

PERSPECTIVE

Health Literacy 2030: Is It Time to Redefine the Term?

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For decades, *health literacy* has been used to describe the ability of individuals to locate, interpret, and apply health information to their decisions. The US Department of Health and Human Services has now proposed redefining the term to emphasize the role of society in providing accessible, comprehensible information. This redefinition would reflect a welcome shift to encompass the roles of those who communicate information, not simply those who seek it. However, redefining an accepted term would have serious negative effects on the indexing of the research literature and create difficulties interpreting studies conducted under the previous definition. Therefore, we strongly caution against redefining the accepted term. Instead, we propose introducing a new term—*health information fluency*—defined as universal effective use of health information. The old term can continue to be used to describe the set of concerns about individual skills, but by promoting the new term, the Department of Health and Human Services can encourage research into creating accurate, accessible health information that people can easily find, understand, and use to inform their decisions.

KEY WORDS: health literacy; health communication; comprehension; Medical Subject Headings; vocabulary.

J Gen Intern Med 35(8):2427–30
DOI: 10.1007/s11606-019-05472-y
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A vast quantity of information about health is available to the public, but it is well known that many people find that information difficult to interpret and apply.^{1, 2} Since the 1990s, the term *health literacy* has been used to describe individuals' ability to find health information, interpret it, and apply it to health-related decisions.^{3–6} A substantial body of research over 3 decades has advanced our ability to measure health literacy,^{7–10} to conceptualize and measure related concepts such as health numeracy^{11–15} and graph literacy,¹⁶ to identify sociodemographic predictors of poor health literacy,¹⁷ to explain and quantify its association with health-relevant outcomes,^{18–22} and to develop interventions to benefit individuals with low health literacy.^{23–25}

Throughout this productive period of activity, health literacy was conceptualized as being a characteristic of each patient or consumer. It represented a combination of literacy skills (such as abilities to read text passages, navigate documents, and manipulate numbers) and health-relevant knowledge (such as familiarity with names of body parts, diseases, and units of measure).

But there were always clues that this skills-focused definition was not capturing the entire picture. For example, many patients have difficulty reading medication instructions. But rephrasing the instructions from “2 pills twice daily” to “2 pills in the morning and 2 pills in the evening” increases the number of patients—especially low-literacy patients—who can correctly state when they are supposed to take the next pill.^{26, 27} Similarly, reformatting a pair of numbers from 1-in- X (1 in 112, 1 in 384) to the mathematically equivalent X -in- N (8.9 in a thousand, 2.6 in a thousand) meant that almost a third more people could identify which number was bigger.²⁸ Health information is more likely to be understood and acted upon by low-literacy patients when it is written clearly and illustrated with appropriate graphics,²⁹ or when it is presented to patients as part of a multicomponent strategy that includes provider communication training²⁵ or low-literacy-appropriate materials and individual patient coaching.³⁰ These were among the many clues showing that more people could use information when it was appropriately designed for their needs.^{27, 31, 32}

If health literacy was an individual patient skill, why did the format, design, and delivery of the information matter so much? The classic explanation (informed by item-response theory³³) was that the informational materials came in different difficulty levels, and the level at which a reader got stuck defined their health literacy level. Health information was like an exam, which patients might pass or fail.

Over recent years, a growing number of experts have suggested turning this interpretation on its head.^{14, 34–37} Instead of considering the patient's skill to be a fixed entity, which is revealed by exposing them to information at different levels of difficulty, the counterargument says: let us consider the reader, the health information, and the creators of the information to be a single system. When a society enables the creation of information that is suited to the informational needs and the cognitive skills of the people in that society, and makes that information widely available and easily accessible, then that information will successfully be obtained by the people who need it, and it will be understood, and it will be applied productively to individual and societal decisions.

Prior presentations: This work has not previously been presented.

Received September 24, 2019

Revised September 24, 2019

Accepted October 9, 2019

Published online October 28, 2019

From this point of view, the ability to use health information in the service of health is an emergent property of a system, not simply a function of individual skills. Health information is *not* like an exam. Health information materials can be made either more or less easy to understand by the people who create it, and their success in creating comprehensible information is influenced by their skills and goals. In addition, comprehension is affected by the oral communication skills of healthcare providers, which are influenced by their training, which in turn is influenced by the priorities of medical schools and employers. Whether healthcare providers communicate effectively in practice is then affected by other factors such as the reimbursement structure of healthcare, which will determine how much time is available for patient–provider communication and whether there are incentives to communicate well. Finally, which health information resources and technologies are easily available is determined by the many different healthcare organizations, public health agencies, businesses, and providers that create and disseminate them.

When we look at health and healthcare in this way, we see that individual health literacy skill is just one component of a complex system. When many components of this complex system are in alignment, then people have access to high-quality information that is easy to understand and easy to act upon.

This systems perspective is reflected in the US Department of Health and Human Services (DHHS) 2019 proposal to redefine “health literacy.” As part of the HealthyPeople 2030 initiative, DHHS adopted the Institute of Medicine definition⁶: “Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions.” Reflecting DHHS policy, the National Library of Medicine adopted this definition for the Medical Subject Headings (MeSH) term “Health Literacy.”

This year, DHHS has proposed a radically new definition for HealthyPeople 2030: “Health literacy occurs when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions.”³⁸

The proposed definition could carry major benefits. It reflects an important understanding that effective dissemination of health information requires a focus on both those who communicate information and those who seek information. Through this wording, DHHS sends an important message that future research and practice should move away from the “deficit model”³⁶ of identifying ways in which people are inadequate to the task of using health information. Instead, we should be examining the information itself: Is it high-quality? Has it been effectively disseminated to those who need it? Can it be interpreted and used by individuals with different needs and abilities? Are health information resources and technologies available in languages other than English? We should also be examining the roles of those who provide the information: doctors and healthcare organizations, public health departments and governmental agencies, manufacturers

of food, pharmaceuticals, and consumer products, advertisers, insurers, pharmacists, journalists, libraries, vendors of patient education materials, and health information technology vendors. Have they clearly identified what readers should do upon reading the information, and designed the materials to support these actions? Do the communicators have the resources (e.g., training, guidelines, and time) to communicate effectively? What are their incentives (or disincentives) for providing high-quality and easily comprehensible information? Finally, we should be looking at societal resources and infrastructure. Is Internet access widespread and affordable by all people? (In 2018, 27% of US homes did not have high-speed broadband, and 29% of adults did not own smartphones.^{39, 40}) Are governments investing in libraries and on-line resources such as MedlinePlus^{41, 42} that provide easy-to-understand and unbiased health information? Are healthcare and health insurance systems straightforward or difficult to navigate? Are private and public insurers incentivizing informed medical decisions and shared decision making?

By enlarging our scope to examine health information and society, we will help more people become more informed about health and healthcare.

But unfortunately, there are also serious hazards to redefining an established and widely used term that is included in standardized terminologies such as the Medical Subject Headings (MeSH) used by the National Library of Medicine.⁴³

One consequence will be that the multiple validated assessment instruments and screeners for health literacy (such as the Brief Health Literacy Screen,⁴⁴ Single-Item Literacy Screener (SILS),⁴⁵ or Test of Functional Health Literacy [TOFHLA]⁷) will immediately be invalidated, because they measure a concept that no longer matches the contemporary definition of the term. It will become meaningless to administer one of these questionnaires to a patient to identify low health literacy if low health literacy now describes the function of an entire society. If the definition is societal, then we would need new screening instruments that screen entire societies to identify the ones that help people use health information and the ones that do not.

A second adverse effect of redefining the term is that using the MeSH term “Health Literacy” to search the literature will produce two very different types of studies. One set will focus on the assessment of patient skills and the impact of skills deficits under the old definition. The newer set of studies will focus on social systems and their role in supporting or failing to support effective use of health information. Unfortunately, articles conceptualized under the new definition will have to be indexed using the old term, and there will be no reliable way to distinguish them from the older articles. This will invalidate or at least greatly complicate future reviews or meta-analyses that attempt to synthesize evidence.

Finally, it is unlikely that the new definition will be immediately adopted universally, leading to a confusing period when different people use the same term to mean different things.

For reasons such as these, the vocabularies we use in healthcare should contain concepts with unambiguous definitions, and each concept, once defined, should be considered permanent.⁴³ Although vocabularies must be able to evolve as language and our understanding of health change, an individually defined concept should not be redefined.⁴³ (The study of vocabularies and terminologies used in healthcare is an important component of our field of medical and health informatics, because information systems depend so heavily on vocabularies. Health informaticists have explored many of the problems associated with poorly defined vocabularies.)

We conclude that because of these disadvantages, DHHS should not redefine the old term health literacy. Instead, the department should find a different way to shift the focus of research and practice about communication. The best way to do this would be to create an entirely new term. We suggest *health information fluency*, defined as *the effective use of health information by those who need it*. A society promotes health information fluency by providing accurate and accessible health information that people can easily find, understand, and use to inform their decisions and actions.

If DHHS chooses this approach, the old term (health literacy) will still be available to describe the narrower set of concerns about individual skills. However, the department can use funding opportunities and public announcements to shift the cutting edge of research and practice to societally focused concerns encompassed in the term *health information fluency*.

The DHHS should be applauded for considering how to promote an updated concept about how health information can best be translated into individual and societal health decisions. However, redefining health literacy is not the best way to do this. Instead, creating a new term will preserve the integrity of indexing of tens of thousands of scientific articles and the validity of decades of research on the (outdated) construct, while creating the terminology needed to promote research and applications of this new (and more useful) construct.

Acknowledgments: *The authors gratefully acknowledge discussions and debates in the Health Numeracy Lab Group.*

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Funding Information *Drs Ancker and Benda are supported by National Library of Medicine R01 LM012964. Ms. Grossman is supported by National Library of Medicine F31 LM054013.*

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