what percent of the daily value of saturated fat would he get from one serving?
Prostate cancer graph	More men die from prostate cancer than from other causes. Based on the chart above, would you say this is true, false, or are you not sure?
Oral	
Telephone recording	If a person was worried about his cough, what number should he press?
Internet	
Calories	Kate weighs 150 pounds. Which activity would burn the most calories?
Lunges	What part of the body do lunge exercises work?

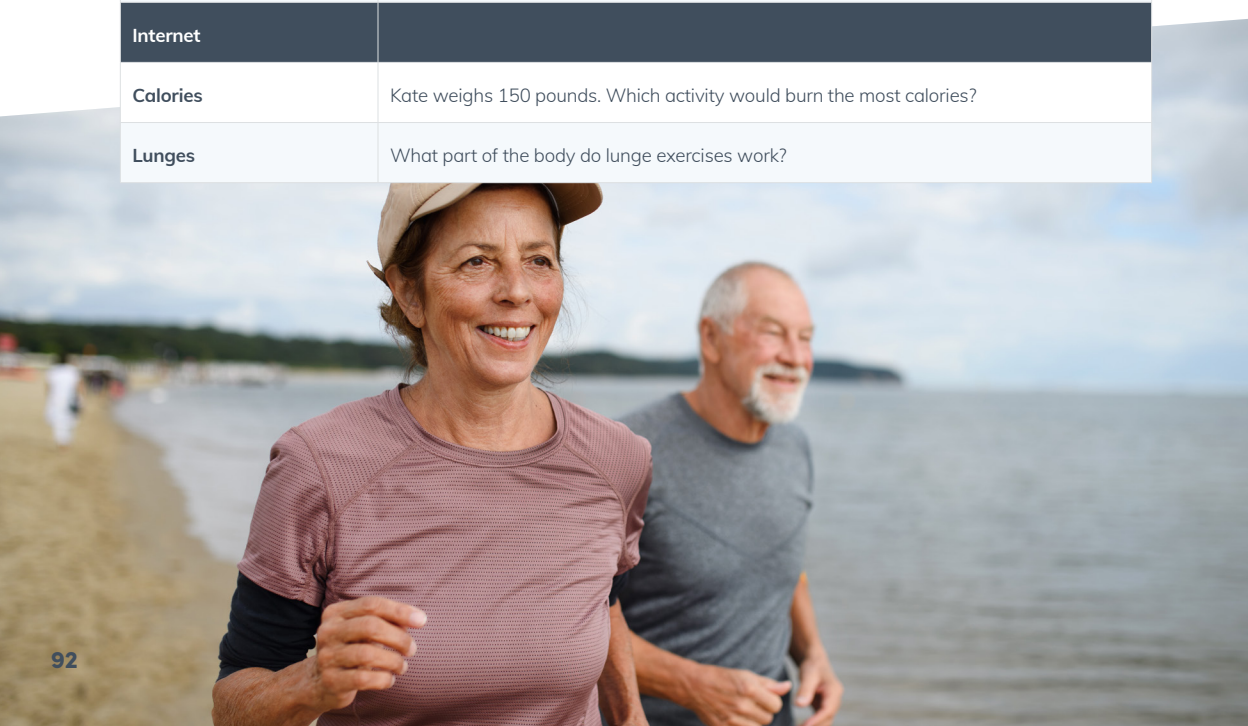


Table 1. Summary of health literacy assessment tools

Tool	HLSI	SAHL-S&E	REALM-SF	NVS	S-TOFHLA
Year published	2012	2010	2007	2005	1999
Time to required to finish (minutes)	5	2.5	1	3	7–10
Number of items	10	18	7	6	40
Modes of administration					
Computer-based	✓				
Face-to-face	✓	✓	✓	✓	✓
Pen and paper	✓	✓			✓
Domains of health literacy					
Information-seeking	✓	✓		✓	
Numeracy	✓			✓	✓
Oral literacy	✓				
Print literacy	✓			✓	✓
Pronunciation		✓	✓		
Language	Eng and Esp	Eng and Esp	Eng	Eng and Esp	Eng and Esp
Validated in the United States	✓	✓	✓	✓	✓
Free	✓	✓	✓	✓	$60

(Collins et al. 2012)(Health Literacy Measurement Tools (Revised) 2019)
(Health Literacy Skills Instrument 2021)

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