

Healthy People 2030 Health Literacy Definition Public Comments June 3, 2019-August 5, 2019

Below are the public comments received in response to U.S. Department of Health and Human Services' solicitation of public comment on the definition of health literacy used by the Healthy People 2030's Secretary's Advisory Committee on National Health Promotion and Disease Prevention. They are reproduced in the order they were received. Salutations, "thank you's," and identifying information have been removed. Each comment represents the view of a single individual, a group of individuals, or an organization. Comments appear only once; identical comments sent from more than one email address are not repeated. Comments that were not related to health literacy are not included. All font colors, highlights, misspellings and typos have not been altered. Comments received after the deadline are not included and were not considered.

Secretary's Advisory Committee's Definition:

"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."

Previous Definition used by Healthy People 2010 and 2020

"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."

1.	I do not believe the proposed definition adequately emphasizes the behavior of the individual. I agree with incorporating the societal obligation to provide information and services that are easy to access and use, but at the end of the day, it comes down to does the individual avail themselves of these resources and does the individual have the capacity to or choose to use them. I believe health literacy is assessed/measured at the individual level.
2.	<p>Solicitation for Written Comments on an Updated Health Literacy Definition for Healthy People 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."</p> <p>Please consider measuring the readability of this proposed definition. https://protect2.fireeye.com/url?k=4694e4cd-1ac1ed1d-4694d5f2-0cc47a6a52de-55c90fb4712d0749&u=https://app.readable.com/text/?demo</p> <p>The sentence is very long. Consider splitting it into shorter sentences. Also, consider rewording to a lower readability grade level.</p> <p>Health literacy occurs when health information and services are easy to find, understand, and use. It can help you make health decisions and follow instructions for care.</p>
3.	<p>I suggest a change in the purposed definition:</p> <p>Health literacy occurs when a society provides accurate health information and services that people can easily find, understand, appraise and use to inform their decisions and actions.</p>

	<p>Why?</p> <p>I think People should evaluate the information and have the power to decide whether the information applies to their reality. It is a question of self-determination</p> <p>Reference used to purpose the change:</p> <p>Sorensen, K. et al. Health literacy and public health: A systematic review and integration of definitions and models. BMC Public Health 2012, 12:80.</p>
4.	<p>I fear that we have just swung the pendulum too far in the other direction with this definition. I think we need to adopt a definition that acknowledges BOTH sides of HL, because we miss opportunities to intervene and help when we only focus on one (either just on individual skills or just on society). The new definition seems to imply that the focus of our efforts should be on society and its contribution to HL... but what about individuals whose skills are not adequate, but could be improved to empower them to find, understand and use more health information and achieve better health...? Also, if we are going to measure HL at an individual level (which we do), we shouldn't exclude that level/construct from our definition.</p> <p>Suggestion:</p> <p>"Health literacy is achieved when individuals' skills match the demands of health systems and society to find, understand and use health information to achieve good health."</p>
5.	<p>I appreciate the goal of an updated definition for the term "Health Literacy", I am disappointed in the proposed new definition. I think it's too vague and doesn't adequately convey the import of this concept nor its multidimensionality as set forth in the NAM's Considerations for a New Definition of Health Literacy.</p> <p>I view health literacy as a health equity issue as set forth in the NAM discussion paper Health Literacy: A Necessary Element for Achieving Health Equity. As someone who teaches on health literacy and advocates for training, funding, programs and services to support the development of health literacy skills, programs and services, I believe a stronger definition is needed and would do much to raise the recognition of health literacy as a social determinant of health and a national health priority.</p> <p>My take on the proposed definition would be something along these lines:</p> <p>"Health literacy occurs when an individual is supported by understandable and accurate health information, health communications and health services that enables them to make decisions and take action in support their or a loved one's health and well-being."</p>
6.	<p>Noted below is my submission for a revised definition for "health literacy". I feel the focus should not be on society's obligation but rather on the person using the information.</p> <p>My suggested wording is:</p> <p>"Health literacy is the capacity of individuals to obtain and understand actionable and accurate health information needed to make informed health decisions for themselves and their families."</p>
7.	<p>I appreciate the move toward include society's role in health literacy, but this definition seems to not include an individual's role which is also important. Keeping an individual in the definition could be important for education funding, etc.</p>

	<p>Suggested change from: “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.”</p> <p>To: “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 take action, and when an individual has the skills needed to easily do these tasks.”</p>
8.	<p>The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for Healthy People 2030 definition: “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.”</p> <p>Proposed definition offered below:</p> <p>“Health Literacy is obtained when all health care providers at any level and discipline receives from patient/client (s) information that is clear and accurate in regard to understanding health messages that have or will have enhanced the life and wellbeing of that individual, family community or aggregates.” The care giver is understood to be beyond those that lay on hands to those who supply ancillary needs (counselors, pharmaceutical, therapists, medical supplies and equipment, producers of pamphlets, brochures, and other handout literature, etc.).Finally, the health information intervention should be reciprocal in that the information deliverer is accessible, clear, concise, culturally appropriate and takes into account the needs and wishes of the receiver.</p> <p>Rationale for this definition: Society should be the objective recipient of health literature interventions. These interventions should be delivered to persons, families, groups, communities intimately yet professionally showing the concern and caring being given to the patient/client.</p>
9.	<p>This effort to build a new definition of health literacy for Healthy People 2030 could be strengthened by building an international consensus on a valid and testable definition of health literacy. The approach to do so would build upon the strongest of the many definitions currently in use around the world – the definitions associated with the European Health Literacy Survey, the Ophelia movement, and the Calgary Charter on Health Literacy. Key attributes those definitions agree upon (evidenced by use of differing words with the same meaning) include finding, understanding, evaluating, communicating, and using information to make an informed decision.</p> <p>The newly proposed definition also diminishes and nearly removes any reference to individual action and empowerment – responsibility is almost entirely placed upon an undefined notion of “society” to provide information and thus disempowers individuals to passive receivers. Empowered individuals are now and have always been envisioned as a key element of the health literacy equation.</p> <p>An intriguing word choice is “occurs” as if health literacy is an object that somehow manifests when a “society” provides information in a largely undefined manner. Health literacy is a social construct. Thus, health literacy does not occur – it is constructed by identification, labeling, and consensus.</p> <p>Finally, this definition does not encourage robust evaluation or testing. A definition of health literacy is a theory – and that theory must be testable. Each of the definitions earlier referred to is testable and the data I am aware of supports their utility and validity</p>

10.	<p>The proposed new definition is flawed in that it attempts to blend two distinct concepts into one definition. It describes a given transaction, rather than describing the parties of the transaction.</p> <p>The capabilities of the consumer, and the capabilities of the system both determine whether a given communication transaction works from a health literacy perspective. However, I think it is better to define the two capabilities separately.</p> <p>The old health literacy definition should be kept to define the competency of the consumer.</p> <p>A new term, “Health Literacy Competency” could be used to represent the competency of the health care system. It would be defined as follows: “A Health Literacy Competent entity is one that is able to effectively communicate with consumers, clients and patients regardless of their level of health literacy.”</p> <p>This has a perfect analogy to language services. “English Proficiency” and “English Literacy” are properties of the consumer. A linguistically competent entity is one that is able to provide translation and interpretation services to persons of limited English Proficiency or Literacy.</p> <p>A transaction is “effective health communication” when the information is provided at a level suitable to the health literacy of the recipient. Only a health literacy competent entity can assure providing that to all levels of health literacy.</p> <p>Consumers can be taught health literacy, health care entities can be taught health literacy competency. These are two separate things, and need to be defined separately.</p>
11.	<p>Suggested edit: Last section of statement should be revised. “...to inform their decisions and actions.” Change to: “...to inform the health-related decisions and actions.”</p>
12.	<p>I would propose only small addition to the working definition posted online:</p> <p>“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.”</p> <p>Could be...</p> <p>“Health literacy occurs when a society provides accurate health information and services that people can easily find, understand, use, AND COMMUNICATE ABOUT to inform their decisions and actions.”</p> <p>The addition of "communicate about" would mirror the work Berkman et al. did in adapting the earlier definition. Highlights the importance of all kinds of communication around health.</p>
13.	<p>In order to achieve health and well-being for everyone in our society it is the obligation of our health authorities to vigorously develop and implement policies and programs which eliminate health disparities, achieve health equity, and promote health literacy. A person achieves health literacy only when they have access to accurate, science-based, culturally appropriate, health information and services that can be easily found, understood, and used to inform their shared health decisions and/or actions when meeting with a provider of their choice. Information and services should be culturally appropriate and empowering for the individual, family and community.</p>
14.	<p>I think the term “society” is so broad that it could be seen and brushed aside as someone else’s responsibility. So I would rather say:</p>

	<p>“Health literacy occurs when both individuals and organizations throughout the society provide accurate health information and services that people can easily find, understand, and use successfully to inform their health care decisions and actions”.</p> <p>I would like to applaud the changes you have made in stressing the “use” of the information and the “actions” that need to be taken. When the Council on Scientific Affairs of the American Medical Association first struggled with a definition (1998), they came up with “health literacy is the ability to read, understand and act on health care information”. As clinicians we were concerned that patients could use the information correctly to successfully manage their own daily care, not just the decisions they needed to make. Carrying out those decisions can be very complicated and challenging to one’s understanding of the original health care message.</p>
15.	<p>There are many components to health literacy which include cultural, social, and individual factors. It also must include one's ability to navigate the health system to gain access to care. The suggested definition implies if the written resources are made simple then healthy literacy should be attainable and that is not accurate.</p>
16.	<p>Working definition – “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.”</p> <p>The current draft definition is accurate in the sense when we just limit to adults across health care spectrum but doesn’t address the issue of literacy in age continuum (young and older people) and also the cultural values with traditional knowledge such as with our natives. I propose to modify the current definition –see my suggestion as highlighted in Yellow</p> <p>“Health literacy occurs when a society provides accurate and culturally adapted health information and services that people in continuum of age group can easily find, understand, and use to inform their decisions and actions.”</p>
17.	<p>The proposed phrasing, “Health literacy occurs when...” makes it not a definition of health literacy per se but a refining of the context surrounding health literacy. I absolutely agree that the context in which health information is made available is a critical component of health literacy. But it’s not complete as a definition. Ideally, a definition of health literacy would combine the role of the individual in health literacy with the role of society.</p> <p>To get there, I’d recommend combining elements of the HP2020 definition with the HP2030 definition:</p> <p>“Health literacy is the is the degree to which individuals have the capacity to obtain, process, and understand basic health information. It is possible only when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions.”</p>
18.	<p>I am not in favor of the “definition” as it is not really a definition. You could consider supplementing the previous definition with this statement, but phrasing it as this, the conditions under which health literacy has occurred, is not a definition, and does nothing to further the public’s understanding of what health literacy. In my opinion by phrasing it in this way, it also puts the responsibility on society, (which people can regard as others) and puts no responsibility on the individual. Thank you.</p>
19.	<p>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.”</p>

	- As well as communicate across diverse cultures.
20.	<p>I propose HHS adopt an alternative definition of health literacy: "the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health" (Ref. 1, 2). This definition has been used by the World Health Organization (WHO) among others. This WHO definition emphasizes the link between the individual and their social resources, linking literacy to equity, local decision-making and patient engagement and Other WHO materials define health literacy as the "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (3). Both WHO definitions link the definition of health literacy to social determinants of health by emphasizing social skills, context and resources, particularly the former WHO definition. By contrast, the HHS definition as proposed seems to conceive of health literacy as being a service like a directory that is the same for all people. In addition to emphasizing the role of social determinants, adopting one of the WHO definitions also would help link Healthy People to global health initiatives.</p> <p>References:</p> <ol style="list-style-type: none"> 1. Health literacy toolkit for low- and middle-income countries : A series of information sheets to empower communities and strengthen health systems, World Health Organization, 2014, https://apps.who.int/iris/handle/10665/205244 2. Rowlands G, Health literacy and the social determinants of health: a qualitative model from adult learners, Health Promotion International, 2017; vol. 32(1): 130-138 3. Sørensen, Kristine et al. "Health literacy and public health: a systematic review and integration of definitions and models." BMC Public Health vol. 12 80. 25 Jan. 2012
21.	<p>I would like to see the definition speak to the fact that people must also be able to have the capability to understand the often contradictory and confusing nature of the medical field as a whole. An example....Father comes into urgent care with sick 4 year old. He was giving her Baby Aspirin for a week. When I counseled him about the dangers of this, he asks, "then why is it called baby aspirin, why is it orange-flavored and why is it chewable?"</p> <p>We certainly do not make it easy for people with no medical background.</p>
22.	<p>The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for Healthy People 2030 used the following working definition: "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."</p> <p>I appreciate the urge to shift the focus of health literacy away from exclusively residing at the individual level! I also like the shift to "to inform"; however, this proposed definition does not work.</p> <ol style="list-style-type: none"> 1) It is not a definition. "Health literacy occurs..." – this simply is not the form of a definition. 2) It is not just information and services – it is also skills. Please include skills. 3) The concept of "easily" is extremely problematic. What is implied here is: "that people WITH LOW HEALTH LITERACY can easily find, understand, and use..." <p>I am writing to comment (again) on the definition of health literacy. Please forgive me if my comments have not been clear. Your definition can be quite influential and I appreciate that you are taking this process seriously. The proposed definition open for public comment is not a step forward in my view. Here are some points that I hope you find to be salient.</p>

1) The predictive validity of the large majority of the evidence for this whole field is based on data that defines health literacy at the individual level. I think this means the individual aspect of the definition cannot be dropped.

2) I am a pluralist. I have engaged with a broad range of people around the world about their definitions of HL. The definition presented for public comment is not within the normal range of the many definitions out there.

3) I firmly support the notion that HL is a contextual phenomenon. If people think about this field and ONLY think about an individual deficit model they will miss the importance and meaning of context in this sense. Many of the solutions will have to come by improving contextual factors. This can be incorporated into the definition -- but -- in my view this is not a requirement per se.

4) Because HL is a contextual phenomenon I recommend not using the word 'basic' (as has been used in the HP2020 definition). The word 'basic' is not appropriate. What a person needs to manage if they have asthma is different than if they have cancer. Self care for diabetes can be really complex - but is largely not relevant for many other people. Please drop the word basic.

5) Please change the word 'appropriate' (as was used in the HP2020 definition) to 'informed'. The word 'appropriate' make this field sound like it is about adherence to what the clinicians want patients to do. The concept of adherence is simply a separate construct.

6) I think the definition should include the term 'skills' -- as there are are a whole range of skills that would not be included in 'information and services'.

7) With these notes in mind I drafted a potential definition at a recent meeting of the NAS Health Literacy Round Table:

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand health information, services, and skills needed to make informed health decisions as well as the organizational and professional attributes needed to empower people for their health.

Please note - this was motivated by the fact that the draft proposed HHS definition so clearly seemed to aspire to include the context IN the definition.

8) I would be completely comfortable with NOT including the context as part of the definition but having clarifying statements that ensure people appreciate the importance of context. For example, when we DEFINE a healthy diet -- the definition itself would not typically include the fact that we need to help improve access to healthy food for people who live in food deserts or who cannot afford to by produce. These are critical contextual factors that will need to be dealt with as part of the solution -- but are not typically part of the definition of a healthy diet.

8) Accordingly, the best approach I think would simply be:

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand health information, services, and skills needed to make informed health decisions.

	<p>This can be supported with statements - effectively that make it clear that solutions need to happen at all levels -- or we are just blaming the victim.</p>
23.	<p>As a public library with a strong health initiative offering access to free nutritional, physical, and mental health resources, services and programs, I thought I'd weigh in the definition that was forwarded to me by our staff member over our Be Well @ NPL program.</p> <p>I find the definition as stated in the 2010 and 2020 more in line with what I think and what we, as a library, do in articulating the meaning. Defining health literacy as - health literacy occurs when....feels odd to me and no longer a true definition of health literacy itself. (becomes an action rather than a definition)</p> <p>I think there's a role for the individual as well as society, not one or the other, and they both need to be 'lifted' together. It's really important the we take responsibility for our health, meaning we need to be aware of information and remain diligent in that effort, AND the healthcare industry absolutely needs to up its game and take more responsibility.</p>
24.	<p>Could it potentially be beneficial to include mention of "cultural adaptiveness" to the proposed updated definition of health literacy. While accessing information and services are essential to health literacy, most services are not necessarily uniformly available and some health information may be restrictive or misunderstood based on cultural norms, lifestyle, or myriad other demographic factors. An updated statement may read as follows:</p> <p>"Health literacy occurs when a society provides accurate, culturally adaptive health information and services that people can easily find, understand, and use to inform their decisions and actions".</p> <p>I would be more than happy to hear about why there might be pushback to this feedback, if any!</p>
25.	<p>I appreciate the opportunity to comment on the proposed change in the definition of "health literacy. I oppose the proposed change, and observe that <u>the proposed new "definition" is not a definition.</u></p> <p>A definition of anything is fundamentally about what something IS. The proposed definition is not about what health literacy IS – it's about factors that may affect it. The current definition and statements about factors that influence it can live side-by-side. No replacement is required.</p> <p>In discussions of both health literacy and literacy in general, literacy is considered to be a characteristic or property of individuals. This is as it should be.</p> <p>Providing information in simplified forms, or in pictorial vs. text forms, does not actually change literacy (or health literacy). Doing that may indeed influence comprehension or subsequent actions, but not literacy per se. Literacy and comprehension or knowledge are not the same things.</p> <p>The proposed "definition", then, is not an accurate statement about literacy. A suggested edit: "Effective comprehension of health-related information occurs when a society provides health information and services that people can easily find, understand, and use to inform their decisions and actions."</p> <p>As noted in the request for comment: "This {current} definition of health literacy has had a tremendous impact on the field, influencing health literacy measurement and improvement efforts around the world." Please don't change to something that is not an actual definition and is not even accurate given well-accepted definitions of health literacy and literacy in general.</p>

26.	<p>Here is my definition:</p> <p>Health Literacy occurs when personalized, actionable and timely information on healthy living and health services are easily accessible to inform, educate and transform people.</p> <p>My Rationale: There is so much information available on health. Unfortunately, this causes information overload for both providers and patients. Making information Personalized, Actionable and Timely is the most effective way to effect positive Behavior Change which is critical for internalizing the consumed information.</p>
27.	<p>Fully support the proposed changes to the definition of health literacy. Shifting the responsibility to institutions and organizations clearly places the onus on them to address and respond to the crisis of poor health literacy and to work towards solutions and services. The former definition was passive and an observation of a state. This definition is a call to action.</p>
28.	<p>My comments on definition of Health Literacy:</p> <p>Proposed definition: 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, was recommended by the Healthy People Secretary’s Advisory Committee.</p> <p>Current definition reads, Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.</p> <p><u>My suggested edit:</u> <i>“Health literacy is the degree to which individuals in a society easily find, understand and use accurate health information and services which inform their decisions and actions”</i>.</p> <p>This definition incorporates the best of both definitions, while keeping the focus on individuals' actions, not their capacity, nor on society's obligations, a whole other topic. Outcomes should be measured of individuals' knowledge and actions, not society's provision of information.</p>
29.	<p>Please see the comment below regarding the updated Healthy People definition of health literacy.</p> <p>The area of focus on the proposed definition is an attempt to shift measurability toward the delivery of services rather than the degree to which individuals acquire, process and act on information. While the current definition is more explicitly worded and consistent with traditional public health frameworks on the individual, it is more difficult to measure from a design and implementation standpoint. I prefer the proposed definition, however with a need for revision to the term “society” as this term is too broad. A more explicit definition would include indications as to what parts of “society” are relevant, namely the healthcare infrastructure.</p>
30.	<p>I am very impressed to see a definition that now puts the onus on the health care industry to ensure that Health information is clearer.</p> <p>I would suggest putting ALL before people to make the definition more inclusive, as just the word people can refer to just Some people . “ this ladder is provided so that people can access the roof”certainly not All people.</p>
31.	<p>It’s semantics.</p> <p>HL does not “occur” when “accurate health information and services” are provided by a society.</p>

	<p>HL is attained when an individual “can easily find, understand, and use” accurate health information and services provided by a society.</p>
32.	<p>The new definition is flawed. Literacy is not an occurrence. Literacy is an ability or competence.</p> <p>Another problem with the new definition is that it will not be useful for people like me who work in a health system, because it talks about “society”. A large part of health literacy work is done in hospitals and health systems, where we work to educate and increase awareness of faculty and staff to health literacy. In our environment this definition will not be applicable. To make it work I would need to change the word “society” to “organization”. Please ensure the new definition would apply to all stakeholders and environments.</p> <p>The definition created by Hudson et al. is much better:</p> <p>Health literacy is one’s ability to find, know, and use health information to make choices each day.</p> <p>Hudson S, Rikard RV, Staiculescu I, et al. Improving Health and the Bottom Line: The Case for Health Literacy. In: National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Population Health and Public Health Practice; Roundtable on Health Literacy. Building the Case for Health Literacy: Proceedings of a Workshop. Washington (DC): National Academies Press (US); 2018 Jul 26. Appendix C. Available from: https://www.ncbi.nlm.nih.gov/books/NBK518850/</p> <p>I would tweak it a bit to Health literacy is one’s ability to find, understand and use health information to make decisions and take actions.</p>
33.	<p>Here are our comments regarding the proposed new definition of health literacy:</p> <ol style="list-style-type: none"> 1. The strength and weakness of the recommended definition is that it is more of a definition of how to achieve health literacy. Perhaps this is an unintended consequence that actually works out for the benefit of all. Health literacy should not be a separate “task” to apply to communications or address certain audiences. We know that inadequate health literacy is pervasive and a fundamental driver of costs. What is needed is how to improve health literacy so that it becomes the popular socialite of corporate culture rather than the uninvited guest that must be tolerated. 2. Our suggested changes: “Health literacy occurs when a society provide promotes accurate health information and services that people can easily find, understand, and use to inform their decisions and encourage their actions.” 3. We’ve studied the issue enough and our current solutions (speak back method, plain language) are not going to impact enough people. Health Literacy will not occur without proper incentives. Attached is a draft case study that highlights the impacts of an innovative health literacy improvement program that taps into the trusted doctor-patient relationship to achieve the Triple/Quadruple Aim. This study was just submitted to JMIR and is expected to be published soon. The additional attachment points to the benefit of aligned incentives between patient and doctor to achieve superior outcomes.
34.	<p>If we envision the achievement of high quality “Health Literacy” to maximize a person’s health within a constellation of health care resources in a given society, then the outdated definitions of Health</p>

	<p>Literacy in Healthy People 2010 and Healthy People 2020, and the proposed definition for Healthy People 2030 are inadequate.</p> <p>1) A review of the 2004 Institute of Medicine publication, Health Literacy, [1] will reveal a constricted concept of Health Literacy that nearly completely focuses on communication skills. A more comprehensive definition of Health Literacy must include the capacity for critical thinking. In an era characterized by a glut of information, individuals must not only be capable of receiving and understanding information about their health, but they must also be able to analyze and screen out messaging that is not evidence-based or is a result of profiteering. Ignoring this capacity has contributed to the anti-vaccine movement and runaway opiate addiction, among many other negative health trends.</p> <p>2) In the newly proposed definition as in the earlier definition, there is an implication that health literacy relates to personal health decisions. In their 2009 article in the American Journal of Preventive Medicine, Freedman et al[2] describe the shortcoming of restricting the definition of Health Literacy to personal health care, a definition that they more aptly refer to as “individual-level health literacy.” The article proposes that Health Literacy be more broadly defined as having two components, including both this “individual-level health literacy,” and what is defined in the article as “public health literacy.” Freedman et al present a compelling argument that a definition of Health Literacy should include both components</p>
35.	<p>Respectfully submitted for your consideration: “Health literacy is the ability to understand health information and use to inform an individual’s decisions and actions”</p> <p>Rationale - The HHS proposed definition does not define health literacy rather it defines one of many tactics that facilitate achieving health literacy. Benefits of the proposed revision is as follows:</p> <ol style="list-style-type: none"> 1. The Healthy People 2030 version makes an assumption the reader knows health literacy equates to understanding 2. This proposed revision defines health literacy and like the original bridges to engagement and activation. 3. The proposed revision is consistent with the health literacy best practices of simplicity and conciseness
36.	<p>The NYU Center for the Study of Asian American Health strongly supports the New Health Literacy Definition for Healthy People 2030.</p> <p>Nationally, Asian Americans (AA), Native Hawaiians, and Pacific Islanders (NHPI) comprise the fastest growing racial and ethnic groups. The American Community Survey (2017) reports that nationally over 66% of AAs and about 20% of NHPIs are foreign-born and over 30% of AAs and 12% of NHPIs have limited English proficiency (LEP), which can limit health and preventive care access, impair patient-provider communication, and inhibit adherence to treatment, resulting in poor health outcomes.</p> <p>To capture the incredibly diverse experiences within AA and NHPI communities, data and research should strive to document and amplify the similarities and differences across ethnic groups and/or nations of origin.</p> <p>The revised definition acknowledges the complex socioeconomic, environmental, and system-level factors influencing this critical social determinant of individual and population health.</p>
37.	<p>New recommended definition:</p>

	<p>Health literacy is the degree to which a society provides an individual with accurate health information and services that are easy for individuals to obtain, process, understand, and use to inform their health decisions and actions.</p> <p>Explanation: We believe the health literacy definition should be more specific toward what health literacy is rather than just how to achieve it. We also believe that health literacy should involve the individual and the society, not just one or the other. If possible, incorporate cultural inclusion into the definition.</p>
38.	<p>The new definition of health literacy proposed by Healthy People 2030 is very simple, concise, and transparent. It is broad and applicable to all component of health literacy and doesn't necessarily limit the numerous categories that can fall under this umbrella term. This renewed generation of the definition ensures that it is reflective of the public's understanding of what health literacy entails. And in addition, it has a new component of involving patient's actions as part of the definition – which is empowering to the patient and provides them with responsibility, control over their care, as well as provide them with knowledge on how to prevent diseases. The only suggestion we'd like to make is that definition should also address patient outcomes. The reason for this is because health literacy is promising better health and to not include this would weaken the credibility of health literacy as a field of promotive action.</p>
39.	<p><u>Strength:</u> The new definition includes “providing accurate health information and services” by the clinician (takes focus/blame away from the individual) while placing more responsibility on the clinician to communicate effectively.</p> <p>Uses more simplified jargon, which is more easily understood by a greater populations.</p> <p>Looks at society's (healthcare providers) contribution to health literacy vs simply the individual</p> <p><u>Weakness :</u> Health literacy helps to increase patient safety, compliance to treatments and a prevention tool which is not mentioned</p> <p>Health literacy is not solely providing “Accurate” information but understandable for all reading levels</p> <p>“Health literacy occurs when understandable health information and services are provided to individuals that are easy to access and use to guide health decisions to improve safety and treatment plans.”</p>
40.	<p>Kindly find below our suggestions for the new health literacy definition.</p> <ul style="list-style-type: none"> • Strength: covers a broad range of issues, so it appeals to a lot of people • Weakness: some terms are too broad and are open for interpretation • Recommendations: <ul style="list-style-type: none"> ○ Instead of “society”, be more specific (does society mean healthcare institutions, government, public health clinics, etc.) ○ Healthy people 2030 is about tackling disparities and the definition is not clear in tackling disparities <ul style="list-style-type: none"> ▪ Edit suggestion: include “acknowledges and addresses health disparities” after “society” ○ Emphasize health equity in the definition

	<ul style="list-style-type: none"> ▪ Combine health equity and self-efficacy approaches in order to empower populations to take charge of their own health ▪ Edit suggestion: include “and modify” after “inform” <ul style="list-style-type: none"> • Suggested definition: <p>“Health literacy occurs when a society (specify what this means - i.e. health care institutions, health care providers, government, etc.) acknowledges and addresses health disparities and provides accurate health information and services that people can easily find, understand, and use to inform and modify their decisions and actions.</p>
41.	<p>Providing accurate health information and services that people can access, understand, and use is imperative to Health Literacy, however, the Health Literacy definition does not provide a clear definition of what Health Literacy is. Furthermore, it absolves responsibility from the individual and does not take into account context or culture. It is supposed to empower the individual, however, it diminishes the individual's self-efficacy. We recommend inclusion of the key concepts of self-efficacy, context and culture. Inclusion of these concepts would strengthen the definition.</p>
42.	<p>Below is our revised health literacy definition based on the shifting perspective from individual deficits to societal assets.</p> <p>"Health literacy is the degree to which the individual is able and willing to explore comprehensible health information and services provided by society to promote wellness, prevent illness, and make informed health decisions."</p> <p>Source: Rikard, R. V., Thompson, M. S., McKinney, J., & Beauchamp, A. (2016). Examining health literacy disparities in the United States: a third look at the National Assessment of Adult Literacy (NAAL). BMC public health, 16(1), 975. doi:10.1186/s12889-016-3621-9</p>
43.	<p>Healthy People 2030's definition of health literacy deserves praise for including a responsibility for personal engagement in using health information to make informed health decisions. However, this definition lacks a few components and can be strengthened by incorporating the idea of civic literacy. The National Assessment of Adult Literacy suggests that civic literacy empowers society to be responsive to health issues, form cohesive ties between communities, and engage in policy making for the benefit of the population (Rikard et al., 2016). For this reason, we feel that civic literacy is imperative to be included in health literacy's definition.</p> <p>Reference</p> <p>Rikard, R. V., Thompson, M. S., McKinney, J., & Beauchamp, A. (2016). Examining health literacy disparities in the United States: a third look at the National Assessment of Adult Literacy (NAAL). BMC public health, 16(1), 975. doi:10.1186/s12889-016-3621-9</p>
44.	<p>Weaknesses: The definition that you are offering for health literacy is not appropriate as a definition for health literacy.</p> <p>Strengths: It is appropriate to define when health literacy occurs and what should be a part of it for society (accurate information). When you state it occurs when accurate health information is provided, you are defining what the state or condition should be for the best or for health literacy to happen.</p>

	<p>You have stated: “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.”</p> <p>That is not a definition of health literacy. It is a definition of when health literacy occurs. It only identifies the health literacy of a society (or community), not an individual. Health literacy for anyone, whether community, society, or person should be defined as follows: Recommended changes (remove the words “occur” and “accurate” to state as follows:</p> <p>“Health literacy is defined as the ability or capacity to find, understand, and easily use health information and services to make informed decisions and take informed actions.”</p> <p>Reference: https://www.healthypeople.gov/2020/tools-resources/evidence-based-resource/national-action-plan-improve-health-literacy</p>
45.	<p>We believe that health literacy is a subset of health equity, therefore, the definition should include a reference to equity with a simple addition (below in yellow highlight).</p> <p>"Health literacy occurs when a society provides accurate health information and equitable services that people can easily find, understand, and use to inform their decisions and actions."</p>
46.	<p>I am writing to share some concerns I have about the new proposed health literacy definition. I have been working in public health communication for over 30 years. I worked with a number of health literacy efforts at CDC, when I was a senior health communication officer there in the late 90s. There’s no doubt that health literacy has grown from its early stages to a more mature stage, but I’m not sure I see good grounds for changing the definition. Firstly, I’d like to know what are the reasons for changing the definition? Is there confusion among academicians, practitioners, or the public? It always makes sense to me to make sure we are solving a real problem when we undertake these definitional change projects or are we just professionals with a “solution looking for a problem.”</p> <p>Secondly, I am concerned that the new definition uses society as the main subject of the definition and not people. That begs the question as to who or what organizations in society are providing this accurate health information? As we know there are a lot of actors on the health stage and some provide medically accurate information and some do not, though both would say their information is accurate. Each side has a lens for how they judge accuracy. Family planning information would be a good example.</p> <p>I have two recommendations. If the committee plans to go forward with this definition, please include the phrase “medically accurate health information and services” to ensure society uses medical information as the basis for information. My final concern with using society as the subject is that it takes the onus off of citizens from being basically health literate. I think that is dangerous and goes against the capacity development spirit of the original definition. I’m not saying we, as more educated folks, need to insist on others having a high education level, but rather a basic level of health literacy, so citizens can make decisions for themselves. This definition puts the information “giving” back in the hands of health care providers, governments, and NGOs. There’s nothing wrong with organizations providing health literate information. I’m all for that. But that is quite different from having a citizenry that is prepared to read, comprehend, and act on that information. If HHS wants both to happen then I think two definitions are warranted. One for the citizenry and one for societal actors.</p>

47.	<p>I like your definition. However, I would replace “society” with “Healthcare Professionals. ” I would also include the word, “simple” before “accurate.”</p> <p>“Health literacy occurs when Healthcare Professionals use simple, accurate language in the services they provide to their clients, which is easy to understand and helps them make confident decisions.”</p>
48.	<p>I believe this definition is simpler and more accurate:</p> <p>Health literacy is the ability to access, understand, and use information about health.</p>
49.	<p>Here’s alternative wording for your current health literacy definition:</p> <p>Health literacy is an understanding of the information and services required to seek medical care.</p>
50.	<p>Strengths:</p> <ul style="list-style-type: none"> • Includes both provider and patient elements rather than just one or the other. <p>Weaknesses:</p> <ul style="list-style-type: none"> • Even when the new definitional elements exist (accurate health information and services), health literacy will not necessarily follow since individual health literacy levels go up and down depending on many other factors such as personal stress etc. The definition should not promise health literacy as a result of such narrow dimensions. • The definition still follows mainly a medical model of health literacy and a cognitive skills approach and is not substantially changed over the current definition. Key public health concepts of culturally relevant communication, active patient/person engagement, and a consideration of the social determinants are missing. • The definition does not foster better quality health literacy research, and thus will not elevate the field. Definitions should help researchers compare apples to apples, determine what programs work, and impact population health, health inequities or health care systems. Elements that will improve health literacy research will include the concepts above as well as empowerment, education and equity. <p>Specific Edit Suggestions:</p> <p>“Health literacy is the use of accurate health information and a wide range of skills for active patient engagement, clear communication and decision-making in all health-related contexts in order to benefit health.”</p> <p>References:</p> <ul style="list-style-type: none"> • Health literacy and public health: a systematic review and integration of definitions and models. Sorensen, K. et al. BMC Public Health. 2012 Jan 25;12:80. doi: 10.1186/1471-2458-12-80. • The Calgary Charter on Health Literacy: Rationale and Core Principles for the Development of Health Literacy Curricula. 2011. https://lincs.ed.gov/professional-development/resource-collections/profile-313
51.	<p>I think that "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" is a very good, aspirational definition of health literacy.</p> <p>I would amend this to say "accurate and nonjudgmental (or welcoming/affirming/inclusive) health information and services ..."</p>

52.	<p>On behalf of our more than 100,000 member physical therapists, physical therapist assistants, and students of physical therapy, the American Physical Therapy Association (APTA) appreciates the opportunity to comment on the US Department of Health and Human Services' (HHS) revised health literacy definition for Healthy People 2030. The mission of APTA is to build a community to advance the physical therapy profession to improve the health of society. Physical therapists play a unique role in society in prevention, wellness, fitness, health promotion, and management of disease and disability by serving as a dynamic bridge between health and health services delivery for individuals across the lifespan. APTA's policymaking body, the House of Delegates, adopted a position of support for health literacy in June 2019: Health literacy is essential for optimal health and well-being of individuals, families, groups, communities, organizations, and populations. The American Physical Therapy Association supports improving health literacy as a means to achieve a just and inclusive society.</p> <p>APTA offers two recommendations: 1) the new definition be modified to ensure it will be interpreted to mean that all populations should have access to health information and services to make informed health care decisions; and 2) that HHS maintain the term "health" before "decisions and actions." For example, the new definition might read: <i>Health literacy occurs when an entire society can easily find, understand, and use accurate information and services to inform their health decisions and actions.</i></p>
53.	<p>In response to the Department of Health and Human Services' (HHS) request for comments on the proposed update to the health literacy (HL) definition, I offer these observations:</p> <p>The working HL definition for Healthy People 2030...</p> <p>1. Lacks specificity. The idea that HL "...occurs when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions" lacks enough specificity to make a sustained, scientific contribution to the field of Public Health. In other words, the working HL definition is too broad to be useful.</p> <p>2. Does not adequately describe other factors that could influence health literacy beyond the individual. I appreciate HHS's societal perspective on HL and their recognition that HL is affected by factors beyond the individual (e.g., in Healthy People 2010 and 2020, noting that HL includes, "...the accessibility, clarity, and actionability of health information and health services"). Nevertheless, the working HL definition does not make enough of these other factors explicit.</p> <p>3. Underappreciates the impacts of social factors and the situational context on health literacy. The new HL definition fails to address how this phenomenon might be impacted by social and situational forces. For instance, individuals with adequate HL might behave in a manner consistent with having limited HL under certain situational constraints (e.g., when confronted with time pressure or under emotional stress after receiving a recent diagnosis¹) but behave in a manner consistent with having adequate HL in other situations (e.g., when treated by a trusted physician who exhibits empathy).</p> <p>Based on these observations, I recommend:</p> <p>1. Integrating aspects of the definition offered by Coleman et al² into the Healthy People 2030 HL definition. Coleman et al² offer a more robust HL definition than the current formulation offered by HHS, which is:</p> <ul style="list-style-type: none"> • <i>HL allows the public and personnel working in all health-related contexts to find, understand, evaluate, communicate, and use information.</i> • <i>HL is the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives.</i>

	<ul style="list-style-type: none"> • <i>These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills.</i> <p>Albeit longer and lacking sufficient discussion of the potential impacts of social and situational factors, this definition offers greater specificity than does HHS' working HL definition.</p> <p>2. Ensuring HHS' working HL definition is holistic: A new HL definition should capture elements of the individual, individual differences in the experience of HL, social and societal factors, the situational context, the healthcare system, etc., and the complex interactions of these components.</p> <p>REFERENCES</p> <p>1 Myers, L. M., & Courtade, L. (2016, March). How Merck evolved marketing research processes to help patients better manage their health. Quirk's Media, Article ID: 201603063. Retrieved December 8, 2018 from https://www.quirks.com/articles/how-merck-evolved-marketing-research-processes-tohelp-patients-better-manage-their-health</p> <p>2 Coleman, C., Kurtz-Rossi, S. McKinney, J. Pleasant, A., Rootman, I., & Shohet, L. (2011). The Calgary Charter on Health Literacy: Rationale and Core Principles for the Development of Health Literacy Curricula. Montreal, Quebec, Canada: The Centre for Literacy. Retrieved from: https://lincs.ed.gov/professional-development/resource-collections/profile-313</p>
54.	<p>Here's my opinion and suggestions about a health literacy definition for Healthy People 2030:</p> <ul style="list-style-type: none"> • The definition should mirror health literacy principles and plain language practices. That includes using terms that everyone easily knows rather than jargon. An example of a word that I think does not work is "society." While I applaud your efforts to find something inclusive, am at a loss to know exactly what you mean. Could well be that my interpretation differs from yours. There seem to be other open-to-interpretation terms in this definition, too. They include "accurate" and "inform." • I created and continue to use a more functional definition of health literacy. It is "Health literacy happens when providers (or anyone on the giving end of health communication) and patients (anyone on the receiving end) truly understand one another." Sometimes I reinforce this message by interlocking my hands and saying that "Health literacy is about mutual understanding." I have a graphic that makes this same point in a somewhat different way. • As someone with a clinical background who has focused on health literacy for 20+ years, I feel that the essence of health literacy is not only to communicate clearly but also listen to those we communicate with. Neither party can achieve these goals alone. I leave that to you to figure out how to measure this.
55.	<p>Proposed health literacy (HL) definition over-emphasizes society's role, ignoring importance of empowering and motivating individuals as active agents in their own health. It is health-care-system centric whereas individual or population health comes largely from prevention, preparedness, social determinants and healthy behaviors people choose to adopt. The HL vision should track the lifespan - early childhood, pregnancy, family, work and school settings. HL is a fundamental asset to improve health equity and well-being.</p> <p>Improvement of HL in the population is a crucial, complex societal goal. It can be achieved by a dynamic, synergistic interaction between individuals and systems, using broad arrays of cognitive, media, communication skills and resources. Successful HL implies active decision making, enhanced by use of navigation, teach back, and reinforcement. When successful, HL results in a person-</p>

	<p>centered, multidimensional solution where individuals are partners in well-being and healthcare; health is not just a simple transaction.</p> <p>WHO HL definition is easily understood. We urge alignment.</p> <p>Successful HL in society means all people have skills, motivation and empowerment* to readily access, understand and utilize information delivered via varied communication media in simple language wherever they work, play, live, gather socially and receive health care. Throughout the lifespan, they can readily find reliable resources about prevention, promoting their family’s health, and make appropriate health decisions for specific medical needs. Empowered individuals have self-efficacy and confidence to ask questions, be respected, make choices, thus becoming true partners in their own health, improving efficiency of the health-care-system and improving health equity.</p> <p>*keys to measurement</p>
56.	<p>Although I am a big advocate for change, I do not feel that the new definition is appropriate. To begin, it is not health literate- “society, accurate, inform their decisions”. Who is this message for- what do you mean when you say society? I am finding this definition very difficult to decipher.</p> <p>My recommendation is to leave as the current, active definition.</p>
57.	<p>I strongly oppose the proposed new definition of health literacy for HP 2030, based on 3 central concerns:</p> <ol style="list-style-type: none"> 1) There is robust research related to health outcomes using current ‘skills based’ definition. There are no established measures or research with outcomes using the proposed definition. Having a definition with no recognized measures risks its utility for HP. 2) “Society” is vague and diffuses responsibility for health literacy. 3) Impact and policy analyses for a new definition should be pre-requisite for its adoption, and none have been done. Current HP definition is in wide use (federal and state laws, professional organizations and societies, community groups). How will current funding and provisions be affected if there is confusion regarding use of a new definition in HP? US Gov definition of “literacy” is skills based. Analyses should consider whether there should be congruence in definitions used by US Gov of ‘literacy’ and ‘health literacy’. <p>As an alternative to new definition, I suggest keeping current definition and adding language to HP2030 that aligns with 2004 IOM Report’s finding 2-1. <i>Health literacy occurs by making the demands and complexities of what is needed for health and health care align with the skills and abilities of individuals and communities.</i> (include widely accepted model : Fig 2 J Health Comm. 15 (2010), 20-23. DOI: 10.1080/10810730.2010.501094.). Responsibility for health literacy must be shared by multiple sectors (including education, health, healthcare, business, social services) to reach the vision of a health literate society.</p>
58.	<p>Just a thought, but this definition is at a college reading level. Maybe make it more ‘plain language?’</p> <p>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."</p>
59.	<p>I’d like to provide feedback on the health literacy definition proposed. There is something throwing me off with “health literacy occurs when”. This wording in itself seems cumbersome and too formal. I keep rereading this statement and what comes to mind is, “Health literacy is when...”. Even “Health literacy happens” is likely to resonate more with the public.</p>

	<p>Also, “society” feels like it’s not a strong enough term and is too vague.</p> <p>Kudos on the streamlined definition. There are some very wordy ones describing health literacy!</p> <p>I would like to propose: Health literacy is when healthcare providers, educators, and communicators provide accurate health information and services that people can easily find, understand, and use to inform their decisions and actions.</p>
60.	<p>I agree it is time to change the definition of Health Literacy and be more inclusive and I am in support of the suggested changes.</p> <p>My one concern was the use of the word “inform” (as highlighted below) I am not sure what “inform their decisions and actions” means in terms of an actionable activity. I might suggest instead of “inform” the use of the work “guide” their decisions and actions</p> <p>“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.”</p> <p>If this was not the proper procedure for submitting suggested changes, please let me know and I will resubmit appropriately.</p>
61.	<p>Weakness of proposed definition: Health literacy does not OCCUR. The proposed definition implies that if society does their job of "providing accurate health information and services that people can easily find, understand, and use," then people will simply become health literate. That is not the case. Literacy, whether health literacy or otherwise, is a continuum not one state of being. By saying that health literacy occurs, the continuum from poor to excellent health literacy is lost. I believe good health literacy is a partnership (like shared decision making) between healthcare entities and consumers. With this in mind, my recommended definition is:</p> <p>The degree to which people are able to find, understand, and use health information and services to guide healthcare decisions and actions. It is the responsibility of healthcare entities to provide information and services in an equitable and accessible manner</p>
62.	<p>A definition of health literacy should be written in plain language. Otherwise, it’s hypocritical of the underlying philosophy of health literacy. The new proposed definition is not written in plain language.</p> <p>The proposed definition does not take into account both sides of health literacy: the personal and the system. It is not just about the system. Even if the health system was doing everything right, personal factors could impact a person’s health literacy.</p> <p>It is likely not possible to draft a full definition of health literacy in one sentence. I do not believe it has to be one sentence. It is best to have a fulsome definition written in a few sentences. And written in a way everyone can understand.</p> <p>Perhaps we need to make a definition for “personal health literacy” and “system health literacy” or similar.</p> <p>Some ideas for a definition:</p>

	<p>System health literacy: how well the health care system gives people information in a way they can understand. The health care system must consider a person’s situation and work with them to make sure they understand the information they need to know.</p> <p>Personal health literacy: how well a person can find, understand and use health information. Personal factors, such as stress, education, and level of pain can all affect how well a person can understand health information.</p> <p>Thank you for asking input on this very important definition.</p>
63.	<p>I work for the National health service in one of the local regions in Scotland and we have been delivering health literacy training to colleagues for a number of years. We use the World Health Organisation (2015) definition of health literacy as we feel the part about empowering people to use health information is crucial:</p> <p><i>“Health literacy is about people having the knowledge, understanding, skills and confidence to find and use health information which promotes and maintains good health. By helping people to access health information and increasing their capacity to use it effectively, health literacy is critical to empowerment”</i></p>
64.	<p>Thank you for removing the "capacity" component from the health literacy definition and for emphasizing accessibility and society's responsibilities.</p> <p>There has been a growing discussion about the ways health literacy diffuses through social networks. It may be common for people with intellectual disabilities to indirectly access health literacy information from formal and informal supports. In bounded social organizations or networks members (e.g., families) may access and retain discrete health literacy information that becomes more complete only when combined with health literacy information by others in their social network.</p> <p>For this reason, please further discuss the following addition:</p> <p>“Health literacy occurs when a society provides accurate health information and services that INDIVIDUALS AND GROUPS can easily find, understand, and use to inform their decisions and actions.”</p>
65.	<p>A few initial thoughts on the suggested revised definition of health literacy:</p> <ul style="list-style-type: none"> - The term “society” is so vague – what is meant by society? - Concern that this new definition is not “measurable” - Also concerned by what is meant by “accurate” health information?
66.	<p>Inequities in health arise from inequities in the social and physical environments in which people are born, grow, live, work, and age, known as social determinants of health.</p> <p>More than 80% of the nearly \$3.5 trillion spent on medical care each year in the U.S. is used on treating chronic diseases—most of which are preventable and related to the conditions of poverty.</p> <p>The working definition of health literacy focuses on capacity and skills to address immediate health care needs while neglecting the underlying social determinants that degrade health equity.</p>

	<p>We cannot expect people to adopt the healthy behaviors and recommendations that health professionals champion when people are disadvantaged by social, economic, and environmental barriers.</p> <p>Moreover, we cannot expect people to advocate for social and physical environments that promote good health for all without an understanding of how social determinants impact health.</p> <p>Please revise the current working definition of health literacy to elevate the importance for both those in need of and those providing health information and services to also embrace the role social determinants play in health, particularly across the other four key domains of social determinants of health: economic stability, education, neighborhood environment, and social and community context.</p> <p>Salud America!’s Suggested Definition: “Health literacy occurs when society provides accurate information about health and social determinants of health that people can easily and equitably find, understand, and use to inform their decisions, actions, and advocacy.”</p>
67.	<p>Genetic Alliance is a nonprofit advocacy organization committed to engaging diverse stakeholder groups to transform health. Our approach to health literacy is rooted in a 32-year old mission of providing individuals, families, and communities with the information they need to make informed and confident health and healthcare decisions.</p> <p>We commend the Secretary’s Advisory Committee on evolving the concept of health literacy to describe systems-level accessibility, clarity, and actionability. As the field of public health matures, we believe the definition should:</p> <ol style="list-style-type: none"> 1. Reflect a people-centered participatory process that acknowledges inequities in the distribution of resources.¹ 2. Reinforce compassionate communication skills of healthcare professionals to translate medical information and build trust within communities.² 3. Embrace the growing demand to navigate the technology landscape for online and digital information.³ <p>As such, our recommended definition is:</p> <p>Health literacy is the practice of communicating accurate and clear health information in a variety of settings where people can easily find, understand, and inform their decisions and actions.</p> <p>¹ World Health Organization. “10 Facts on Health Inequities and their Causes.” (2017). https://www.who.int/features/factfiles/health_inequities/en/</p> <p>¹ Powell, M. Paige, Amanda J. Young, and Hyunmin Kim. "A Journey in Capacity Building: Revisiting the Mullins Framework for Meaningfully Engaging Patients in Patient Centered Outcomes Research." <i>Frontiers in public health</i> 6 (2018).</p> <p>¹ Office of Disease Prevention and Health Promotion US Department of Health and Human Services. (2010). <i>National action plan to improve health literacy</i>. US Department of Health & Human Services. https://health.gov/communication/hlactionplan/pdf/health_literacy_action_plan.pdf</p>
68.	<p>The current Healthy People 2020 Health Literacy definition, “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”.</p>

	<p>Although clear and concise, use of the word “appropriate” is very subjective. What is appropriate to the health care provider may not be so to the patient and vice versa.</p> <p>With modern health care trending towards a Whole Health approach, my suggestion would be to incorporate use of key patient centered terminology and simplifying the statement so that the definition itself, meets health literacy guidelines. The current statement has a grade reading level of 16.82, with a reading ease score of 19.03.</p> <p>Suggested Revisions: “Health literacy is when people have the ability to obtain, process, and understand basic health information that allows them to take charge of their health and well-being” Grade level: 13.45 Reading Ease: 48.49</p>
69.	<p>I am writing this email in response to the new proposed definition of Health Literacy published on the CDC website June 26 2019. https://www.cdc.gov/healthliteracy/pdf/June_26_Health_People_2030_HL_Definition_Webinar_Final.pdf</p> <p>We have been advocating to incorporate Health Literacy as a priority taking into consideration an “ecological” definition of health literacy as in the systems and environments in a society that enable individuals to obtain, understand, and use to inform their decisions and actions”.</p> <p>However, we are struggling to find a measurement tool- the available research, literature and validated tools confine health literacy to “patient safety and medical errors” - and this is hampering advancing Health Literacy on our agenda to promote health in our society.</p> <p>We really look forward to see how the new context and breadth will be measured.</p>
70.	<p>Suggested edits: “Health literacy occurs when a society responsibly provides accurate health information and services that people can easily find, access, understand, and use to make informed decisions to take action on matters effecting their health outcomes.”</p> <p>Comment: While people may be able to find information, they may experience difficulties accessing the information due to the delivery format.</p> <p>Ex: A state agency factsheet on immunization may be available in a four or five languages; however, if the native language of a community of immigrant people is not represented, finding those other language versions is of no help to those people.</p>
71.	<p>It would be helpful to have an online subject source of roadmaps and examples for people to access when faced with a new diagnosis, change in healthcare needs or other health related challenge. For example, if a person thinks their loved one may need memory care they could look it up in the subject source. The source could provide stories of people that have faced similar health challenges.</p> <p>For example: Jill notices her mother is becoming very forgetful and is beginning to not remember her way home from routine walks. Not knowing what to do Jill references the subject source and retrieves in part this related story: <i>Jane routinely visits her mother every Thursday evening on her way home from work. Recently Jane notices her mother is forgetting to take her blood pressure medicine and forgets to turn off the oven after preparing her meals. When Jane asks her mother if</i></p>

	<p><i>everything is okay, her mother smiles and says “Don’t worry, everything is fine”. Recently her mother’s neighbor told Jane that her mother keeps locking herself out of her house but fortunately the neighbor has an extra key and lets her back in. Jane begins to worry and decides to call her mother’s primary care physician and asks what she should do. Her physician’ office helper makes an appointment for her physician to evaluate her mother’s condition. Jane also contacts a memory care expert/ educator and schedules an appointment for herself and her siblings to meet and become familiar with memory care related issues. Next “typical” steps, next typical steps etc.....</i></p> <p>These examples or roadmaps would be based on best practices and contain links to resources. They could tell a story of the typical (best practice) steps and actionable items for reference. They would provide a blueprint for people to follow. It would be resource centric and not directed towards self-diagnosis.</p>
72.	<p>I have read your 19 slides presentation where you asked for feedback. I think this is a very important and interesting exercise. Thank you for sharing and for giving the opportunity to share views.</p> <p>My comments:</p> <p>1. Public Health Scenario 2 What should the educator consider before choosing a website as the best approach to informing the community? Before the investment and the effort, the educator should consider:</p> <ol style="list-style-type: none"> 1. The impact of rabies in the community risk perception: Is rabies a problem for this population? Usually, rural population is scattered and health events are communicated and perceived in diverse ways. 2. Being a rural community, how is the population regarding literacy level, cultural issues, social and economic dynamics?, in order to assess the success of developing a website. How many persons actually will have access to this strategy? How many of them use internet, or even have a computer or a mobile? 3. Being a rural community, what do people know , understand or believe about rabies and about how the health service cares or follows this threat. 4. Which will be the healthcare team participation, in order to provide sustainability for the website tool or for another strategy? <p>2. Regarding the Health Literacy definition, the first one certainly makes emphases on individuality and somehow, in individual responsibility. I think this first definition is true, but uncomplete. It could say: 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, supported by a societal net of effective health communication. In the first definition, Health Literacy “is a degree of... information”. In the second one, Health Literacy “is something that occurs... or not”</p> <p>I think the definition could be more comprehensive if we say: Health Literacy is the level of effective communication that a society reaches by means of managing health information nets in such a way that individuals and communities can easily access, understand and use it to have the capacity to make the best practices and decisions regarding their health condition, security and wellbeing. I respectfully leave the former text for your consideration.</p> <p>3. On the other hand, I think it is very important to be careful regarding that the new proposed definition “is measurable”. If this is good for our quantitative/Positivist approach of health (and I do</p>

	<p>agree we need it), if underlined or exclusive, this entails the risk of working under an “instrumentalism” that gives privilege to numbers and low appreciation to qualitative elements deeply involved in the communication and service processes and nets dynamics. Actually, we know that it is possible that even our best-qualified health-worker make an omission mistake, due to the complexity of the health problem that have to assist in a given moment, in a given context. That is, even the Systemic Approach is practical, we must consider all the health services scenarios, procedures and actors the diseased person has to be in touch during the experience of seeking/having access to healthcare. That may be the case of very complex events, such as Chagas Disease, for instance. We are the healthcare providers or organizers. How do we deal with the contribution of each person to the surveillance system functioning, just to mention the surveillance system? How do we deal with the relationship community-health service in this case? We could analyse every aspect about the Chagas Disease management and we would find challenging taking into account every component, to build an effective health literacy experience for this metaxenous disease.</p> <p>Therefore, what I think we can gain in the whole process of addressing health literacy is to consider carefully (as health managers and researchers) not only the biological and clinical and administrative aspects people should manage themselves, but also, the level of understanding and management they have about the health system and the health events. Obviously, It is also needed that health-workers have their respective technical management and ability to communicate (both within teams and with people) on specific health situations, problems and conditions, with empathy. Does this mean that we must consider a health literacy design for each health problem/situation/condition per scenario, per moment? Probably we must.</p> <p>4. We know that Health Promotion includes prevention among its five elements, as well as includes communication, information, education and social mobilization. We also know that Health Promotion and Health Equity are top international health policies. In agreement with that and with the proposed definitions for Health Literacy, this may be considered a strategy to give support and expresion, that translate those policies, HL may be considered a tool that operationalizes those policies and that it is aligned with their objectives.</p>
73.	<p>This has stimulated great conversations among my colleagues. This is one version that we like.</p> <p>Health Literacy is the degree to which clear communication is used among healthcare providers, patients, and their families, leading to the confident self-management of one's health.</p>
74.	<p>I am submitting a comment for the Health Literacy definition on behalf of the National REACH Coalition.</p> <p>Revised Definition: Health literacy occurs when a society provides accurate, accessible, and culturally appropriate health information, services, and resources that its recipients can easily find, understand, and readily use to inform their health decisions and actions.</p> <p>The National REACH Coalition (NRC), a unified entity of grantees of the Centers for Disease Control and Prevention’s Racial and Ethnic Approaches to Community Health program, proposes the above revised definition of Health Literacy for the Department of Health and Human Services’ Healthy People 2030.</p> <p>The NRC serves a diverse group of racial and ethnic communities across the country, including African Americans, Asian Americans, Pacific Islanders, Hispanic/Latinos, Native Americans, and Caribbean</p>

	<p>Islanders. Part of our coalition’s work involves the promotion of Health Literacy by empowering and mobilizing community members to seek better health practices, and encouraging the utilization of appropriate care and services.</p> <p>We believe that culturally tailored and community-driven interventions are crucial in achieving the best possible health outcomes as every community perceives and utilizes health information, services, and resources differently.</p> <p>The revisions made to the working definition emphasizes the importance of not only the availability of health information but also its accessibility. As a coalition serving incredibly diverse populations, we advocate for equally diverse interventions to increase Health Literacy.</p>
75.	<p>OLD “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.”</p> <p>PROPOSED BY HHS “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.” This working definition reflects the evolution of the concept of health literacy toward a consensus that health literacy is affected not only by an individual’s capacities, but also by the accessibility, clarity, and actionability of health information and health services.</p> <p>COMMENT The original definition appropriately emphasizes that literacy is a characteristic or achievement of an individual. This should not be lost.</p> <p>The addition of the environmental factors (“accessibility, clarity, and actionability of health information and health services”) is laudable but should be added, rather than replacing, the focus on the individual’s abilities. These are both vital components.</p> <p>Also, “society” is too limiting – these resources MAY be provided in many settings, such as specific providers, libraries, schools, etc.</p> <p>PROPOSED REVISION “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. It is facilitated and enabled by accurate health information and services that can easily be found, understood, and used to inform their decisions and actions.”</p>
76.	<p>I am writing to submit public comment regarding the Healthy People 2030 proposed definition of health literacy.</p> <p>For my MPH capstone I did a project assessing health literacy initiatives in the state of Oregon, which included a deep dive into the literature around health literacy definitions. My research highlighted the many challenges associated with current definitions, and the difficulty among researchers attempting to develop a more cohesive definition.</p> <p>Having spent a long time knee deep in health literacy definitions, I am beyond excited to see that Healthy People 2030 is including a new and improved definition. Healthy People is such an instrumental platform to redefining and more accurately addressing the evolution of health literacy.</p>

	<p>The definition used in 2010 and 2020 have been used so extensively that the impact that this new definition will have is immeasurable, therefore making it critical to “get it right” this time.</p> <p>As is, this proposed definition does a lot of things right, and I am content with where it is at. However, in writing this comment I had originally wanted to dive into the nuances of how “society” feels vague and how this definition isn’t accounting for supportive mechanisms that help people navigate the health systems. In thinking this over, though, I think I will boil it down to one recommendation:</p> <p>“Health literacy occurs when a society provides accurate health information and services that all people can easily find, understand, and use to inform their decisions and actions.”</p> <p>Simply adding “all” forces this definition to meet the needs of everyone, which is critical when thinking of health equity for more marginalized communities. I am thinking of when a local health system or a community hospital takes this definition and tries to make sense of it, seeing “all people” will drive them to really think about all people, not just those in the forefront.</p> <p>Thank you so much for your work to promote healthier communities. I look forward to seeing how this evolves and getting to use this new definition.</p>
77.	<p>Truth Initiative applauds the proposed change in definition of health literacy for Healthy People 2030, particularly the change in focus on access to health information rather than on individual capacity. It is vital for individuals to have access to clear and comprehensive health information in order to make informed decisions regarding their wellbeing. The updated definition encourages accurate health information and services be available to all individuals.</p> <p>Certain communities often are unable to receive adequate health care due to a lack of clear and comprehensive health information. In tobacco control, for example, we see this in the health disparities of tobacco use and cessation. Lesbian, gay, and bisexual individuals have higher rates of tobacco use and lower quit attempt rates than the general population.^{1,2} Studies have shown that LGBT smokers are less likely to ask about tobacco cessation during doctor visits and may experience barriers to cessation services, including limited access to treatment.³⁻⁵ Additionally, low health literacy may be associated with poor smoking cessation outcomes, particularly for low socioeconomic status (SES) racial and ethnic minority populations which have higher smoking rates.^{1,6} Lower-income smokers may face more barriers to cessation treatments as fewer lower-income smokers quit successfully than those living at or above poverty, despite similar quit attempt rates.^{7,8} This could be due to a lack of access to accurate smoking cessation information and services.</p> <p>Ensuring that all individuals are provided health information that they can find, understand, and use will greatly reduce health disparities across communities.</p>
78.	<p>Thank you for the opportunity to provide feedback on the proposed definition of health literacy. I believe this definition is moving in a positive direction as it is shifting the onus away from the individual patient/person receiving services. My concern is that the word “society” is somewhat vague and may be interpreted in such a way as to decrease responsibility from organizations and individuals providing services. While it would lengthen the definition, one approach to clarify the definition would be to state, “Health literacy occurs when a society, including public policy, communities, institutions, and individuals promote and provide accurate health information and services that people can easily find, understand, and use to inform their decisions and actions.”</p>
79.	<p>Below are my comments on the forthcoming updated Health Literacy definition for Healthy People 2030.</p>

	<p>“Health literacy occurs when a society provides accurate and accessible health information and services that people can easily find, understand, and use to inform their decisions and actions. Accessibility in information and services includes all forms of written, as well as, visual languages. Understanding occurs not just through the use of the appropriate congruous language, but by ensuring that people truly understand the meaning of the words and not just the words themselves.”</p> <p>Citation: Pollard, Jr., R.Q., & Barnett, S. (2009), Health-related vocabulary knowledge among deaf adults, <i>Rehabilitation Psychology</i>, 54, 182-185. http://dx.doi.org/10.1037/a0014771.</p> <p>“The Perfect Storm: Health Literacy Among Prelingual Culturally Deaf Aged ≥ 50 Years”. <i>Ethnicity & Disease</i> – 2019;29(Supp 1):209-226; doi:10.18865/ed.29.S1.209 (see page 224 / page 16 in the pdf)</p>
80.	<p>The new health literacy definition places responsibility for health literacy on “society” – which is a good thing – but which does little to inspire clinicians/healthcare systems to make the problem of health illiteracy THEIR problem for which they need to create solutions. The word “society” makes everyone responsible, and no one accountable. When clinicians do not realize their obligation to assess patient’s health literacy, and make adaptations to their patients’ care plans to meet patients’ healthcare literacy needs, their patients’ needs will not be addressed (Home Health Quality Improvement Campaign, 2018). Therefore, I recommend that healthcare systems and clinicians should also be identified as having a special role in promoting patient understanding within the definition.</p> <p>Health literacy occurs when a society/healthcare systems/clinicians provide accurate health information and services that people can easily find, understand, and use to inform their decisions and actions.</p> <p>Home Health Quality Improvement Campaign. (2018, January). Actions to Improve Health Literacy. Webinar. https://protect2.fireeye.com/url?k=64378c16-38628505-6437bd29-0cc47adb5650-397280abfb003ace&u=http://www.homehealthquality.org/UP/Jan-2018.aspx</p>
81.	<p>While I agree with the goal of using a definition that avoids sole responsibility on the individual – I worry about placing responsibility on “society” might be too vague and then no one is responsible for it. In addition, how would we measure whether society does something? I’m not sure the new proposed definition is measurable. Below is a revised proposed new definition which admittedly uses passive voice. One alternative is to use “organizations” but not everything is an organization. It is the organizations/institutions/agencies/entities that should be providing the information in this manner.</p> <p>“Health literacy occurs when accurate health information and services are provided so people can easily find, understand, and use it to inform their decisions and actions.”</p> <p>Measurement could be then done at the organizational and individual level.</p>
82.	<p>We believe that health literacy is a subset of health equity, therefore, the definition should include a reference to equity with a simple addition (below in yellow highlight)....</p> <p>Further discussion around stakeholder bias when developing programs, treatments, and communications yielded another addition to the statement, so our recommendation now reads:</p>

	<p>"Health literacy occurs when a society provides un-biased and equitable services that people can easily find, understand, and use to inform their decisions and actions."</p>
<p>83.</p>	<p>Comment and Definition: Health communication is an interaction, but shifting the definition away from the individual undermines intervention. We must consider both individual knowledge and skills (accumulated through experiences and education, mediated by values, interests, and intelligence) and the knowledge and skills of interlocutors (and clarity of materials).</p> <p>We should promote a baseline of 21st century knowledge through education: how the human body and the natural world work, what decisions are individual choices (DNR, termination) versus social needs (immunization, right to choose.) Without this, citizens are not equipped to make personal health decisions or weigh in on policy choices.</p> <p>Assessments/screenings must be more comprehensive. Both oral and written skills matter; text is not merely a recording of speech. We should look at developing a CALS-like tool. CALS (though it applies to academic communication) is relevant in that it moved away from a one-dimensional predictor (vocabulary) to a cohort of skills.</p> <p>Thus, I propose: Health literacy is the set of world and health knowledge and beliefs, general intelligence and literacy, and communication skills that allows an individual to seek, obtain, understand, assess, and apply health information in daily life and health care contexts. This ability is mediated by culture, education, language, and the knowledge, intelligence, literacy, and communication skills of health care and health information providers who have a responsibility to provide health information in plain language, that is, in coherent, cohesive, adequate, and accessible language.</p> <p>Operationalizing this definition would call for separate assessments for: -individual health literacy -provider health communication aptitude -communications/materials plain language</p>
<p>84.</p>	<p>The phrase "when society provides" is passive and does not directly address the person. Literacy resides in the person, not in what society provides. I suggest the following: "Health literacy occurs when a person has easy access to accurate and understandable health information and services that is used to inform their decisions and actions."</p> <p>This suggested wording changes the focus from "society providing" to the person using and taking action.</p> <p>Please see the work that the State of Colorado has done regarding Consumer Engagement, Empowerment and Health Literacy at the following link. https://www.colorado.gov/pacific/sites/default/files/FINAL%20Consumer%20Engagement%20Final%20Report%202019-06-27%20%281%29.pdf</p>
<p>85.</p>	<p>The following definition was created by the Patient Education team at Sanford Health: Health Literacy is the ability to provide and use clear communication to manage health and wellness with confidence.</p>

<p>86.</p>	<p>We are grateful for the opportunity to contribute comments to the health literacy objectives of Healthy People 2030. We recommend making slight changes to the definition to be sensitive to the limited educational level of segments of the population and to reflect the rapidly changing and variety of ways in which modern society communicates information.</p> <p>Though health care thrives through personal interaction, technology plays an important role in reaching most segments of our society, including those people who are only accessible by phone or computer. HP 2030 should ensure that health information is adaptable to populations who communicate mostly through computer programs, social media, and text messaging (a rapidly increasing segment of the population).</p> <p>Health literacy initiatives should be sensitive to language barriers while providing people of all education levels access to information through various means of communication. In this way, health information must become adaptable to the ever-changing ways that people of all educational levels communicate.</p> <p>Additionally, we continue to see a need for basic health education in elementary school, continuing through middle- and high school.</p> <p>Below are our suggested changes to the health literacy statement: “Health literacy occurs when a society provides accurate health information and services that people of all education levels and access to technology can easily find, understand, and use to inform their decisions and actions.”</p>
<p>87.</p>	<p>We applaud DHHS’ endorsement of the reality that effective health communication requires a focus on society, not on patient skills alone. However, as informaticists, we recommend against redefining a term that is included in standardized terminologies including the Medical Subject Headings (MeSH). Changing the meaning of a term in a standard terminology has well-established negative consequences [1].</p> <p>First, validated assessment instruments for “health literacy” (such as the SILS, TOFHLA, or NVS) will immediately be invalidated, because they measure a construct that no longer matches the contemporary definition of the term.</p> <p>In addition, using “health literacy” to search the indexed literature will produce two different types of studies. One will focus on patient skills, and the other will focus on social systems but will have to be indexed using the old term.</p> <p>Instead of redefining “health literacy,” we recommend retiring it. To capture the new construct, create a new term: “health information fluency.” “Our society promotes health information fluency when we provide accurate health information and services that people can easily find, understand, and use to inform their decisions and actions.”</p> <p>Retiring the old term while creating a new one 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. 1. Cimino JJ. Desiderata for controlled medical vocabularies in the twenty-first century. <i>Methods Inf Med.</i> 1998;37(4-5):394-403.</p>

88.	<p>I suggest the current definition of health literacy should be retained within Healthy People 2030 because it is grounded within U.S. statutory law and is evidence-based.</p> <p>Title V, subsection A of the Affordable Care Act defines ‘health literacy’ as: “the degree to which an individual has the capacity to obtain, communication, process, and understand health information and services in order to make appropriate health decisions” [1].</p> <p>I suggest an advisory committee that represents the U.S. Department of Health and Human Services should strive to secure (not undermine) health literacy’s legal standing and authority. In addition, the field’s evidence-base firmly supports the existing rather than the proposed health literacy definition.</p> <p>However, health literacy is an evolving research construct that currently contains three dimensions: improving the capacities of individuals to understand medical information; enhancing the responsiveness of the health care delivery system to the complexities of patients/caregivers; and health literacy’s role as a social determinant of health.</p> <p>As a compromise, I suggest Healthy People retain the current definition and briefly explain that health literacy has become a multidimensional construct. The latter simultaneously endorses innovative research and practice while reinforcing the field’s legal and evidence-based foundations.</p> <p>[1]Patient Protection & Affordable Care Act, 42 U.S.C. § 18001 et seq. (2010). Full text available from: http://housedocs.house.gov/energycommerce/ppacacon.pdf</p>
89.	<p>Expecting Health is a maternal and child health advocacy organization committed to engaging families in better health. Born from Genetic Alliance, a nonprofit organization rooted in 32 years of community programs and representing national voices and family-centered experiences, we share science-based and policy-informed information that reflects the lived experiences of individuals and their families. Expecting Health has a rich history of bringing parents, families, and other stakeholders to the table to inform and lead quality projects; empowering people to make the right choices for them using clear, accessible, and accurate information.</p> <p>As such, we commend the Secretary’s Advisory Committee on evolving the concept of health literacy to describe systems-level accessibility, clarity, and actionability. We would like the definition to either explicitly state and consider as part of an overall framework:</p> <ol style="list-style-type: none"> 1. Technology as a health information modality (e.g., health IT), along with principles around ensuring tech literacy. 2. The importance and challenges of access to health IT, as well as awareness of where to go for information as a critical component of health literacy. 3. The critical need of healthcare professionals to meet patients where they are to advance the translation of medical information and build trust. 4. A lens of equity and appreciation for varying techniques and approaches to supporting the literacy of different populations, individuals, and families based on their background, macro, and micro systems.
90.	<p>Easy-to-find:</p> <ul style="list-style-type: none"> • Patients report receiving printed patient instructions at the end of their appointments. • Patients report knowing online resources (video and text-based) for looking up more health information. • Patients report that patient portals are easy to use. <p>Understandable:</p> <ul style="list-style-type: none"> • Patients report that printed patient instructions are easy-to-understand.

	<ul style="list-style-type: none"> • Patients report knowing specific online resources* that provide understandable health information. *(not just Google or YouTube) • Patients report that patient portals provide understandable health information. <p>Useable:</p> <ul style="list-style-type: none"> • Patients report using the printed patient instructions that they received. • Patients report using health information from specific online resources. • Patients report using health information from patient portals. <p>Ideally, patients will receive quality health information from their health care providers. This would include printed materials, recommended online resources (video as well as text-based) and usable information in patient portals.</p>
91.	<p>Thank you for the opportunity to provide feedback on the working definition of health literacy for Healthy People 2030. I think the proposed definition is a good starting point, but is not sufficient. The definition is more description of an end-state rather than a true definition. In my proposed definition below, I have attempted to expand the lens beyond society to be more comprehensive of all the necessary levels. In addition, I've tried to wordsmith the existing content to be more definitional in nature while acknowledging the fluid state and the role of culture in health literacy.</p> <p>Health literacy occurs at the societal, system, organizational, and individual level. Health literacy, a non-static, culturally-informed state, is when health information, including insurance coverage and health services, are provided in an accurate, easy-to-find, easy-to-understand way to inform decisions and actions related to health and well-being.</p>
92.	<p>I am writing in response to the call for proposed changes to the definition of "health literacy" being sought on behalf of Healthy People 2030.</p> <p>The current definition reads, <i>"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."</i></p> <p>Before providing a proposed statement, I will offer the following context to the current definition to explain the need for change:</p> <p>"Health literacy occurs..." – This assumes a measurable outcome based on the provision of accurate health information, services, and understanding. Health literacy does not simply 'occur' under the correct conditions. It is a process that is learned over time through various experiences with previously known or unknown health care systems.</p> <p>"When a society provides accurate health information and services.." - What is 'accurate' to me living in a more developed county may not be accurate to someone coming from a developing country whose health care culture, traditions, and services have served them well to this point. Stating 'accurate health information and services' implies that these things can only exist in a first world setting and that all other health ideology and/or practice is irrelevant to health literacy on the basis of science alone. This ethnocentric view creates a disadvantaged space for those who are trying to integrate into a better, though incredibly flawed, health care system. Likewise, services alone do not always improve health literacy. On the contrary, they can create more confusion, especially if people do not understand why the services are being performed.</p>

“..that people can easily find, understand, and use” –That which is ‘easy to find, understand, and use’ is subjective and unique to the individual. The phrasing suggests that if you can find it, you will understand it, and therefore use it. This is a crucial assumption as the three variables are not necessarily inextricably linked. Though society can attempt to create information and services that are easily accessible and tailored, those things do not guarantee their use by populations or necessarily improve health literacy through their use.

“..use to inform their decisions and actions” – This is vague and needs relevant measures and context to prove. Using health information is subjective. The statement lends itself to more questions; ..use to inform which decisions? Which actions? On behalf of whom? With what outcomes?

The Merriam-Webster dictionary expands the term ‘[literacy](#)’ to include the quality of being [literate](#). Their definition includes education, culture, being versed in literature, and knowledge in addition to reading and writing as constructs.

Health literacy is a global endeavor that embodies more than just written, oral, or visual health communication. Health knowledge and understanding span across a spectrum of physical, emotional, social, spiritual, environmental, occupational, and other dimensions. Therefore, **health** literacy is a unique type of communication and comprehension in each of those areas. Health literacy needs to invite culture, religion, life experience, and social determinants of health to act as supportive players in the elevation of the definition and practice of health literacy, not just the way we communicate it.

When health literacy is spoken of, it is often referred to as ‘low health literacy’ or ‘high health literacy’ introducing shame, judgment, inequity, or bias onto a person. Just because an individual does not understand your language does not mean that they are not health literate. It means that society needs to do more to individualize the health care experience to meet the needs of that person.

I propose the following, more inclusive statement, that considers aspects of health previously unrecognized:

Health literacy is the process of dynamic learning, communication, experience, and adaptation to known or unknown cultures, societies, and health systems that seek to communicate equitable and reliable health information and services to increase the potential for positive health outcomes through informed choices.

- Health literacy shown as a ‘process’ demonstrates that it is a journey rather than a destination
- Health literacy shown as ‘dynamic’ demonstrates that it can happen at any time, in any form, for any learning style, and in any sphere
- Health literacy shown as ‘learning, communication, experience, and adaptation’ demonstrates a wide scope of opportunity for connection to health information
- Health literacy shown as ‘..known or unknown cultures, societies, and health systems’ demonstrates inclusion of things learned and things yet to learn
- Health literacy shown as entities [seeking] “..to communicate equitable and reliable health information” demonstrates equity and the intention to address social determinants of health
- Health literacy shown as a goal to “..increase the potential for positive health outcomes through informed choices” demonstrates the intention of health literacy to improve quality of

	<p>life through fluid encounters between the person and the information they receive and connect with.</p> <p>As a Certified Health Education Specialist working in the field of Public Health I value the accurate portrayal of definitions to inform the planning and dissemination of interventions we provide to people in our communities.</p>
93.	Health literacy and patient/family education should be part of Nursing School programs.
94.	<p>I strongly oppose the new definition of health literacy and would suggest an amended use of the original Ratzan and Parker definition reflecting new opportunities that have emerged through research stimulated by the original. Any proposed change in the definition, must be vetted for utility and measurability and policy implications as well as for the impact upon decades of research data based on the Ratzan and Parker definition.</p> <p>The weaknesses of the proposed definition include:</p> <ol style="list-style-type: none"> 1. The term “society” is amorphous and inherently unmeasurable. Placing the emphasis on society providing products and services and indicating that the public will “find, understand, and use” these materials and services is a leap. Further, research is needed to understand how decision-making occurs and why action is taken. 2. The proposed language not include a range of literacies in both an individual, over a lifetime, through differing states and abilities. 3. The proposed language does not embrace the significant finding of the significant actual and potential roles of health literate organizations (health, education, private, public) in the process. Organizations are a much more measurable entity than “society.” 4. The proposed definition does not capture the key communicational component central to health literacy success that it is transactional, two-way, audience-centric strategies known historically as feedback and operationalized by Schillinger as “teach back.” 5. Notably, the paper Pleasant et. al. called for: consideration of system demands and complexities; measurable components; analysis for change; informed decisions and actions not adequately addressed here.
95.	<p>“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.”</p> <p>Health literacy happens when a society provides current and accurate health information and services that are easy to find and follow, enabling each person to make the best possible health care choices.</p> <p>I feel “Happens” is a stronger verb. If society does the following, health literacy will happen. I feel “Understand” is too vague. My understanding may not be accurate. I feel that “<u>inform</u> their decisions and actions” does not make sense. I feel that the goal of health literacy is making the best possible health care choices. This implies and includes both attitude and behavior changes.</p>
96.	<p>As a patient and patient advocate, I view the definition of Health Literacy as an essential model for healthcare organizations to follow so American healthcare can transform into patient-centered care. My observations are:</p> <ol style="list-style-type: none"> 1. Despite the committee’s desire to be brief, the use of the term “society” connotes otherness. It’s somebody else’s responsibility, not mine. The phrase “healthcare-related organizations” is both broad and yet more inclusive. 2. True Health Literacy is the key to successful patient-provider communication. Communication is by definition always a two-way process. The proposed HL definition suggests it’s one-way. We can push all the information we wish but without ensuring it’s received, understood, and actionable, we

	<p>do not have health literacy.</p> <p>3. We recognize the importance of patient centered care as one of our highest ideals. The current definition is not patient-centered because it neglects the role of the patient as a team member; it neglects their observations, data, questions, and concerns. Hence the addition of the word: “discuss.”</p> <p>A proposed revised definition that is actionable by all parties is:</p> <p>Health literacy is the ability of a patient to access, understand, discuss, and act on information provided to make fully informed medical decisions. Success requires multiple variables: the patient’s ability and will to learn, the individual provider’s communication skills, and all healthcare-related organizations’ delivery of relevant medical resources, including the patient’s own records.</p>
97.	<p>Healthy People 2030 used the following working definition: “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.” According to the Merriam-Webster dictionary, the word “literacy” means the ability to read and write, and knowledge that relates to a specified subject. "Literacy" implies possession of a certain skill set.</p> <p>But in the health care context the word has wider meanings that apply just as much to the providers of information and services as they do to the patient or family member.</p> <p>The proposed definition puts an onus on the patient to understand, when in fact, comprehension could depend on how the conversation or instructions are actually shared by a clinician. Both parties must be "health literate" and the definition should reflect that.</p> <p>Health literacy as defined above also does not encourage the patient nor family to question information being shared. It only labels them on a scale of health literacy. The term “to improve patient outcomes,” and an understanding of care must include two-way communication, a dialogue.</p> <p>Communication encourages someone to ask for clearer or better information while making the provider aware that they are not speaking in terms someone can understand.</p> <p>It is the responsibility of people in all career roles to be sure their clients or customers understand them, but in healthcare it often seems that the responsibility is put on the customer (patient) instead. Why should already vulnerable people take the responsibility for failure to communicate? I would propose a more accurate description using “communication” and avoid the term literacy when there is provider / patient dialogue.</p>
98.	<p>Enforce EMTALA with actual Police Investigations.</p> <p>Require all Code Gray Warning be reported to the Medical Board and the Medical Police and the Police to prevent the fraudulent use of Code Gray Warnings to Dump Patients.</p> <p>Investigate what happened to my Mother at West Hills, CA ER on March 10, 2018 that directly led to her death, see PDF below.</p> <p>LAPD apparently is not enforcing SB 1191, which passed in January of 2019 and is designed to investigate when Seniors are abused within Healthcare Facilities.</p>

	<p>Enjoin the FBI to investigate EMTALA. EMTALA is a Federal Mandate and that is the excuse local agencies use to not enforce EMTALA, yet the Los Angeles FBI does not even know what EMTALA is.</p>
99.	<p>The American Association of Diabetes Educators (AADE) appreciates the opportunity to respond to the Office of Disease Prevention and Health Promotion’s (ODPHP) solicitation for written comments on the updated health literacy definition for Healthy People 2030. The updated definition is as follows:</p> <p><i>“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.”</i></p> <p>AADE is an interdisciplinary association of healthcare professionals dedicated to integrated clinical and self-management as a key component in the care of people with diabetes and related chronic conditions. Representing over 14,000 professional members including nurses, nurse practitioners, physician assistants, dietitians, pharmacists, exercise specialists, and others, AADE has a vast network of clinicians working with people who have, are affected by, or are at risk for diabetes. Health literacy plays an important role in diabetes self-management and can affect diabetes-related health outcomes. As such, AADE has offered comments on the updated definition of health literacy proposed for Healthy People 2030.</p> <p>AADE believes there are strengths in the updated definition, specifically with the addition of the statement related to providing <i>accurate</i> health information. Health information is readily and easily accessible to individuals through many channels including television, smart phones and apps, the Internet, friends, family and social media platforms. However, the information presented may be inaccurate or misleading to individuals seeking health information. AADE values ODPHP’s emphasis on providing accurate health information and remains committed to contributing to the body of accurate health information.</p> <p>In addition to focusing on the importance of providing accurate health information, AADE proposes the following edits to further enhance the updated definition:</p> <ul style="list-style-type: none"> • Health literacy incorporates the ability to read. AADE believes the verb “read” should be included in the definition. • Numeracy also plays an important role in health literacy, and to reflect this, AADE recommends including the word “interpret.” • AADE urges ODPHP to consider a person’s culture and how that may impact how they access health information. <p>AADE has incorporated our proposed edits in the definition below: <i>“Health literacy occurs when a society provides culturally sensitive and accurate health information and services that people can easily find, read, understand, interpret and use to inform their decisions and actions.”</i></p> <p>Below is a list of references that support AADE’s suggested changes:</p>

	<p>Bailey, S. C., Brega, A. G., Crutchfield, T. M., Elasy, T., Herr, H., Kaphingst, K., ... Schillinger, D. (2014). Update on Health Literacy and Diabetes. <i>The Diabetes Educator</i>, 40(5), 581–604. https://doi.org/10.1177/0145721714540220</p> <p>Foronda, C., Baptiste, D.-L., Reinholdt, M. M., & Ousman, K. (2016). Cultural Humility: A Concept Analysis. <i>Journal of Transcultural Nursing</i>, 27(3), 210–217. https://doi.org/10.1177/1043659615592677</p> <p>Lee, E., Kim, C., Lee, J., & Moon, S.H. (2017). Self-administered health literacy instruments for people with diabetes: systematic review of measurement properties. <i>Journal of advanced nursing</i>, 73 9, 2035-2048. https://doi.org/10.1111/jan.13256</p>
100.	<p>The proposed 2030 definition does not align with the approach taken by health teachers in schools teaching health skills to improve students ability to access health information/skills and use them to make themselves and those around them more healthy.</p> <p>If you wish to include the 'health services' angle then I suggest that you keep the existing definition of health literacy that "has had a tremendous impact on the field" and add the fact that an individuals health literacy is best improved when supported by a "society which provides accurate health information and services that people can easily find."</p>
101.	<p>As a patient, I view the definition of Health Literacy as an essential model for healthcare organizations to follow so American healthcare can transform into patient-centered care. As a retired Federal Employee, I realize that we in the Federal Government have a special obligation to lead the way in transforming our systems into models for the rest of the country and beyond that, the rest of the free world.</p> <p>I am 61 years young and have witnessed and been subject to all manner of health care. Last September (2018) I had my first surgeries last September 2018 and was horrified by the hospital and health care worker-centered system in place, pushing defensive medicine. My patients rights were ignored (never presented) and there was no informed consent (nor consent form!) for my anesthesia.</p> <p>As a result, several errors occurred which have had a profound effect on my life and that I'll never be free of. What was planned to be two elective simple procedures to greatly improve my quality of life has turned into one of the most horrible experiences of my life. While it would take hours to explain and go over all my records, I'll condense that into the following statement:</p> <p>Centering Healthcare around the patient is essential as a solid foundation for high quality and safe healthcare. The patient absolutely MUST come first, centered, and the rest of the providers/team must plan AROUND the patient.</p> <p>My thoughts on this are:</p> <ol style="list-style-type: none"> 1. Despite the committee's desire to be brief, the use of the term "society" is much too vague for a base. It denotes health care and patient rights and safety as somebody else's responsibility, not my problem. Dealing with my healthcare providers after my medical errors shows me that medicine has got to be patient centered to work. The phrase "healthcare-related organizations" is both broad and yet more inclusive. 2. True Health Literacy is the key to successful patient-provider communication. Communication is by definition always a two-way process. The proposed HL definition suggests it's one-way. We can push all the information we wish but without ensuring it's received, understood, and actionable, we do not have health literacy. Mechanisms to ensure understanding have got to be part of the system. 3. My wife and I recognize the importance of patient centered care as one of our highest ideals. The

	<p>current definition is not patient-centered because it neglects the role of the patient as a team member; it neglects their observations, data, questions, and concerns. Hence the addition of the word: “discuss.”</p> <p>4. The patient MUST ne included at the center of their care or there can be nop true informed consent. And without the patients input, there is a lack of information that deeply affects safety in even basic care (and really goes much deeper in more complicated care!).</p> <p>A proposed revised definition that is actionable by all parties is: Health literacy is the ability of a patient to access, understand, discuss, and act on information provided to make fully informed medical decisions. Success requires multiple variables: the patient’s ability and will to learn, the individual provider’s communication skills, and all healthcare-related organizations’ delivery of relevant medical resources, including the patient’s own records.</p>
102.	<p>The Blue Cross Blue Shield Association (BCBSA) – a national federation of 36 independent, community-based and locally-operated Blue Cross and Blue Shield companies (Plans) that collectively provide healthcare coverage for one-in-three Americans – would like to provide feedback on behalf of Plans regarding the Healthy People 2030 proposed definition for health literacy.</p> <p>We support the new definition and believe that, if leveraged correctly, it can help focus the conversation on the information made available to consumers and help promote the dissemination of meaningful and actionable data.</p> <p>However, we do have concerns with the typical methods for assessing health literacy. We believe that any evaluations used in relation to this definition should incorporate the latest in learning science and technological advancements when assessing the competency of individuals in making healthcare decisions. Evaluations should not only focus on the quality of the information being provided, but also how accessible it is to users. For example, any tools made available should be designed with the user in mind and be provided through mediums that are widely accessible (e.g., web-based as well as other mediums).</p>
103.	<p>I offer strong support for an updated and expanded version of health literacy.</p> <p>A very narrow view of health literacy was initially adopted in the 1990s with a focus on the skills and abilities of the lay public. The responsibility for accessing, understanding, and using health information was placed on the shoulders of individuals. However, we in the health field have learned from scholarship in literacy and have come to understand that literacy skills and abilities vary depending on the communication skills of those providing information, on the difficulty and complexity of texts, on the complications involved in taking action, and on the characteristics of the environments where these health activities are taking place.</p> <p>A definition shapes research by suggesting a focus, determining the measures to be used, as well as specifying who or what is to be measured. If the definition of health literacy continues to focus on patients’/people’s skills, so too will the measures and so too will program and policy efforts. We know that health literacy skills are linked to health outcomes. Because of the limited definition, until recently researchers have not fully explored the contribution made by inadequate communication, unnecessarily difficult written instructions and information, or overly taxing or complex expectations as people navigate health care institutions and systems..</p> <p>Furthermore, we, in the health field cannot take responsibility for improving the literacy skills of the public. We can, however, improve our communication skills, make health information accessible - not</p>

	<p>just available, make health related activities easier to accomplish, and remove unnecessary barriers in hospitals, health centers, and public health offices. With such actions, we can improve access to health information, care, and services.</p> <p>As was noted in Objective 11-2 of the USDHHS 2003 Communicating Health: 'although the literacy and verbal skills of individuals are of critical importance, so too are the demands made by the health materials themselves, the communication skills of those in the health field, and the complicated nature of the healthcare and public health systems.'</p> <p>The newly proposed definition firmly expands the concept of health literacy. We do well to revisit and now replace what was a limited concept of health literacy and forge a more logical path to improvements.</p>
104.	<p>Doctors Hospital at Renaissance is a 530-bed, general acute-care South Texas. OHR serves over 1.3 million people in an underserved region. Over 25% of Rio Grande Valley residents receive Medicaid benefits, double the state average of 12.5% and more than 39% are uninsured. Given our position in the Rio Grande Valley, we recognize the need to address the social determinants of health and the importance of having a viable working definition.</p> <p>We support the new wording that includes" ... accurate health information and services that people can easily find, understand, and use to inform their decisions and actions" as this broadens what should be available and what actions that information should facilitate.</p> <p>However, we believe that the use of the word "society" removes the personal responsibility to be "health literate" from the individual. Patients must not only have access to accurate understandable information, but must also take the personal responsibility to use it.</p> <p>Further, the word "society" is overly broad and creates an opportunity for increased administrative burden on providers in future policy-making. Under the current administration, reducing unnecessary administrative burden is a priority and the use of the word society in this definition is counter to that priority.</p> <p>We propose the definition should be: "Health literacy occurs when individuals have the capacity to access accurate health information and services that they can easily find, understand, and use to inform their decisions and actions."</p>
105.	<p>The International Health Literacy Association (IHLA) appreciates the opportunity to comment on the proposed health literacy definition for <i>Healthy People 2030</i>. IHLA is run by and for its members and is broadly inclusive of people promoting health literacy in many different contexts. Therefore, we encouraged feedback by individual members, some of which represent divergent perspectives. Their input is summarized below.</p> <p>Although some members were excited to see health literacy expressed as a shared opportunity for individuals and organizations to be informed on accurate health information that is equitable and accessible, there were concerns regarding the proposed definition:</p> <ul style="list-style-type: none"> • It doesn't describe how to provide accurate health information; assumes design is part of the process.

	<ul style="list-style-type: none"> • Measurement and accountability need to be addressed in order to allow research to follow the definition. • It sounds more like an endpoint of a health literate society than a definition of health literacy. • It doesn't address goals of understanding and choosing treatments through preventive measures. <p>Specific suggestions:</p> <p><u>Keep current definition:</u> 1) There is robust research related to health outcomes using current 'skills based' definition. There are no established measures or research with outcomes using the proposed definition. 2) "Society" is vague and diffuses responsibility. 3) Impact and policy analyses for a new definition have not been done. Current definition is in wide use and the most cited definition in application of health literacy and technology globally¹.</p> <p><u>Keep current definition, add language that aligns with 2004 IOM Report²:</u> <i>Health literacy occurs by making the demands and complexities of what is needed for health and health care align with the skills and abilities of individuals and communities.</i>³</p> <p><u>Add the following [bold] text:</u> <i>Health literacy occurs when a society provides accurate health information and services that are proven to help all [or] that are designed to help all people easily find, understand, and use to inform their decisions and actions.</i></p> <p>Huhta A, Hirvonen N, Huotari M. Health literacy in web-based health information environments: systematic review of concepts, definitions, and operationalization for measurement. J Med Internet Res. 2018; 20: e10273. DOI: 10.2196/10273.</p> <p>Institute of Medicine. Health Literacy: A Prescription to End Confusion. Washington DC: National Academies Press, 2004.</p> <p>Parker R & Ratzan SC. Health Literacy: A Second Decade of Distinction for Americans (Figure 2), J Health Comm. 2010; 15:sup2, 20-33, DOI: 10.1080/10810730.2010.501094</p>
106.	<p>On behalf of the American Academy of Family Physicians (AAFP), which represents 134,600 family physicians and medical students across the country, I write in response to the solicitation for written comments on an updated "Health Literacy" definition for Healthy People 2030 as posted in the June 4, 2019 Federal Register.</p> <p>The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for Healthy People 2030 proposes to use the following working definition: "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."</p> <p>The AAFP's health literacy definition is: "Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health care decisions. The AAFP champions the promotion of health literacy throughout all aspects of the healthcare system including but not limited to strategic and organizational design, research and quality improvement metrics and provision of direct patient care, especially to patients with low health literacy. Family physicians, medical staff, residents and medical students should receive training on health literacy</p>

	<p>and communication strategies to improve patient engagement and self-management.”</p> <p>The AAFP does not object to the proposed definition, however we urge HHS and other stakeholders to join the AAFP in championing the promotion of health literacy throughout all aspects of the healthcare system.</p>
107.	<p>As a therapist, patient advocate and patient, I view the definition of Health Literacy as an essential model for healthcare organizations to follow to transform American healthcare into patient-centered care.</p> <p>My observations:</p> <ol style="list-style-type: none"> 1. Understandably the committee desires brevity, but the use of the term “society” connotes otherness. It’s somebody else’s responsibility, not mine. The phrase “healthcare-related organizations” is still broad, but more inclusive. 2. Communication is by definition a two-way process. The proposed HL definition implies that it’s one-way. We can push all the information we wish, but without ensuring it’s received, understood and actionable, we do not have health literacy. 3. We recognize the importance of patient-centered care as one of our highest ideals. The current definition is not patient-centered because it neglects the role of the patient as the primary team member; it neglects their observations, data, questions and concerns. Hence the addition of the word “discuss.” <p>A proposed revised definition that is actionable by all parties:</p> <p style="padding-left: 40px;">Health literacy is the ability of a patient to access, understand, discuss and act on information provided to make fully informed medical decisions. Success requires multiple variables: the patient’s ability and will to learn, the individual provider’s communication skills, and all healthcare-related organizations’ delivery of relevant medical resources, including the patient’s own records.</p>
108.	<p>On behalf of the National Center for Farmworker Health</p> <p>“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.”</p> <p>Moving beyond individual to “society” is appropriate as it demonstrates a shared responsibility from a greater community and not just focusing on the individual. However, I would define society. If the new definition suggests that a society provides accurate information and services, then defining society is important because one cannot guarantee that ALL information will be accurate or up to date especially if getting information from the Internet. Shared responsibility should include the individual, all providers of health care and other organizations responsible for ensuring accurate and culturally and linguistically appropriate health information that any person can understand and act on.</p> <p>Strengths: shared responsibility; working together as a community we can achieve greater results Weaknesses: society is not clearly defined; how will accuracy be measured</p> <p>Editing suggestion:</p> <p>Health literacy occurs when providers of health care, community organizations, and individuals provide accurate health information and services that people can easily find, understand, and use to inform their decisions</p>

109.	<p>We are a group of health services researchers who have worked over the last 2 decades advancing health literacy. Our studies span the development of metrics, clinical trials, investigations of related disparities costs, and outcomes. Collectively, we have presented and published the majority of outcomes-based research in this now firmly established field. We are delighted to see health literacy noted in the foundational principles and overarching goals of Healthy People 2030.</p> <p>We would like to share directly with you our rationale for why we oppose the new definition for health literacy proposed for HP 2030. We also have individually posted comments to the Federal Register’s notice.</p> <p>We strongly recommend keeping the current definition for three key reasons:</p> <ol style="list-style-type: none"> 1) There is a robust evidence base related to health outcomes using the current ‘skills based’ definition. There are no established measures or research with outcomes using the proposed definition. Having a definition with no recognized measures risks its utility. 2) “Society” is vague and diffuses responsibility for health literacy. Who/what is accountable? 3) The proposed new definition lacks the pre-requisite policy/impact analyses that would justify its adoption. The current definition is in widespread use (federal/state laws, professional and community-based organizations). The U.S. government definition of “literacy” is skills based; ideally there should be congruence in government definitions of literacy and “health literacy”. <p>We encourage keeping the current definition and adding subsequent contextual language in HP2030 that aligns with the 2004 U.S. Institute of Medicine seminal report’s finding 2-1.</p> <p><i>Health literacy occurs by making the demands and complexities of what is needed for health and health care align with the skills and abilities of individuals and communities. Multiple sectors (including education, health, healthcare, businesses, social services) have responsibility for reaching the vision of a health literate society.</i></p> <p>Health literacy is nascent - this discourse now over its definition is understandable, not the least as sober acknowledgement that we must remain unified as our work is far from done. Rather than move away from a longstanding definition that can be readily measured, understood and acted upon by critical healthcare and community stakeholders, we should continue, if not intensify our many existing efforts towards making health and healthcare more accessible.</p>
110.	<p>The American Medical Writers Association provides these comments on the proposed health literacy definition.</p> <ul style="list-style-type: none"> • Health literacy should be defined as a state, not a transactional event. The proposed definition doesn’t define what health literacy is. • Society is not the provider of health information. We understand a desire to define health literacy beyond the recipient, as proposed by Rima Rudd. However, using the term “society” holds no one accountable and places too much emphasis on health information providers. Consequently, other elements of the communication process—the message, channel, and receiver—are unaccounted for. The most important point, which should form the basis of the definition, is that recipients understand health information, not that society (or even a specific sender) provides it.

	<ul style="list-style-type: none"> • Health literacy represents a skill set, similar to reading and writing literacy, that both providers and recipients need. Providers must know what recipients specifically need to understand the information, and recipients must ask questions when they don't understand. • We support the use of simpler words in the proposed definition compared with the previous definition ("find" and "understand" rather than "obtain, process, and understand") and the addition of "use," which is the ultimate goal of health communication. We suggest a definition similar to this: "Health literacy is a skill set for both health care providers and communicators as well as current and potential recipients of health care. This skill set enables all parties to communicate clearly with each other to promote and achieve optimal health and well-being."
111.	<p>The University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD) works with self advocates, their family members, professionals, researchers, and policy makers to change perceptions and remove barriers for people with disabilities. Communication has long been a barrier for some with disabilities. Therefore, as an organization, we endorse the updated definition of health literacy proposed by the Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for Healthy People 2030. The definition is clear, comprehensive and uses plain language accessible to the widest range of health care consumers, including those with developmental disabilities.</p>
112.	<p>On behalf of the National Hispanic Medical Association (NHMA) Board of Directors, we would like to encourage the proposed update to the health literacy definition for Healthy People 2030 but feel that "stakeholders" should replace the word "society" to be clearer on who provides information about health.</p> <p>The Secretary's Advisory Committee on National Health and Disease Prevention Objectives for 2030 presenting this new definition progresses the delivery of health literacy in a clearer message. We appreciate that health literacy is one of the frameworks of Healthy People 2030. This distinction is important to help improve the health of all Americans.</p> <p>NHMA is a non-profit organization that seeks to empower Hispanic Physicians to lead efforts that improve the health and wellness of Hispanic and other underserved groups. NHMA represents the interests of more than 50,000 licensed physicians, providing leadership and advocacy for its members and partners across the country.</p> <p>In summary, NHMA strongly recommends that the new definition for health literacy, along with our proposed change.</p>
113.	<p>Planned Parenthood Federation of America (Planned Parenthood) and Planned Parenthood Action Fund (the Action Fund) submit these comments in response to the proposed definition of health literacy for Healthy People 2030. Planned Parenthood is the nation's leading women's health care provider and advocate and a trusted, nonprofit source of primary and preventive care for women, men, and young people in communities across the United States.</p> <p>We support the new definition of health literacy. In particular, we appreciate that the new definition implicitly reflects that the burden to improve health literacy falls on government and health industry stakeholders. We also interpret "easily find, understand, and use to inform" to include language access services that are necessary to ensure that people who have limited English proficiency can meaningfully engage in their own health care. As your department seeks to implement Healthy</p>

	<p>People 2030 and related policies, we ask that your department continue to keep in mind the resources and services patients and providers need to improve language access in health care, including provider reimbursement for translating and interpreter services, designing and distributing printed materials in different languages, and collecting data related to language services.</p>
<p>114.</p>	<p>Given the challenges of the proposed definition:</p> <ol style="list-style-type: none"> 1. It doesn't describe what health literate health information means to people; 2. It doesn't provide a measure in terms of what people should be able to do and include a shared accountability with the health care system; 3. It sounds more like the long-term strategic goal of a health literate society rather than a definition of health literacy; 4. It doesn't address goals of understanding and choosing treatments through preventive measures; and 5. Lastly, it comes across as cold and "legal speak" which is the exact opposite of what health literate health care should achieve. <p>I respectfully submit this proposed definition:</p> <p>“Health literacy is linked to literacy and entails people’s knowledge, motivation and competencies to access, understand, appraise and apply health information in order to make judgements and decisions in every-day life concerning health care, disease prevention and health promotion to maintain or improve quality of life throughout the life course (Sorenson, 2012). Health literacy hinges on simplifying the demands and complexities of the health care system to match the skills and abilities of health care consumers (Parker, 2009) empowering them by presenting health concepts, messages and materials in an easy to understand format.”</p> <p>Sørensen K et al. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health, 2012, 12:80.</p> <p>Parker R. Measuring health literacy: what? So what? Now what? In Hernandez L, ed. Measures of health literacy: workshop summary, Round- table on Health Literacy. Washington, DC, National Academies Press, 2009:91–98.</p>
<p>115.</p>	<p>On behalf of Health Care Education Association (HCEA) Board and Patient Education Guidelines Work Group:</p> <p>Suggested wording for health literacy definition:</p> <p>“Individual and population health literacy is positively impacted when society, especially healthcare professions and organizations, effectively provides health information and care which is easy for people to obtain, process and understand to make health decisions, and ultimately , manage their health.”</p> <p>Background of HCEA:</p> <p>The Health Care Education Association is a multi-disciplinary professional organization comprised of health care educators who are committed to improving healthcare outcomes through evidence-based education.</p> <p>Its focus is geared toward patient, family and consumer health education, health literacy, patient engagement, patient-centered care and documentation.</p>

	<p>The Patient Education Guidelines Development Work Group is currently developing national patient education guidelines for health care professionals. The work group is comprised of HCEA members and other healthcare education professionals with expertise in patient education and health literacy.</p> <p>The members of the HCEA board and the Guidelines Work Group are healthcare education professionals who are committed to providing the highest quality evidence-based education for patients and consumers. After much research of best practices within our group and in other professional organizations, the two groups reached consensus on the key points of the recommended wording of the proposed new definition of health literacy. We appreciate the opportunity to contribute ideas based on our collective experience and expertise.</p>
116.	<p>The Society for Health Communication is professional organization composed of many of today’s leading health communication practitioners, researchers, and thought leaders – including published scholars and experts in the field of health literacy. We’re grateful for the opportunity to review and comment on this new definition. Our comments reflect the opinions of our diverse membership.</p> <p>We see several limitations of the proposed definition of health literacy for Healthy People 2030.</p> <p>First, health literacy is a function of <i>both</i> the individual and the healthcare/public health system. The role of individual competencies (knowledge, skills, and abilities) is downplayed in the proposed definition. Health literacy is ultimately a function of communication, which encompasses more than just “providing information.”</p> <p>Second, health literacy is a continuum. The phrasing “health literacy occurs” implies that it is all or nothing; it either occurs or it doesn’t. The use of “degree” in the original definition more accurately reflects the continuum that exists in the population.</p> <p>Similarly, reference to “attaining health literacy” (a Healthy People 2030 foundational principle) is also problematic and does not reflect the fluid and context-specific nature of health literacy – it is not an individual achievement.</p> <p>Third, the term “society” in the proposed definition is not well defined. The phrasing is vague to the extent that it masks the specific responsibility of healthcare/public health institutions to provide audience-appropriate information.</p> <p>Finally, we are concerned about the implications of a definition change without additional analysis. The original definition (with the added word “communicate”) is in statutory law (42 USCS § 295p(21)) and widely cited in the U.S. and abroad. A definition change will likely have far-reaching consequences and merits further study.</p> <p>Should the committee proceed with changing the definition of health literacy, we suggest the following version, which expands on the current definition while leaving the original wording intact (in italics below). We believe this definition captures the spirit of the Committee’s proposed definition for Healthy People 2030.</p> <p style="text-align: center;">Health literacy is a combination of <i>the degree to which an individual has the capacity to obtain, communicate, process, and understand health information and services in order to</i></p>

	<p><i>make appropriate health decisions</i>, and healthcare communicators' ability to provide that information in an understandable form.</p>
117.	<p>Nemours Children's Health System is an internationally recognized children's health system that developed a research-informed adolescent health literacy curriculum, which is being used in schools and communities in 14 states.</p> <p>Health literacy reflects “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”¹ It requires an ability to apply information- via skills for self-advocacy, skills for communicating with providers, and knowledge of how to navigate the complexities of the health system.</p> <p>Nemours encourages HHS to broaden the definition as follows.² <i>“Health literacy is the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills.”³</i></p> <p>1 U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. National action plan to improve health literacy. Washington (DC): Author; 2010. 2 Pleasant, A., R. E. Rudd, C. O’Leary, M. K. Paasche-Orlow, M. P. Allen, W. Alvarado-Little, L. Myers, K. Parson, and S. Rosen. 2016. <i>Considerations for a new definition of health literacy</i>. Discussion Paper, National Academy of Medicine, Washington, DC. http://nam.edu/wp-content/uploads/2016/04/Considerations-for-a-New-Definition-of-Health-Literacy.pdf. 3 Coleman, C., Kurtz-Rossi, S., McKinney, J., Pleasant, A., Rootman, I., & Shohet, L. (2008). The Calgary charter on health literacy: Rationale and core principles for the development of health literacy curricula. <i>The Center for Literacy of Quebec</i>.</p>
118.	<p>We appreciate the opportunity to comment on the working definition of Health Literacy for Healthy People 2030. As patient advocates, we believe that a good definition is critical for advancing patient-centered care and for improving communication and interaction between health consumers and health professionals. Often, health literacy is affected by not only patients’ capability to process the information but how it is prepared and communicated to patients so that they are able to understand, ask questions, discuss concerns, and therefore make informed health care decisions. So, we support the effort to refine the current working definition of health literacy 2030. However, we are concerned that this working definition does not address literacy adequately in health care, where the biggest impacts occur on people’s lives and safety.</p> <p>Here, we would like to suggest a slightly modified working definition that reflects an equal emphasize on health care: “Health literacy is the competency of a society and health professionals to provide accurate information so that health consumers can easily understand and use the information to make informed health care decisions and take appropriate actions.”</p>
119.	<p>Healthy People 2030 working definition of health literacy: 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.</p> <p>Weaknesses....The working definition does not recognize the following:</p> <ul style="list-style-type: none"> • Health literacy does not “occur.” Health literacy is dynamic. It is the effective exchange of messages appropriate for target audiences.

- Senders' ability to communicate understandable and actionable information vary.
- Target audiences' ability to understand and act on information they obtain vary.
- Information exists within a multimodal framework.

Rationale for editing the above definition:

Health literacy is dynamic, not static. Ever-changing environmental, contextual, and individual characteristics determine how effectively information is exchanged, understood, and used. Senders' ability to transmit understandable and actionable information vary in a multimodal framework, in which health information is transformed as it is transmitted.

Proposed definition for health literacy:

Health literacy is the degree to which senders communicate health information that their target audiences can obtain, understand, and use to make informed decisions about their health.*

**Senders include people and systems that initiate, alter, or move information.*

Sources:

Pleasant, A., R. E. Rudd, C. O'Leary, M. K. Paasche-Orlow, M. P. Allen, W. Alvarado-Little, L. Myers, K. Parson, and S. Rosen. 2016. *Considerations for a new definition of health literacy*. Discussion Paper, National Academy of Medicine, Washington, DC. <http://nam.edu/wp-content/uploads/2016/04/Considerations-for-a-New-Definition-of-Health-Literacy.pdf>.

Rima E. Rudd (2015) *The evolving concept of Health literacy: New directions for health literacy studies*, *Journal of Communication in Healthcare*, 8:1, 7-9, DOI: <https://cdn1.sph.harvard.edu/wp-content/uploads/sites/135/2015/04/The-evolving-concept-of-health-literacy-new-directions-for-health-literacy->

120. The Academy of Nutrition and Dietetics appreciates the opportunity to submit comments on the *Updated Health Literacy Definition for Healthy People 2030*. As the largest association of nutrition and dietetics practitioners¹, the Academy is committed to a world where all people thrive through the transformative power of food and nutrition.

The Academy supports the definition of health literacy for HP2030 as we agree with the shift from a sole focus on individual-level capacities to obtain, process, and understand basic health information, to a focus on accessibility of health information and services. The working definition for HP2030 is similar to the definition issued by the Agency for Healthcare Research and Quality,² and is also consistent with the socio-ecological approach applied by Community Tool Box Services, Center for Community Health and Development at the University of Kansas.³

We agree with the conceptual shift from health literacy as an attribute of persons to one of society in which ownership and accountability for literacy's components are distributed to all.

Since access and uptake of health communications may be dependent on other criteria, the Academy is also exploring inclusion of these other factors in health literacy: culture, behaviors, attitudes, current health concerns and social determinants of health.⁴⁻⁵ At some point in the HP2030 process, ODPHP may want to consider exploring the impact of these additional factors in the definition of health literacy.

1. The Academy represents over 107,000 registered dietitian nutritionists (RDNs), nutrition and dietetics practitioners, registered, and advanced-degree nutritionists. The Academy has approved the optional use of the credential "registered dietitian nutritionist (RDN)" by "registered dietitians

	<p>(RDs)” to more accurately convey who they are and what they do as the nation’s food and nutrition experts. The RD and RDN credentials have identical meanings and legal trademark definitions</p> <ol style="list-style-type: none"> 2. “Health Literacy.” Agency for Healthcare Research and Quality. https://www.ahrq.gov/topics/health-literacy.html Accessed August, 2019. 3. “Community Tool Box.” Center for Community Health and Development, University of Kansas. https://ctb.ku.edu/en 4. Carbone ET, Zoellner JM. Nutrition and health literacy: a systematic review to inform nutrition research and practice. <i>J Acad Nutr Diet.</i> 2012;112(2):254-265. 5. Thomas H, Azevedo Perry E, Slack J, et al. Complexities in Conceptualizing and Measuring Food Literacy. <i>J Acad Nutr Diet.</i> 2019;119(4):563-573.
121.	<p>As a patient activist and medical scientist, I view the definition of Health Literacy as an essential model for all healthcare organizations to follow so American healthcare can become patient centered.</p> <p>A proposed revised definition that is actionable by all parties is:</p> <p>Health literacy is the ability of a patient to know the right questions to ask, and to access, understand, discuss, and act on information provided to make fully informed medical decisions.</p> <p>I propose this definition in light of a study I just had published in BMJ Open in which the wishes of a ‘reasonable patient’ are elicited through a national survey. The conclusions of that study were as follows:</p> <p>“Through two targeted surveys and a U.S. national survey, we have affirmed that a reasonable patient will want to know far more information than is generally conveyed during typical shared-decision making that leads to no more than a partly informed decision by the patient. Survey respondents wanted to know risks and benefits of all treatment options, the risks and benefits of off-label and box-warning drugs. They wished to view decision aids, know precisely who will perform the procedure, and their anticipated out-of-pocket costs. Their desire was for an advocate to be present during shared-decision making, have periodic opportunities to review their medical record, have a full day to review informed-consent documents, and to be made aware of expected outcomes and restrictions after the procedure. We expect our findings to have implications for what defines a reasonable patient standard for informed consent.”</p> <p>The link to it is: https://bmjopen.bmj.com/content/bmjopen/9/7/e028957.full.pdf</p>
122.	<p>Thank you to you and to the U.S. Department of Health and Human Services, the Office of the Assistant Secretary for Health, and the Office of Disease Prevention and Health Promotion for your efforts in soliciting public comment on the working definition of health literacy from the Secretary's Advisory Committee on National Health Promotion and Disease Prevention.</p> <hr/> <p>Among the strengths of the working definition is its emphasis on the accessibility, clarity, and actionability of health literacy. These qualities are essential to consider in providing health information and services - one side of the health literacy relationship.</p> <p>Patients are the other side. It is well understood that adults come to healthcare settings with a wide range of knowledge, experiences and skills in reading, writing, talking about, and using digital media around issues of health^{1,2,3}. As shown by decades of research, this knowledge, experience, and skill</p>

	<p>can be the starting point for expanding individuals’ and groups’ health literacy^{4,5}.</p> <p>The goal is to increase the use of health literacy in people’s daily lives. Health literacy has been increased when health professionals recognize and understand the ways individuals and groups already access, understand, and use health information and services^{6,7}.</p> <p>Therefore, a definition should take as a starting point what individuals already use, access, and find helpful. This is done by making explicit reference to the ways people already read, write, think, and talk about their health, in and beyond the clinical encounter. This approach has been used successfully for decades in small- and large-scale engagements in adult literacy and in global health.^{8,9,10,11}</p> <p>Health literacy occurs when people read, write, speak, listen and use digital media around issues of health. Health literacy is increased when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions.</p> <p>-----</p> <ol style="list-style-type: none"> 1. Freebody, P., & Freiberg, J. (1997). <i>Adult Literacy and Health. Reading and Writing as Keeping-Well practices</i>. Research into practice series No. 5. Melbourne (Australia): National Languages and Literacy Inst. 2. Papen, U., & Dray, S. (2004). Literacy and health: towards a methodology for investigating patients’ participation in healthcare. <i>Journal of Applied Linguistics</i>, 311-332. 3. Rogers A, Street BV. (2011) <i>Adult literacy and Development: stories from the field</i>. National Institute of Adult Continuing Education (England and Wales), Leicester, UK, 2012, 18. 4. Hunter, J., & Franken, M. (2012). Health Literacy as a complex practice. <i>Literacy and Numeracy studies</i>, 20, 25-44. 5. Santos M, Handley M, Omark K, Schillinger D. (2014) ESL Participation as a mechanism for advancing Health literacy in immigrant communities. <i>Journal of Health Communication</i>, 19:89–105. DOI: 10.1080/10810730.2014.934935 6. Hunter, J., Franken, M., & Balmer, D. (2015). Constructions of patient agency in healthcare settings: Textual and patient perspectives. <i>Discourse, Context & Media</i>, 7, 37-44. doi:10.1016/j.dcm.2015.01.002 7. Papen, U. (2009). Literacy, learning and health - a social practices view of health literacy. <i>Literacy and Numeracy Studies</i>, 19-34. 8. Papen, U., & Walters, S. (2008). <i>Literacy, learning and health: research report</i>. London: National Research and Development Centre for Adult Literacy and Numeracy. 9. Robinson-Pant, A. (2001). <i>Why eat green cucumber at the time of dying: Exploring the link between women's literacy and development-a Nepal perspective</i>. Hamburg (Germany): United Nations Educational, Scientific and Cultural Organization. 10. Green, J., Lo Bianco, J., & Wyn, J. (2015). Discourses in interaction: the intersection of literacy and health research internationally. <i>Literacy and numeracy studies</i>, 15(2), 19-38. 11. Papen, U., & Walters, S. (2008). <i>Understanding literacy and health: a literature review from four fields of research</i>. London: National Research and Development Centre for Adult Literacy and Numeracy.
123.	<p>The Journal of Health Communication has been the foremost peer-reviewed Journal for the field of health communication for over two decades. Over that time, the field of health literacy has evolved significantly, as predicted by a 2001 article written by Everett Rogers and others. The Journal of Health Communication has been a premier site for expanding the field of health literacy, publishing over 450 articles that contributed to the growing evidence base. A large proportion of these</p>

	<p>publications, including articles contained in eight supplemental issues supported by agencies including AHRQ and the CDC, used the current definition of health literacy.</p> <p>We see several limitations of the proposed definition of health literacy for Healthy People 2030. Chiefly, the current definition of Health Literacy is foundational to the established evidence base, and there are no recognized metrics for the new proposed definition. The original definition is widely cited in the U.S. and abroad.</p> <p>Should the committee proceed with changing the definition of health literacy, we suggest including additional explanatory content to increase understanding and provide information on how best to achieve health literacy.</p> <p>However, we strongly support the continued use of the current definition for Healthy People 2030.</p>
124.	<p>On behalf the Health Literacy Network Germany and German Network for Health Services Research</p> <p>We value the updated definition of health literacy, and we appreciate it addresses health systems design features as essential prerequisites for individual health literate decisions and actions. We are, however, not sure whether health literacy ‘occurs’ as a direct function of a societal environment; in our view this underestimates individual agency in terms of motivational aspects and people’s active contribution to the unfolding of health literacy.</p> <p>The suggested new definition puts health literacy close to “competencies” a concept widely used in educational and occupational settings. Competencies are latent constructs that manifest when needed, they can be taught and their availability can be measured, preferably under defined conditions. We would agree with such a concept for health literacy, in deed the German translation of health literacy is health competence.</p> <p>We therefore propose an extension, rather than a replacement, of the previous definition by integrating individual and environmental aspects.</p> <p>Editing suggestions: Health literacy is the degree to which individuals are enabled by their educational, social, and/or health system to obtain, process, and understand health information needed to make appropriate health decisions.</p>
125.	<p>The Roundtable on Health Literacy of the National Academies has operated since 2006, convening dozens of workshops on health literacy and producing papers, proceedings, and other projects dedicated to the study of health literacy. Throughout this work there have been several themes that have emerged:</p> <ul style="list-style-type: none"> · Low health literacy is widespread. Many people cannot understand health information as it is usually presented. · Health literacy is contextual. Most people will at times lack the skill to decipher health information. · Health literacy should never be assumed with an individual or a group. · Organizations and systems can recognize where low health literacy is affecting patient outcomes, develop and test interventions to address low health literacy, and successfully implement those interventions. · Systemic interventions aimed at “meeting people where they are” can improve health literacy and health outcomes.

	<p>The field has evolved so that the original definition, focused entirely on the individual, no longer fully encompasses the concept of health literacy. I am concerned that the proposed definition is too passive and implies that health literacy is something that happens instead of something that can be achieved through study and intervention. This proposed formulation of health literacy is not measurable and leaves out specific actors that are responsible for designing systems and delivering information. The original definition can be modified or supported to include organizational responsibilities while continuing to emphasize individual capacity as the starting point of health literacy.</p> <p>For supporting documentation please visit http://nationalacademies.org/hmd/Activities/PublicHealth/HealthLiteracy.aspx#publications.</p>
126.	<p>As a _patient advocate, former licensed massage therapist for 25 years, and person who was surgically assaulted and then the crime was covered up,____ [patient advocate, physician, patient, etc.], I view the definition of Health Literacy as an essential model for healthcare organizations to follow so American healthcare can transform into patient-centered care.</p> <p>My observations are:</p> <ol style="list-style-type: none"> 1. Despite the committee’s desire to be brief, the use of the term “society” connotes otherness. It’s somebody else’s responsibility, not mine. The phrase “healthcare-related organizations” is both broad and yet more inclusive. 2. True Health Literacy is the key to successful patient-provider communication. Communication is by definition always a two-way process. The proposed HL definition suggests it’s one-way. We can push all the information we wish but without ensuring it’s received, understood, and actionable, we do not have health literacy. 3. We recognize the importance of patient centered care as one of our highest ideals. The current definition is not patient-centered because it neglects the role of the patient as a team member; it neglects their observations, data, questions, and concerns. Hence the addition of the word: “discuss.” <p>A proposed revised definition that is actionable by all parties is:</p> <p>Health literacy is the ability of a patient to access, understand, discuss, and act on information provided to make fully informed medical decisions. Success requires multiple variables: the patient’s ability and will to learn, the individual provider’s communication skills, and all healthcare-related organizations’ delivery of relevant medical resources, including the patient’s own records.</p> <p>Patients need to participate in and approve of their own records, or their will continue to be mistakes, gross errors, and cover-ups via fabricated records.</p> <p>I would also add this paper to any patient safety effort ---</p>
127.	<p>I submit this comment on the proposed health literacy definition as requested in the Federal Register.</p> <p>...the Current Bibliography of Medicine on Health Literacy compiled by the National Library of Medicine (Selden et al., 2000) served as the evidence base with 479 citations examining theories, strategies and tactics in the published literature. This bibliography and subsequent research supported the definition of 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.” It was accepted by the Institute of Medicine consensus committee, adopted by HHS, incorporated into the Affordable Care Act and Statutory law (Public Health and Welfare: 42 USCS § 295p(21)).</p>

I have been involved in the Healthy People process in the past and have served on a variety of Federal committees most recently concluding a term on the CDC Board of Scientific Counselors.

In short, there is no clear exigence for changing the definition at this juncture. The unanticipated and unintended consequences of changing the definition could be immense, notwithstanding the economic cost, confusion amongst the health polity from the community to system level, and the Healthy People 2030 integrity to advance a health literate society.

Here is a brief history and rationale:

Healthy People 2010 was the first to add a health literacy objective based on the HHS definition.

- “Improve the health literacy of persons with inadequate or marginal literacy skills. (11-2) There were subsequent NIH program announcements: Understanding and Promoting Health Literacy with thirteen sponsoring institutes and offices with AHRQ. There were over \$8 million in federal funds offered with HRSA also funding community-based organizations for health literacy activities and research.

Healthy People 2020 applied the definition of health literacy and added additional relevance:

- “Health literacy is not just the result of individual capacities but also the health-literacy related demands and complexities of the health care system.”[i]

Healthy People 2030 has taken a different approach, one that I commented on January 17th 2019, suggesting that objectives and measures be added to the definition (email herewith in Annex 1).

- The review of the documents and the slides presented on June 26, 2019 by the Healthy People 2030 Health Communication and Health Information Technology Workgroup Health Literacy Definition Committee are excepted herewith providing support for the current (ACA) definition.[ii]

Slide 5 is titled: Health IT as A Facilitator of Health Literacy

- I commend the committee for recognizing the importance of health IT. Further, the USG leadership in this space with the current health literacy definition has contributed to the operational use and publication as the most cited definition globally as presented in a recent systematic review in the Journal of Medical Internet Research.[iii]

Slide 10 is titled: Evolution of health literacy. It reads:

- “Growing recognition of limitations of focus only on individual skills
- Call for more dynamic, systems approach to health literacy that reflects the:
 - Complexity of health information and tasks
 - Situational character of health literacy
 - Important role health and educational organizations play in determining the clarity and actionability of health information and navigation of health services”

These points do not recognize that HP2020 adequately addressed these concerns by clarifying how

the current definition and approach could be addressed in policy, programs and research. To reiterate the HP2020 text: “[H]ealth literacy is not just the result of individual capacities but also the health-literacy related demands and complexities of the health care system. [iv].

Furthermore, research, programs, and training have been advanced throughout the US, integrated in a majority of states, and numerous educational courses using the current definition. The Journal of Health Communication has published nearly 500 peer reviewed articles advancing health literacy. There are over 34 validated measures and scales and publications in multiple fields including the application to vaccination and other societal issues.

Slide 11 is titled “Our Goal” with the following text:

- “A 2030 Healthy People Health Literacy definition that aligns with the contemporary views of the health literacy community.”

There is no data/evidence presented on what the “contemporary views” are being referred to. A prominent group of fifteen health services researchers (see Annex 2) have submitted comments to the Federal Register and for publication with data/evidence/science base to keep the definition. Theirs would be the evidence-based expert opinion (more than a “contemporary view”), as they have also conducted research with validated instruments, NIH sponsored research and programs, and peer-reviewed publications enhancing health literacy and health outcomes as anticipated by the governmental actions associated with health literacy.

Finally, in reviewing the materials proposing a change, there is no impact assessment nor analysis of how this change could affect research, services and ultimately the public. The unanticipated and unintended consequences of changing the definition could be significant that could derail the intent of HP2030 for alignment, galvanization and action with Healthy People 2030.

In summary, there is no clear exigence for changing the definition at this juncture. Additional clarification and context to offer public health professionals, planners and policymakers from the community to system level could be the necessary addition for Healthy People 2030 to follow on the foundation of prior Healthy People references to advance a health literate society. As others have suggested, we can keep the current definition and add contextual information as has been the case in prior Healthy People publications.

I have been involved in this field since engagement with the American Medical Association Signature Program on health literacy, presenting the US definition at the Fifth Global Health Conference on Health Promotion sponsored by the World Health Organization in Mexico City in 2000, and on the IOM Forum on health literacy seeking to advance the development and ethical application of health literacy for the public good.[v]

i HP2020 reads: “Health literacy is the alignment of available health information and services in a society with people's capacities to find, understand, and use health information and services for informed decisions and actions.

[AHRQ: <https://www.ahrq.gov/professionals/clinicians-providers/resources/health-literacy.html>; National Action

Plan to Improve Health Literacy: <https://health.gov/communication/initiatives/health-literacy-action-plan.asp>; CDC

Understanding Health Literacy <https://www.cdc.gov/healthliteracy/learn/Understanding.html>; U.S. Department of Health and Human Services. 2000. Healthy People 2010. Washington, DC: U.S. Government Printing Office.

Originally developed for Ratzan SC, Parker RM. 2000. Introduction. In National Library of Medicine Current Bibliographies in Medicine: Health Literacy. Selden CR, Zorn M, Ratzan SC, Parker RM, Editors. NLM Pub. No. CBM 2000-1. Bethesda, MD: National Institutes of Health, U.S. Department of Health and Human Services.”

ii
https://www.cdc.gov/healthliteracy/pdf/June_26_Health_People_2030_HL_Definition_Webinar_Final.pdf).

iii Huhta A, Hirvonen N, Huotari M. Health literacy in web-based health information environments: systematic review of concepts, definitions, and operationalization for measurement. J Med Internet Res. 2018

iv <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventionsresources/health-literacy#3>

v Ratzan, S.C., “Health Literacy: Communication for the Public Good.” *Health Promotion Int’l*. (16,2), 207-214. 2001.

ANNEX 1

Dear HP2030 comment committee:

I am writing this by the deadline for public comment today despite the federal government shutdown. Thank you for the opportunity to offer comment on Health People 2030.

I have been involved and contributed with past Healthy People in a myriad of ways. To keep this short, I would like to commend the committee for the following overarching publication, and in particular highlighting health literacy:

Foundational Principles

Foundational principles explain the thinking that guides decisions about Healthy People 2030.

- Health and well-being of all people and communities are essential to a thriving, equitable society.
- Promoting health and well-being and preventing disease are linked efforts that encompass physical, mental and social health dimensions.
- Investing to achieve the full potential for health and well-being for all provides valuable benefits to society.
- Achieving health and well-being requires eliminating health disparities, achieving health equity, and attaining health literacy*
- Healthy physical, social, and economic environments strengthen the potential to achieve health and well-being.

- Promoting and achieving the Nation’s health and well-being is a shared responsibility that is distributed across the national, state, tribal, and community levels, including the public, private, and not-for-profit sectors.
- Working to attain the full potential for health and well-being of the population is a component of decision-making and policy formulation across all sectors.

Overarching Goals

- Attain healthy, thriving lives and well-being, free of preventable disease, disability, injury and premature death.
- Eliminate health disparities, achieve health equity, and attain health literacy to improve the health and well-being of all.
- Create social, physical, and economic environments that promote attaining full potential for health and well-being for all.
- Promote healthy development, healthy behaviors and well-being across all life stages.
- Engage leadership, key constituents, and the public across multiple sectors to take action and design policies that improve the health and well-being of all.

* Health literacy is the alignment of available health information and services in a society with people's capacities to find, understand, and use health information and services for informed decisions and actions.

[AHRQ: <https://www.ahrq.gov/professionals/clinicians-providers/resources/health-literacy.html>;
National Action Plan to Improve Health Literacy:

<https://health.gov/communication/initiatives/health-literacy-actionplan.asp>; CDC Understanding Health Literacy

<https://www.cdc.gov/healthliteracy/learn/Understanding.html>;

U.S. Department of Health and Human Services. 2000. Healthy People 2010. Washington, DC: U.S. Government Printing Office. Originally developed for Ratzan SC, Parker RM. 2000. Introduction. In National Library of Medicine Current Bibliographies in Medicine: Health Literacy. Selden CR, Zorn M, Ratzan SC, Parker RM, Editors. NLM Pub. No. CBM 2000-1. Bethesda, MD: National Institutes of Health, U.S.Department of Health and Human Services.

As one of the co-authors of the definition of health literacy adopted by HHS and integrated in the Affordable

Care Act, I believe it is mandatory to have specific objectives and a plan integrated into the 62 page PROPOSED OBJECTIVES FOR INCLUSION IN HEALTHY PEOPLE 2030. With the exception of the areas highlighted above, I did not find any reference to health literacy.

These can be integrated throughout based on guidance from past Institute of Medicine reports as well as ideas published in the *Journal of Health Communication* (supplements supported by AHRQ over the last decade). Many of these also require effective, ethical, evidence-based communication and new technologies at its core.I am volunteering my time to help develop these specific objectives and plan on health literacy in consultation with the appropriate people involved in HP2030.

ANNEX 2

We are a group of health services researchers who have worked over the last 2 decades advancing health literacy. Our studies span the development of metrics, clinical trials, investigations of related disparities costs, and outcomes. Collectively, we have presented and published the majority of

	<p>outcomes-based research in this now firmly established field. We are delighted to see health literacy noted in the foundational principles and overarching goals of Healthy People 2030.</p> <p>We would like to share directly with you our rationale for why we oppose the new definition for health literacy proposed for HP 2030. We also have individually posted comments to the Federal Register’s notice.</p> <p>We strongly recommend keeping the current definition for three key reasons:</p> <ol style="list-style-type: none"> 1) There is a robust evidence base related to health outcomes using the current ‘skills based’ definition. There are no established measures or research with outcomes using the proposed definition. Having a definition with no recognized measures risks its utility. 2) “Society” is vague and diffuses responsibility for health literacy. Who/what is accountable? 3) The proposed new definition lacks the pre-requisite policy/impact analyses that would justify its adoption. The current definition is in widespread use (federal/state laws, professional and community based organizations). The U.S. government definition of “literacy” is skills based; ideally there should be congruence in government definitions of literacy and “health literacy”. <p>We encourage keeping the current definition and adding subsequent contextual language in HP2030 that aligns with the 2004 U.S. Institute of Medicine seminal report’s finding 2-1. Health literacy occurs by making the demands and complexities of what is needed for health and health care align with the skills and abilities of individuals and communities. Multiple sectors (including education, health, healthcare, businesses, social services) have responsibility for reaching the vision of a health literate society.</p> <p>Health literacy is nascent - this discourse now over its definition is understandable, not the least as sober acknowledgement that we must remain unified as our work is far from done. Rather than move away from a longstanding definition that can be readily measured, understood and acted upon by critical healthcare and community stakeholders, we should continue, if not intensify our many existing efforts towards making health and healthcare more accessible.</p>
128.	<p>Thank you for considering a new definition of health literacy. We represent the Multi-Regional Clinical Trials Center of Brigham and Women’s Hospital and Harvard and applaud the direction being taken by HHS to acknowledge that health literacy goes beyond an individual’s capacity to understand to include the abilities of the people responsible for communicating health-related information. We recommend broadening the scope of this definition even further to include concepts that fall under the umbrella of health literacy to support clear communication such as plain language, numeracy, design, and culture. Further, other areas that relate to health and impact health-related decision making, including data literacy, clinical research literacy, and insurance literacy, should be mentioned. Substantively, we believe that the concept of “society” as included in the new definition put forth for Healthy People 2030 does not assign sufficient specific responsibility for ensuring clear, health-related communications and should be removed. As such, we put forth the following definition for your consideration:</p> <p style="padding-left: 40px;">Health literacy is the ability of all people in a position to share accurate and balanced health-related information to do so in ways that are easy for the intended audience to find,</p>

	<p>understand, and act upon. Health related content includes treatment, data, clinical research, and insurance information. Clear health-related communications incorporate plain language, numeracy, design, and cultural considerations.</p>
129.	<p>“Health literacy” is the capacity to fully understand the content and consequences of the information provided by a healthcare professional or peer-reviewed source.</p>
130.	<p>I strongly appreciate the proposed definition’s consideration for the duality in the communication of health information. Within the proposed definition, there is an emphasis placed on the quality of information being communicated, and this opens the door for conversations surrounding the responsibility for healthcare providers to ensure that information is communicated purposefully and properly understood by all individuals. Because our current healthcare climate places the burden of understanding solely on the receiver of the information, the proposed definition offers reflection into these current practices and the role of the healthcare provider.</p> <p>However, the proposed definition- while succeeding in the aforementioned ideals, lacks the attention needed to be given directly to the health literacy of the individual. In order to achieve a societal value of health literacy, the definition needs also reflect a personal quality. I suggest merging the two definitions into something like:</p> <p>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, and is advanced to the highest degree when healthcare providers deliver accurate and actionable information and services that are measured for reliability and equity, across the continuum of care.</p>
131.	<p>As a private patient advocate , I view the definition of Health Literacy as an essential model for healthcare organizations to follow so American healthcare can transform into patient-centered care and informed consent has real meaning for patients.</p> <p>My observations are:</p> <ol style="list-style-type: none"> 1. Despite the committee’s desire to be brief, the use of the term “society” connotes otherness. It’s somebody else’s responsibility, not mine. The phrase “healthcare-related organizations” is both broad and yet more inclusive. 2. True Health Literacy is the key to successful patient-provider communication. Communication is by definition always a two-way process. The proposed HL definition suggests it’s one-way. We can push all the information we wish but without ensuring it’s received, understood, and actionable, we do not have health literacy. 3. We recognize the importance of patient centered care as one of our highest ideals. The current definition is not patient-centered because it neglects the role of the patient as a team member; it neglects their observations, data, questions, and concerns. Hence the addition of the word: “discuss.” A proposed revised definition that is actionable by all parties is: <p>Health literacy is the ability of a patient to access, understand, discuss, and act on information provided to make fully informed medical decisions. Success requires multiple variables: the patient’s ability and will to learn, the individual provider’s communication skills, and all healthcare-related organizations’ delivery of relevant medical resources, including the patient’s own records.</p>
132.	<p>Over the years, information technology (IT) has become ubiquitous in can be found in all walks of life. Health literacy is not exempt from being affected by this phenomenon. The proposed definition for Healthy People 2030 underpins very strong concepts such as the availability and accessibility of accurate health information and services. However, the venue to obtain the above might not be obtainable to everyone, hence this predicament tends to create disparities among different strata in</p>

	<p>society. To bridge the gap, incorporating “Health Coach” in the definition might assist with the disparities.</p>
<p>133.</p>	<p>As a healthcare provider & patient advocate, I view the definition of Health Literacy as an essential model for healthcare organizations to follow so American healthcare can transform into patient-centered care.</p> <p>My observations are:</p> <ol style="list-style-type: none"> 1. Despite the committee’s desire to be brief, the use of the term “society” connotes otherness. It’s somebody else’s responsibility, not mine. The phrase “healthcare-related organizations” is both broad and yet more inclusive. 2. True Health Literacy is the key to successful patient-provider communication. Communication is by definition always a two-way process. The proposed HL definition suggests it’s one-way. We can push all the information we wish but without ensuring it’s received, understood, and actionable, we do not have health literacy. 3. We recognize the importance of patient centered care as one of our highest ideals. The current definition is not patient-centered because it neglects the role of the patient as a team member; it neglects their observations, data, questions, and concerns. Hence the addition of the word: “discuss.” <p>A proposed revised definition that is actionable by all parties is:</p> <p style="text-align: center;"><i>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. This includes their willingness to learn and their ability to communicate openly with their care providers. It also includes the clarity of such communication and the skill of the individual provider or healthcare organization in delivering information. Finally, it considers the methods of delivering communication, whether verbal, written or electronic and the ease with which information is obtainable.</i></p>
<p>134.</p>	<p>As an organizational representative of Healthwise, Inc., a health-literacy focused non-profit, we would like to commend HHS in their new definition of health literacy, as it adequately outlines how people may make better health decisions for themselves and others. However, we request further clarification of the term ‘society’ within the proposed definition. In addition, we encourage alignment between regulatory requirements proposed by sub-agencies of HHS (e.g., the Centers for Medicare & Medicaid Services, or CMS) and the need for addressing health literacy as a societal obligation. For example, rather than removing patient specific education requirements from CMS regulation, ensure that promotion of interoperability includes health information technology standards based contextually relevant, plain language information so the public can understand their data. Using automation and standards like HL7 FHIR, health literacy can be improved without putting undue burden on providers.</p>
<p>135.</p>	<p><u>Healthy People 2010 and Healthy People 2020</u>: “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.”</p> <p><u>Proposed for Healthy People 2030</u>: “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.”</p> <p>Several scientists at the National Institute on Minority Health and Health Disparities agree that adding a societal component to the definition of health literacy is a great idea and should be complementary</p>

to the individual definition currently used. The fact that the proposed statement does not include the individual is a major step in the wrong direction. The use of “society” as the source of accurate health information, is too broad, suggesting it’s no one’s responsibility yet everyone’s responsibility. Generally, when one thinks about “health information” there are certain sources that people turn towards, such as health and health related systems. The inclusion of systems beyond the individual moves away from blaming someone who does not have health literacy but does not make a society responsible when there are no tangibles.

As mentioned in the *Federal Register Notice* “This working definition reflects the evolution of the concept of health literacy toward a consensus that health literacy is affected not only by an individual's capacities, but also by the accessibility, clarity, and actionability of health information and health services.” However, the new definition use of the term “society” is vague and appears to be an 180° shift to the system.

In our opinion there are two components of health literacy, *individual* and *structural*. Individual 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. Structural health literacy is the degree to which entities involved in health care delivery (e.g., clinicians, healthcare systems, insurers) or dissemination of health information (e.g., government agencies, professional organization, the school system) provide accurate health information and services that people can easily find, understand, and use to inform their decisions and actions.

The new definition includes the contribution of system attributes to the individual’s abilities with measurable parameters that are analyzable for change and a linkage between informed decisions and actions. However, the new definition lacks sufficient connection to the previous definition. That said, the new definitions could serve well as an effective addition to the HP2010 /HP2020 definition of health literacy.

Additionally, as written the explanation for the revised definition seems to *privilege* system-level action and *discounts* local input and assessment of need. The proposed definition needs to retain the current definition, which reflects the micro context/circumstances for different individuals (e.g., language, employment status, available resources, access to health care providers). The latter statement expands the understanding of health literacy as an embedded process that occurs at the intersection of societal influences (e.g., local and state programs, changes in health care industry practices). The same would be true of “financial literacy”, which is understood in terms of individual understanding/actions (micro economics) that take place within the context of complex of system-level financial activities, monetary policies, and economic outcomes (macroeconomics).

This definition of health literacy has had a tremendous impact on the field, influencing health literacy measurement and improvement efforts around the world. It is important to maintain the *precedence* of the original definition.

Below are two suggested revisions of the proposed definition.

	<p>Proposed 2030 Healthy People addition to the health literacy definition. The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives proposes this working definition of health literacy for 2030:</p> <p>“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.”</p> <p>“Health literacy [is optimized] when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions.”</p> <p>This [expanded] definition [intends to incorporate] the concept of health literacy as individual capacities [that are affected by the societal context, including] the accessibility, clarity, and actionability of health information and health services.</p> <hr/> <p>Health literacy occurs when health and health related systems provide accurate health information and services that match the health literacy of local people, such that a person can easily find, understand, and use the information to inform his/her health, well-being, decisions and actions.</p>
136.	<p>Founded in 1950, SOPHE is a 501 (c)(3) professional organization that provides global leadership to the profession of health education and health promotion. SOPHE contributes to the health of all people and the elimination of health disparities through advances in health education theory and research; excellence in professional preparation and practice; and advocacy for public policies conducive to health. SOPHE is the only independent professional organization devoted exclusively to health education and health promotion. Members include behavioral scientists, faculty, practitioners, and students engaged in disease prevention and health promotion in both the public and private sectors. Collectively, SOPHE’s national and chapter members work in universities, medical/health care settings, businesses, voluntary health agencies, international organizations, and all branches of federal/state/local government.</p> <p>The current definition, used since <i>Healthy People 2010</i>, specifies: <i>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.</i></p> <p>The proposed revision, to be used with <i>Healthy People 2030</i>, specifies: <i>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.</i></p> <p>Overall, SOPHE supports broadening the definition to be inclusive of the role health and educational organizations play in determining the clarity and actionability of health information and navigation of health services. It requires organizational and policy supports as well as organizational capacity to implement such programs and models, including workforce development. However, to support this concept, SOPHE proposes additional language as follows:</p> <p><i>Health literacy occurs when a society provides accurate and easily accessible health information and services that people can easily find, understand, and use to inform their decisions and actions.</i></p>

	<p>SOPHE also acknowledges the data and measurement systems using the current definition of health literacy that have been tracked and collected since 2010. We urge HHS to retain such measurement systems, while also collecting new data to encompass the broader definition. We believe it is important to continue tracking progress on individual’s health literacy as well as developing measures to encompass the organizational impacts addressed in the new definition.</p> <p>SOPHE also stresses the role of health education specialists in achieving the new definition of health literacy. Well-designed health communication can attenuate barriers and thus can improve health literacy and numeracy to empower individuals and populations—especially underserved and vulnerable audiences—for improved health decision-making and the promotion of health equity. Health education specialists can play vital roles in educating health care providers on effective patient communication, cultural competency, health numeracy and literacy, as well as effective organizational strategies for promoting health literacy.</p> <p>Nearly 90 million American adults have difficulty understanding and using health information. The U.S population also is aging and becoming increasingly diverse. At the same time, advances in digital health technology and devices present new waves of opportunity to help people and communities achieve their highest levels of health potential. The widespread use of the Internet, smart phones, and other mobile digital devices has created a unique opportunity for public health. Some digital technologies and applications have been demonstrated to contribute to the promotion of public health and effectively used in disease self-management, whereas the majority are yet to be fully tested and their credibility with different audiences may vary because of a complex array of factors. Despite growing evidence that supports the promise of digital communication in health promotion, there has been limited exchange and integration of data and information across the public and private sectors about how it can be maximized to improve public health. SOPHE has been working with executive leaders in the public and private sectors to address this chasm for improved public health outcomes (www.digitalhealthleaders.org) and offers HHS further assistance in addressing health literacy goals.</p> <p>Throughout its history, the <i>Healthy People</i> initiatives have focused on reducing health disparities and achieving health equity. SOPHE applauds this sustained commitment to health equity and will continue to advocate for using existing data collection and research to create action plans to move the nation toward a more equitable and healthy society. It is also consistent with the Robert Wood Johnson Foundation (RWJF) expanded notion of health promotion -- the creation of a “Culture of Health.” The RWJF model calls for improving population health, well-being, and equity by working within four action areas: making health a shared value; fostering cross-sector collaboration to improve well-being; creating healthier, more equitable communities; and strengthening the integration of health services and systems. Equity is an underlying condition for all these actions.</p> <p>Finally, <i>Healthy People 2030</i> has an opportunity to shift our national investment toward health promotion. Such a move will require that <i>Healthy People 2030</i> break through silos and considers what will drive progress toward making the U.S. the healthiest nation. <i>Healthy People 2030</i> can provide the impetus to shift investment priorities and consider innovative thinking.</p>
137.	<p>On behalf of the Asian & Pacific Islander American Health Forum (APIAHF)</p> <p>We support the focus on “society,” acknowledging that there are multiple entities and stakeholders responsible for ensuring that individuals are able to understand health information and use services. However, the current framing implies that if society provides information and services, then health</p>

	<p>literacy will be attained. The definition could be framed more broadly as an ongoing process whereby systems are continuously evolving and improving in order to provide the most accurate and useful health information by the best possible methods to all people regardless of their background, educational level, or other social characteristics. It should encompass the idea that all stakeholders from private, public, and non-profit sectors are continuously working together with individuals and communities to ensure that all people can attain health literacy.</p> <p>The definition should also emphasize the importance of all forms of communication in addition to written materials (images, symbols, videos, other forms of audio-visual media) that can be used to provide health information to people with low literacy levels who may rely solely on the spoken word and in languages other than English. The definition could be revised as follows: "...services that all people, regardless of their ability to read and write, can easily find..."</p>
138.	<p>On behalf of the Asian Pacific Islander Caucus for Public Health</p> <p>We support the focus on "society", acknowledging that there are multiple entities and stakeholders responsible for ensuring that individuals are able to use knowledge and health services to improve individual and community health. However, the current framing implies that if society provides information and services, then health literacy will be attained. The definition could be framed more broadly as an ongoing process whereby systems are continuously evolving and improving in order to empower people with the most appropriate knowledge that will enable them to achieve and sustain health. It is important to be inclusive, and engage reach people, of all cultures, backgrounds, educational levels, linguistic capacity, and/or other physical and social characteristics.</p> <p>The definition should also emphasize the importance of all forms of communication in addition to written materials (e.g., images, symbols, audio-visual media/videos, braille) that can be used to empower thealth knowledge to people with low literacy levels who may be visually/auditorially impaired, or rely solely on the spoken word, and in languages other than English. The definition could be revised as follows: "Health literacy occurs when society provides individuals and communities with accurate health knowledge and services that all people, inclusive of their level of ability to see, hear, read, or write can easily find, understand and use, in English or a non-English language, to empower their health decisions and actions to achieve optimal health."</p>
139.	<p>On behalf of AUCD's (Association of University Centers on Disabilities) National Center on Disability in Public Health</p> <p>Based on the definition, we've identified the following:</p> <ul style="list-style-type: none"> • Strength – places more responsibility on systems/societies instead of on the person with disability or families. This helps to not blame the victim when discussing health literacy. • Weakness – "...inform their decisions actions" sounds a little too technical. Maybe change "inform" to either "shape" or "guide" to keep the wording simpler.
140.	<p>The members of the USDA National Institute of Food and Agriculture, Adult Development and Aging Workgroup (ADAW), appreciate and endorse the proposed new "health literacy" definition for Healthy People 2030. We recognize the strength of the recommended definition in that it shifts health literacy from occurring at the person/individual level to a societal (policy, system, environment) level responsibility. Thus, societal sectors are accountable for providing accurate health information and services to people, so that diverse individuals, demographic groups and subpopulations can easily find, understand, and use to inform their decisions and actions, an equitable health literacy approach.</p>

	<p>We acknowledge this proposed definition has positive implications:</p> <p>(1) For land-grant universities’ Cooperative Extension (societal sector that <u>provides accurate health information and services</u>), which includes a Health Literacy priority area in the organization’s National Framework for Health and Wellness, available at https://nifa.usda.gov/resource/national-framework-health-and-wellness;</p> <p>(2) For ADAW target audiences/subpopulations of similarly attributed <u>people</u> (aging adults/older adults); and</p> <p>(3) For determining/evaluating whether stakeholder audiences/priority populations (people) have “easy access” to available [Extension] information and services that <u>impact health (can easily find, understand, and use to inform their decisions and actions)</u>, and assessing/conveying health impact of information and services efforts and activities.</p> <p>We do suggest the following edit: <i>“Health literacy occurs when a society provides accurate health information and services that <u>the diversity of people can easily find, understand, and use to inform their decisions and actions.</u>”</i></p>
141.	<p>I am in favor of the updated health literacy definition for Healthy People 2030. It places the responsibility on society to create an environment where people can become health literate. It also moves away from the individualistic nature of previous definitions, where low health literacy sounded like an individual shortcoming rather than a product of many higher-level factors.</p> <p>I have no suggested edits.</p>
142.	<p>Thank you for the opportunity to provide comments on the new HHS proposed definition of health literacy.</p> <p>SHAPE America – Society for Health and Physical Educators is the nation’s largest nonprofit membership organization of health and physical education professionals. Since its founding in 1885, the organization has defined excellence in health education and physical education, and provides programs, resources and advocacy to support health and physical educators at every level, from preschool to university graduate programs.</p> <p>While we appreciate the focus on affecting change in society as a whole in the new definition, we would like to still see a focus on individual health literacy and recognition that these skills can be developed in a range of populations. We also value the importance of high-quality, skills-based health education in school settings towards the development of individual health literacy. We agree it is essential to focus on environmental changes, as we know in terms of impact that changing the environment will likely result in larger scale implementation but it should be done in tandem with individualized education programs throughout communities and schools, at all age levels.</p> <p>As the department moves forward in adopting a final health literacy definition, we hope to see the importance of developing individual skills still reflected.</p>
143.	<p>As stated, the current definition states “it is the degree to which individuals have the capacity to obtain, process and understand basic health information.....”.</p> <p>The proposed definition states that “ health literacy occurs when a society provides accurate health information.....”</p>

	<p>In both cases, the definition does not provide a bidirectional approach. When mentioning only individuals have <i>the capacity to understand information</i> or, by stating that <i>society provides accurate information</i>, neither lends itself to an intersection of these two worlds. Further, terminology in both definitions opens the door to question the definitions of “capacity” (what is the threshold of an acceptable level of “capacity “ and, how is this measured during an interaction between the recipient and the deliverer of the information?). In the proposed definition, what is the definition of “accurate” and by whose standards or perception? Both give the sense that the onus falls on the individual receiving services and not the healthcare provider, therefore the arrow pointing only one way- with the responsibility falling towards the patient. More often than not, the provider unintentionally uses jargon specific to their environment. This is a challenge when both or all parties involved in the health exchange conduct a conversation in English. Adding a cultural and linguistic layer to this situation has the potential (and unfortunately the case) of becoming even more convoluted. Health literacy is to be woven throughout the work we do in order to provide clear messaging which will lead to healthy outcomes. If the proposed definition is considered to be more of a reflection of the attempt to clarify and/or update the current definition of health literacy, then this definition itself is not health literate.</p>
144.	<p>This definition is a critical component of any guidance for healthcare organizations to provide patient-centered care. I am directly involved in improving communication that enables patients and their care partners to manage their health, and I appreciate this opportunity to comment.</p> <ol style="list-style-type: none"> 1. I think the term “society” could stall progress. It implies a governmental mandate and discourages individual or industry responsibility. The phrase “healthcare-related organizations” is broad and inclusive of regulators (medication labeling), payors (restrict a patient’s response to what a provider recommends), and others that can make or break the process of acting on one’s care. 2. Please reference patient-provider communication, and the skills provider’s need to ensure their recommendations are understood, and actionable. 3. The proposed revision removed the patient’s contribution. Observations, data, questions, and concerns from the patient need consideration while providers develop care recommendations. I’ve added the word “discuss.” 4. The word “ability” captures the ability of an individual within their unique constraints (e.g., insurance, social, geographical). <p>A proposed revised definition that is actionable by all parties is: Health literacy is the ability of a patient to access, understand, discuss, and act on information provided to make fully informed medical decisions. Success requires multiple variables: the patient’s ability and will to learn, the individual provider’s communication skills, and all healthcare-related organizations’ delivery of relevant medical resources, including the patient’s medical records.</p>
145.	<p>As both a physician and a patient, I applaud you for making Health Literacy a key factor in ensuring patient-centered care.</p> <p>My suggestion and comments on the definition of Health Literacy are:</p> <p style="padding-left: 40px;">“Health literacy is the ability of a patient to make informed decisions on managing his or her own healthcare needs”.</p> <p style="padding-left: 40px;">Informed = being aware of her/his own healthcare needs and the available options to deal with those needs, through obtaining, processing and understanding health information from multiple sources</p> <p style="padding-left: 40px;">Decision = using this information to decide on the preferred management option in the context of her/his own values and healthcare goals</p>

146.	<p>My suggestion is to modify the previously-considered definition in the following way:</p> <p>“Health literacy is the degree to which individuals have both the capacity and the awareness/consciousness to obtain, process, and understand basic health information needed to make appropriate health decisions, and having the capacity to appropriately apply this knowledge to not just treating, but also avoiding, diseases, including those affecting themselves and others.”</p>
147.	<p>As one of the co-authors of the Healthy People 2030 health literacy brief, I propose that a new definition that places “society” at the center of the definition is entirely appropriate. Although some people may claim that “society” is vague and doesn’t assign responsibility to any one organization or group, “society” is the appropriate term when limited health literacy is a human-caused problem that must addressed through systemic changes in multiple sectors, including education, healthcare, media, and government. People are not born with limited health literacy, but it can inform or even define their life experiences as a result of social factors, such as poor quality educational systems.</p> <p>The Healthy People 2010 and 2020 definition that focused on individuals’ knowledge, skills, and capacities was appropriate for the early days of the field that focused on documenting the many barriers people face finding and using health information and services. But the field has advanced and has shifted to a structurally-based analysis of limited health literacy as the result of organizational and professional policies, practices, and routines for creating and delivering health information and services. Although clinical researchers continue to study patients’ health literacy skills, the major policy documents and frameworks, such as the <i>National Action Plan to Improve Health Literacy</i> and the <i>Ten Attributes of a Health Literate Healthcare Organization</i>, and now Healthy People 2030 place appropriate attention on the systems of care and information that must be transformed to get at health literacy’s root causes. The new definition provides a forward looking view of health literacy and should be adopted.</p>
148.	<p>The newly proposed definition of health literacy (e.g. the working definition used by the Secretary’s advisory committee) is useful in taking an actionable approach to health literacy; however, it conflates an individual’s capacity to obtain and use information with the success of interventions designed to create an individual’s capacity to obtain and use information. While these two issues are undoubtedly related, they are not the same and it seems advisable to investigate their relationship (i.e. through a national-level investigation of mediators and moderators) prior to changing the definition. Further, any definition should consider the consensus of the field; there are now consensus definitions of health literacy (see Sørensen et al. BMC Public Health 2012, 12:80) based on the work of research in the field. Consensus definitions are likely to engage those doing research and taking action; thus, it would be great to see you use the consensus of the field.</p>
149.	<p>Health literacy:</p> <p>Health literacy occurs when society provides information about health that is accurate, accessible, and understandable in the context of life experience, educational level and cultural norms, for people to use to inform their decisions, actions, and self-advocacy.</p>
150.	<p>As members of the Academic Pediatric Association Health Literacy Special Interest Group, we are submitting the following comments on the proposed change to the definition of health literacy in HP2030, and proposing an alternative definition.</p> <p><u>We suggest the following alternative revised definition of health literacy:</u></p> <p>“Health literacy, the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions, is not static but</p>

varies over time and circumstances, and is directly impacted by the demands and complexities of health-related tasks and information put forth by the health care system and society.”

Following are reasons why we do not support the change proposed in the Federal Register, and the reasons why we think our suggested alternative is more appropriate, recognizing the foundational definition while expanding it:

1. For individuals, health literacy is the degree to which they have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.
 - The field of health literacy including measures, known outcomes, and interventions use the working definition based on individuals’ skills. Having a definition with no connection to the robust field of health literacy research is concerning for implementation and measurement.
2. Health literacy is and has been defined at the individual level. But it is not static; in stressful times anyone can struggle with health literacy.
 - Health literacy does not simply “occur” when a society provides information and services in a certain way.
3. Health literacy is impacted by the health literacy-related demands put on the individual/family member by the healthcare and societal/public health systems.
 - While system- and societal-based definitions are important and reflect where change needs to occur, the proposed definition eliminates the individual. This takes responsibility from society focusing on individual health literacy, which can occur through K-12 programming and community interventions.
 - Addressing health literacy means not only improving the skills of individuals, but also the skills of myriad systems in communicating with those individuals as patients, family members, employees, staff, and communities.
 - A health literate health care organization makes it easier for people to navigate, understand, and use information and services to take care of their health, supporting patient-provider communication to improve health care quality, reduce medical errors, facilitate shared decision-making, and improve health outcomes.
 - Health literacy is fundamental to quality care and relates to safety, patient-centered care, and equitable treatment; it is a cross-cutting priority for improving health care quality and disease prevention.
4. Therefore, health literacy can be further described by building on the definition of health literacy for individuals. Together, including individual and societal dimensions form a more comprehensive model of health literacy.
5. Responsibility for health literacy must be shared by multiple sectors (including education, health, healthcare, business, social services) to reach the vision of a health literate society.
6. Impact and policy analyses for a new definition should be pre-requisite for its adoption, and these have not been done. The current HP definition is in wide use (federal and state law, professional organizations and societies, etc.). There will be concerns for how current and future funding, provisions, and initiatives will be affected if there is a new definition in HP.

	<p>(References: IOM HL Report, 2004; Quality Chasm Priority Areas; Morrison et al., Health Literacy: Implications for Child Health, 2019; Brach et al., 10 Attributes of a Health Literate Healthcare Organization; Rudd, 2003; Baker, 2006)</p>
151.	<p>In my opinion, a major weakness of the recommended definition is using the word “occurs”. Health literacy is a spectrum with varying degrees and capacities of proficiency, not a fixed endpoint that all of a sudden ‘occurs’ - like death, which ‘occurs’ when there is permanent cessation of all biological functions that sustain a living organism.</p> <p>It would be helpful to the reader if the definition clearly revealed the following two sides/aspects of the ‘spectrum’ of health literacy:</p> <ol style="list-style-type: none"> 1. society’s obligation to provide accurate, age appropriate health information and services; and, 2. the individual’s obligation to develop the knowledge, skills, abilities and capacity to understand and communicate appropriate health information. <p>Finally, I believe the definition in the Affordable Care Act (ACA) of 2010, Title V, Subtitle A, is better than the proposed one:</p> <p>the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.</p> <p>https://www.cdc.gov/healthliteracy/learn/index.html</p>
152.	<p>I am writing to comment on your proposed definition for Health Literacy: “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.”</p> <p>I respectfully ask that you consider a more robust definition that not only defines health care literacy (as you have above), but that also gives literacy a context. Why? Because health literacy is the gateway for many people to access and understand care at their level. It is a critical component to receiving informed consent. It can have life-changing or even life and death implications when patients are facing procedures such as high risk surgery or cancer treatment. For these reasons, I would ask that you consider adding a phrase about the critical need to have informed consent literacy for all patients. My suggestion would be to add this to your current definition:</p> <p><i>Health literacy can apply to a spectrum of health care situations for patients. It can be the ability to understand a handout or educational pamphlet. It can also be the ability and right to receive informed consent by having all options for a treatment or procedure, as well as risks and benefits, clearly explained in a way that patients can understand, comprehend, and have the opportunity to have their questions answered.</i></p> <p>I hope you agree that health literacy plays a critical role in patient outcomes. By providing a context in your definition, it raises the bar for providers & hospitals to ensure that all patients receive the information they need, at the critical times they need it.</p>
153.	<p>I’ve been working in the field of adult and child literacy, in the US and in Asia, Africa and the Middle East, for over 40 years. I write in support of the updated definition of concept of health literacy.</p>

	<p>The earlier definition focused on the skills of individuals without attention to the other key components of comprehension. Even adults with the strongest literacy skills find poorly written texts, poorly organized speech, or jargon a barrier to comprehension. Non-literacy factors, such as the social and physical environment or the stakes involved in making an error can profoundly affect comprehension.</p> <p>Those of us in the adult literacy field were upset when health researchers offered a definition of health literacy that focused on the person alone rather than on the entire context, which includes the skills of the individual, the complexity of the text, the difficulty of the task, and the context within which the literacy activity is taking place. This new definition comes closer to addressing all components of literacy</p>
154.	<p>The “standard” definition of health literacy that was incorporated into Healthy People 2010 and 2020 is rooted in a perspective that is now at least two decades old. That standard definition treats health literacy as a trait or skill attributable to individual lay persons. Throughout those decades, consequently, health literacy has generally been treated as an immutable individual difference. Usually it has been regarded as a deficit for the nearly 40% believed to “possess” less than adequate levels of that trait. Thus in the electronic health records of some healthcare systems, patient health literacy levels are annotated, much like a diagnosis of COPD or liver disease.</p> <p>To the contrary, patients’ capacities to process health information are highly variable and situational, depending on factors like emotional arousal, pain, and most of all the clarity of the discourse to which they have been exposed. Thus health literacy is more like a state than a trait. Moreover, in the years since the standard definition of health literacy was developed, the consensus of scholars and practitioners has moved away from a singular focus on patient traits toward acknowledging provider communication practices and healthcare system navigability as at least equally potent vectors in determining health literacy. In short, health literacy is a context-determined <i>process</i>.</p> <p>The proposed Healthy People 2030 definition of health literacy is to be lauded for several reasons. First, it characterizes health literacy as something that “occurs.” It is more a verb than a noun. It is a process. Therefore practitioners are likely to treat health literacy as a phenomenon that is eminently amenable to deliberate intervention.</p> <p>Second, the proposed definition highlights the social nature of health literacy. Health literacy processes are contingent on social forces such as the commitment of healthcare organizations, on the ways entertainment and information sources portray health in the mass media and social media, and on the interaction of community members who often serve as health opinion leaders and information gateways. This social perspective thus invites public health and population health teams to join clinical health practitioners in promoting a climate of health literacy. The societal focus also highlights the role of public education, a component that has been curiously under-represented in past efforts to enhance health literacy.</p> <p>Despite these strengths of the proposed definition, it is lacking in one respect. The phrase, “when a society provides” may imply to some readers that the locus of health literacy change resides only in the tides of larger cultural and governmental forces. The phrase seems to minimize organizational and especially individual agency. One thread of health literacy advocacy—for example the thread that grew from early roots in adult literacy education—has insisted that health literacy is empowering. Thus any definition of health literacy must also cast consumers and patients and their healthcare providers as active seekers, advocates, and sharers of clear, accurate, and actionable</p>

health information. The issue of empowerment also speaks to reducing health inequities, for all members of the society are to achieve access to health information, not only members of privileged groups

Accordingly, I propose the following minor revision to the proposed definition:

“Health literacy occurs when a society **and its members actively share accurate** information and services that all people can easily find, **understand, communicate**, and use to inform their decisions and actions **to assure health and well-being.**”