

**Coming to consensus on health literacy measurement:
An online discussion and consensus-gauging process**

- **Andrew Pleasant, Ph.D., Director of health literacy and research, Canyon Ranch Institute, Tucson, AZ**
- **Julie McKinney, M.S., Health literacy specialist, World Education, Boston, MA**

Abstract

Health literacy continues to experience the normal growing pains of an emerging field of inquiry and practice. The evolving concept of health literacy requires the development of new measurement tools in order to adequately study interventions and identify best practices. This article describes a multi-stage process of engaging the largest known international group of health literacy professionals in an online discussion about health literacy measurement. The goal was to gather input and identify important themes in the discussion using both quantitative and qualitative evaluation methods to gauge the strength of any consensus about health literacy measurement and start to identify topics that should be considered and addressed by those working to develop new tools to measure health literacy.

**Coming to consensus on health literacy measurement:
An online discussion and consensus-gauging process**

- **Andrew Pleasant, Ph.D., Director of health literacy and research, Canyon Ranch Institute, Tucson, AZ**
- **Julie McKinney, M.S., Health literacy specialist, World Education, Boston, MA**

The importance of the role of consensus in advancing scientific understanding cannot be underestimated. Scientific consensus helps inform policy and practice decisions, funding streams, and educational content. As importantly, consensus provides a point of reference for development and testing of alternate hypotheses, and the assessment of the risk of errors in logic and in the scientific process. Consensus processes are one of the points where social processes interact with scientific reasoning. The process of forging consensus, and then testing and possibly altering that consensus may well be the core contribution of science to the larger human endeavor of advancing knowledge.¹⁻⁵

This article first provides a brief overview of existing health literacy screeners, often called health literacy measures, and then reports on a multi-stage process to identify areas of consensus regarding the measurement of health literacy. The goals of this interactive online process were to:

- gather input and identify important themes using both quantitative and qualitative evaluation methods,
- gauge the strength of any consensus about health literacy measurement,
- and

- identify topics that should be considered and addressed by those working to develop new tools to measure health literacy.

A brief overview: The field of health literacy

While the origins of the study of health literacy are truly global, in the United States the field emerged during the past decade in no small part through the development and use of what are better referred to as health literacy screeners, rather than the more commonly used descriptor of measures of health literacy.⁶

The priority of screening is to identify quickly and easily who does and does not exhibit a characteristic. The functions of measurement include advancing knowledge by testing hypotheses, exploring and explaining the structure and function of a phenomenon, monitoring effectiveness and equity of interventions, defining problems facing society, and contributing to policy. The move from screening to measurement of health literacy parallels the move in clinical terms from old-fashioned blood pressure cuff, as well as stethoscopic and manual health check-up, to an integrative and comprehensive health examination focusing as much on prevention as on diagnosis.⁷

Existing health literacy screeners include the various versions of the Rapid Estimate of Adult Literacy in Medicine (REALM)⁸⁻¹¹, various versions of the Test of Functional Health Literacy in Adults (TOFHLA)^{12, 13}, two analyses of three screening questions^{14, 15}, the Health Activities Literacy Scale (HALS)¹⁶, the Newest Vital Sign (NVS)¹⁷, Stieglitz

Informal Reading Assessment of Cancer Text (SIRACT)¹⁸, Medical Achievement Reading Test (MART)¹⁹, Literacy Assessment for Diabetes (LAD)²⁰, Nutrition Literacy Scale (NLS)²¹, the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA)²², an instrument targeting Canadian adolescents²³, a “talking touchscreen” approach²⁴, and the 2003 National Assessment of Adult Literacy (NAAL).²⁵

The use of these screeners generally demonstrates a correlation between these measures and various indicators of quality of life, health status, and health system performance.^{8, 12, 14, 15, 17, 26} However, a number of specific critiques of the existing screeners can be found in the academic literature.^{6, 16-18, 24, 26-38}

These critiques include critical observations that existing screeners and measures of health literacy:

- are not designed to test or advance an underpinning theory of health literacy,
- are limited to evaluating skills, for example some overly rely on the cloze formatted reading test while others only evaluate word recognition and not understanding,
- lack cultural sensitivity and can exhibit bias toward certain population groups,
- are not directly useful for informing or evaluating health promotion and communication interventions (e.g. a pre-post design), curricula, policy, or schemes to pay health professionals based on performance,
- place a problematic burden and potentially harmful label on patients being tested in clinical settings,

- do not evaluate spoken communication skills,
- do not consider health literacy as a public health issue,
- have ambiguous wording on some items,
- do not adequately distinguish between people at very low and very high levels of health literacy,
- were not subjected to rigorous psychometric analysis,
- have not been used in a consistent way,
- focus on a single skill, content area, or conceptual domain, e.g. reading or medication labels, while most theories and definitions of health literacy involve multiple skills and conceptual domains, e.g. writing, speaking, civic or critical, culture, or scientific;
- may be biased toward those with recent experience with the health care system or content area; and
- Due to the variations among the tools, make it difficult to compare experiences or results across studies and to establish the relationship of health literacy to health status.

Functionally, existing health literacy screeners emphasize what some individuals cannot do or understand in fairly specific simulated clinical contexts. For example, current screeners ask what foods and beverages can be consumed prior to a medical procedure. The negative consequences of this approach often include blaming individuals and elevating the jargon and technical language of medicine while devaluing the

communicative skills and abilities (e.g., verbal and visual) that literate and low-literate individuals often do possess.³⁹⁻⁴¹ As a result, while the most commonly used screeners report varying success at identifying individuals who lack or “suffer” from low health literacy, they are based on the mistaken assumptions that literacies in general and health literacy in particular are politically neutral and universally applicable as well as assume that people are passive recipients of health information.⁴²

Another area of concern is the initial validation samples of existing measures of health literacy (Table 1). None of the existing measures were validated with a random sample drawn from the general population. For example, the REALM was initially validated with predominately black women who had low levels of education. The TOFHLA was initially validated with mainly Hispanic and African Americans with low levels of education. The Newest Vital Sign was initially validated with predominately Hispanic women. While this lack of validation among other populations is not necessarily a fatal blow to the ultimate validity of any social science tool, it is generally preferable to validate an instrument with a sample that accurately reflects the population of interest.

Another concern emerges from a recently published systematic review of the connections between literacy and health wherein only two of the 24 articles that met the review criteria involved a random sample, and none were reported to involve a control group.³⁷

The authors of this article are not aware of a peer-reviewed report of any project designed to improve participants’ performance on any of the existing health literacy screening or

measurement tools and then definitively linking that improvement to a change in health status. In practical terms, that would be the strongest validation a measure of health literacy could receive.

The field of health literacy was also propelled by the findings of the National Adult Literacy Survey (NALS) in 1993 and the National Assessment of Adult Literacy (NAAL) in 2003. While the 1993 NALS did not include a measure of health literacy, the findings did impact perceptions of the role of literacy skills in health-related behaviors and health status, and generated interest in the many potential implications of low literacy. The 2003 NAAL did include a measure of health literacy and those results have generated even further interest in the connections between literacy and health in the United States. However, as the exact methodology of the NAAL is not available for use by others it is not a candidate for broad adoption as a health literacy tool.

An underlying challenge: Problems of definition and theory development

Despite, or perhaps because of, the rapid growth that the field of health literacy has experienced, several variations in definitions of health literacy indicate a lack of consensus.⁴³ For example, Healthy People 2010 defines 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.⁴⁴ An U.S. Agency for Healthcare Research and Quality (AHRQ) effort limits individuals in that definition to “patients’ ability” and thus emphasizes clinical settings over public health or other

contexts.⁴⁵ An American Medical Association (AMA) ad hoc committee on health literacy defined health literacy as a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment.⁴⁶

Kickbusch and Maag offer a context-driven definition of health literacy as the ability to make sound health decisions in the context of every day life – at home, in the community, at the workplace, in the health care system, in the market place, and in the political arena. Thus, in this definition, health literacy is a critical empowerment strategy to increase people’s control over their health, their ability to seek out health information, and their ability to take responsibility for their health. There is also a rather straightforward yet equally difficult to operationalize definition of health literacy as people’s practical ability to make decisions about their health.⁴⁷

Researchers in Canada and at the World Health Organization offer a definition of health literacy as people’s ability to find, understand, appraise, and communicate information to engage with the demands of different health contexts to promote health across the life-course.⁴⁸ Zarcadoolas et al. defined health literacy as the wide range of skills and competencies that people develop to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life.^{31, 32}

There is a recent move toward defining and practicing health literacy as a theory of health behavior change, not just a set of skills that people may or may not have. For example,

the Calgary Charter on Health Literacy proposes “health literacy allows the public and personnel working in all health-related contexts to find, understand, evaluate, communicate, and use information.”⁴⁹ This definition moves past the top-down bias inherent in the notion of “appropriate decisions” found in other definitions. The logic model in the Calgary Charter on Health Literacy starts with finding information – then moves through understanding, evaluating, and communicating – and concludes with using information (i.e. behavior change). While that work is not done, this model seems ‘testable’ with defined measures for each stage that can reflect both the public’s and health professionals’ roles. This definition also inherently contains a logic model that all people, programs, and institutions can follow as they try to make, or help people make, informed decisions about health.

It is important to note that despite this wide range of definitions, to the knowledge of this article’s authors, none of the existing definitions of health literacy or approaches to health literacy as a theory of behavior change were explicitly used as the conceptual basis for any of the many attempts to screen or measure health literacy. Some attempts at measure development have created ad hoc definitions that reflect a limited range of the above conceptualizations. As a result, there is a distinct mismatch between the attributes included in the most recent definitions and theories of health literacy and the attributes actually included in existing screening or measurement devices for health literacy.

There is also a growing body of health literacy curricula that target a wide variety of audiences and content areas. (See, for example,

<http://www.advancinghealthliteracy.com/curricula.html>) A comparison of the content and targeted audiences of these curricula with the content and populations used to initially validate existing health literacy measures reveals another mismatch between existing measures and actual practice. Of the very broad, and growing, range of contexts and content targeted by health literacy curricula, existing measures of health literacy are loosely applicable to roughly about one-quarter of that content.

To sum up this short history, while health literacy is now generally accepted as a concept indicating much more than the lack of an ability to read health information, current measures of health literacy only test a narrow range of reading and, occasionally, numeracy skills^{18, 31, 32, 43, 50-53}. This severely limits, for example, the ability to comparatively evaluate the growing number of health literacy initiatives in any depth beyond the superficial aspects of what happened (e.g. how many documents were rewritten or physicians trained), versus the more complex and useful understandings about why change did or did not occur at the individual, community, or health system level.

In addition, researchers and practitioners are currently using inconsistent investigative methods, measures and underlying assumptions about health literacy. As Kelly (2004) once wrote, such a situation will ultimately produce “disjointed, perhaps even contradictory findings a few years from now, as funded studies with widely disparate views of even the most basic precepts of health literacy work their way to completion. Even worse . . . statistical power that is inadequate, both within and across studies, to

yield trustworthy findings and interventions . . . This scenario typifies what happens when funding occurs before consensus is reached on what the underlying construct of interest is and is not.” The field has recently witnessed at least a partial example of the types of outcomes predicted by Kelly with the widely promoted “Ask Me 3” program being found to not produce statistically significant differences between a control and intervention group.⁵⁴

Building a comprehensive measure of health literacy explicitly designed to test and advance the theory of health literacy may well be the most significant and necessary task facing health literacy research and practice.

The NIFL discussion list and the process of gauging consensus

To further explore issues related to health literacy measurement and gauge whether consensus on health literacy measurement is possible, the authors designed and conducted a week-long discussion on the health literacy discussion list that is sponsored by the LINCS (**L**iteracy **I**nformation **a**nd **C**ommunication System) program. The discussion list creates the largest-known connected community of health literacy researchers and practitioners in the world. The list is moderated by Julie McKinney, health literacy specialist at World Education, and the discussion was guest moderated by Andrew Pleasant, director of health literacy and research at Canyon Ranch Institute.

The Health Literacy Discussion List began in 1996 as one of several literacy-related listserves offered by the LINCS program. The LINCS program includes discussion lists, resource collections, and three regional resource centers, all of which offer professional development and technical assistance in adult literacy education. Since it began, the Health Literacy Discussion List has experienced growth paralleling that of the field of health literacy and now has more than 1500 subscribers from throughout the United States and from Canada, England, Ireland, Taiwan, Australia, New Zealand, Netherlands, and Israel

The members of this discussion list approach health literacy from a broad range of perspectives: they include adult literacy practitioners, public health practitioners, librarians, health educators, researchers, medical school faculty, health center and adult education administrators, clinicians, and professionals and students from many other disciplines. A range of perspectives is valuable in a consensus-building plan for a multidimensional concept like health literacy, and is a good reason to use such a discussion list for this purpose.

In advance of the week-long discussion, suggested reading and discussion questions were made available to all list members. These remain online and can be viewed at <http://lincs.ed.gov/lincs/discussions/healthliteracy/10Measures>.

During both the online discussion and the following online consensus-gauging survey, participants were encouraged to contribute as many qualitative comments as they desired.

There was no cap to an individual's participation, nor was participation required of anyone except the guest moderator and moderator of the discussion group.

With a total of 231 posts from approximately 80 individuals, the discussion was very busy in comparison to normal listserv activity. Each day several themes emerged that were richly explored by a broad range of people from a variety of fields. At the end of each day, guest moderator Andrew Pleasant posted a mini-review of the day's themes. List members expressed that the daily summary of themes proved very useful as there was so much information and so many views expressed that it was hard to keep track of it all each day, and even more challenging over the period of the five-day week. The thematic reviews were used as a first step in gauging any consensus as well as helping to keep the discussion thematically organized to aid in later analysis.

After the five-day discussion, individual submissions to the discussion were analyzed both quantitatively and qualitatively. Qualitatively, a thematic analysis was employed that was based on the content of each individual post and the other posts, if relevant, the message was sent in response to. Thus, messages were analyzed for themes both individually and in relation to the stream of the discussion of which they were a part. Themes were identified and short summary statements of the content those themes addressed were developed. Those summary statements were quantitatively counted to reflect frequency of appearance in the discussion.

The entire discussion is accessible online at
<http://lincs.ed.gov/lincs/discussions/healthliteracy/10Measures>.

At the conclusion of the discussion, in order to further investigate and identify the current state of the field of health literacy and any possibility of consensus, listserv members were asked to respond to a short series of questions and statements posed via www.surveymonkey.com. This survey received responses from 123 individuals over four consecutive days.

The ultimate goal is that this consensus identifying process can serve as groundwork for moving forward with the process of developing new measures of health literacy.

However, there is not a universally agreed-upon process of defining consensus. The International Standards Organization (ISO), for example, defines consensus when two-thirds of the votes are in agreement and not more than one-quarter of votes are in disagreement.⁵⁵

Anticipating critiques from a divided field, this consensus-gauging process set a higher bar than the ISO approach, identifying as areas of consensus issues where between 80 percent and 89 percent of the responses are in agreement with a statement (defined as selecting “Agree” or “Strongly Agree” on a four-step Likert scale). Areas of strong consensus are where 90 percent or more of the responses are in agreement. Areas with below an 80 percent level of agreement are identified as areas where consensus is lacking.

The online discussion: Identifying and exploring the issues and themes

An analysis of the themes that emerged in the online discussion revealed 18 identifiable themes to the online discussion. (Table 2). Many messages, not reported here, reflected single themes. Single messages could and did take, at times, opposing views on the same theme.

The most common theme in the discussion was related to existing measures of health literacy and how they are used. This theme primarily reflects the extent to which health literacy researchers and practitioners have not found a suitable measure or screening device that meets their needs – despite their desire to do so. The next four most-frequent themes indicated criticisms of existing health literacy screeners and uncertainty about the appropriateness and use of those existing tools. Taken as a whole, the top five themes indicate that a vast amount of the discussion reflected unhappiness with and uncertainty about the state of the field as they included 136 messages while the next 13 most frequent themes included only 44 messages.

For instance, a submission reflecting the three most common themes, argued “There are numerous ‘literacies’ all tangled up in the concept of health literacy and since no one has researched the linkages between them, it is impossible to develop a tool that could actually capture all dimensions at this time. Instead we have some good tools that

examine specific literacies (functional, clinical, etc.) that we can integrate into a set of proxy measures. More research needs to be done exploring using multiple tools to establish a Health Literacy Index. This triangulation is what is needed to paint a more complete picture until our understanding and research methods have advanced enough for us to develop a true multidimensional measurement instrument.”

Another person asked, “Are there tools, checklists, or measurement devices that are specifically geared to and validated for the provider setting that can be used to facilitate change management and CQI [continuous quality improvement] activities? I think we have enough information to prove that health literacy is a problem, I think we need to start identifying and accelerating the adoption of practices that are known to create positive outcomes and work in populations with low health literacy.”

One person, responding to the variety of approaches, commented, “I do not think one measure/ tool/ approach could possibly suffice.”

Another message, critical of some approaches to assessing health literacy wrote, “When we talk about everything under the sun like it IS health literacy, you really aren’t defining health literacy, and if you can’t define health literacy, what are you really measuring?...a mixed bag of various factors that in the end you can’t separate out what you really want to measure (health literacy). The key is to focus on SKILLS (again...not just patients or individuals!) as being distinct (but not removed) from context. If you can measure skills,

and find out what skills are at low level, then you can focus interventions on those specific skills.”

Comments reflecting the second most common theme – disconnects between measures and definitions – followed the course of this representative statement. “It is critical for the academic field to come to consensus as to definition, and to examine the ways that it communicates health literacy concepts to those with the means to influence it.”

Examples of comments reflective of the third most common theme – What and who should we measure? – included:

- “If health literacy is indeed a set of processes and outcomes shared between patients/families/populations and health care professionals/systems, then the ultimate measure of health literacy may require an assessment of the quality of the interaction BETWEEN these two entities, rather than trying to measure something about one of the entities in isolation from the other.”
- “I’d also add something about numeracy (understanding and using numbers and statistics) because it’s critical to assessing risk.”
- “While universal precautions should be adopted, there is some burden on the patient/consumer to integrate into the dominant culture. That suggests that there needs to be a meeting in the middle – not just one side doing everything – so any measure needs to consider both sides.”

A comment reflecting the second and third most common themes also resonates as it rather accurately depicts the challenges facing health literacy measurement. A participant wrote, “The clinical setting represents only a sliver – in terms of health literate behaviors. Public health is a domain in which health literacy has to be practiced. Because of these dimensions, I’m afraid measurement becomes extremely difficult. As I see it, we may well need to find a very robust instrument that can capture the various elements – fundamental, scientific, cultural and civic - that (Pleasant) and (Zarcadoolas) have proffered in their work - Advancing Health Literacy. The question is: Can these concepts be operationalized to provide an instrument that could yield a true measure of health literacy?” was coded as reflecting both the second and third most common themes.

Other representative examples of messages, by theme, include:

Fourth most common theme – Who measures and for what purpose?

- “I don’t agree that we are measuring health literacy when we consider the skill sets of practitioners. This usage bothers me. I see it as health communication on their part and health literacy on the part of the ‘consumer.’”
- “I endorse (the) suggestion that we focus on measuring the ability of the health care system to communicate effectively with diverse audiences of varying levels of health literacy. With these kind (sic) of data we can develop interventions to improve the effectiveness of health communication.”
- “While I’m generally skeptical about the need and intentions of those assessing health literacy I would support and engage in a conversation about new approaches and

measures that do not support the dominant paradigm or dominant culture. I would frame new approaches to health literacy as a change agent – changing the existing hierarchy of knowledge and power, especially within the medical establishment and its diaspora.”

Fifth most common theme – Principles of health literacy/ avoid labeling

- “I teach our medical students and residents that health literacy is a shared process between patients and health care professionals, but that the RESPONSIBILITY for ensuring that health literate communication has occurred is actually somewhat more on the shoulders of the health care professional at the end of the day. If it has not already been mentioned in this context, the Calgary Charter on Health Literacy (<http://www.centreforliteracy.qc.ca/aboutus.htm>) attempts to reframe the concept of health literacy in these terms.”

These few examples from a large and robust discussion demonstrate both the level of thought and the complex issues that participants engaged with during the week. There is strong evidence that the discussion participants have a high level of knowledge about health literacy, that they are aware of the different communities of practice and thought that currently make up the field, and that many sustain a strong passion regarding their work addressing health literacy.

While there are clearly agreed-upon areas of interest, within those areas there was much more discussion than explicit moments of agreement during the week. In general, the

discussion focused more on questions about what existed in health literacy measurement rather than specific suggestions of what could be done to measure health literacy in a robust and meaningful manner.

The diverse discussion seemed to indicate that reaching consensus on what health literacy is and how to measure that construct might be best described as an impossible dream. The next phase of this process tested that assumption.

Results from an online survey tool to gauge consensus: Moving toward agreement

In the online consensus-gauging survey, participants were first asked to respond to statements describing various positions about health literacy measurement that had been posted during the listserv discussion and/or are found in the academic literature about health literacy. Eleven of the 19 statements received 90 percent or greater agreement (those choosing Agree or Strongly Agree). These statements are areas of strong consensus. Four statements received between 80 percent to 89 percent agreement. These statements reflect areas of consensus. Three statements received less than 80 percent agreement. These statements identify areas lacking consensus.

Participants were asked to respond to a series of descriptive statements about health literacy measurement, organized here by strength of consensus (Tables 3 - 5), what skill areas should be included in a health literacy measure (Table 6), and what conceptual domains or literacies should be included (Table 7).

These areas of strong consensus reflect a strong desire to follow a very rigorous scientific approach to development of a new measure of health literacy and, overall, that the existing measures are not accepted by the field at large. Additional areas of strong consensus include health literacy being a two-sided concept (i.e. that the health system and professionals as well as the general public and patients have, or do not have, health literacy).

Identified areas of consensus indicate that participants see health literacy as:

- more than the ability to read the written word,
- a determinant of health status, and
- extending beyond clinical settings into multiple domains of health and society.

Statements about health literacy measurement that lack consensus indicate that there remains interest in measurement focused on clinical settings, but it is not an overwhelming interest. Further, there is a lack of consensus on the need to distinguish health literacy from communication.

One important item that did not achieve consensus was a proposed element of health literacy that was taken directly from the U.S. Institute of Medicine definition of health literacy – namely that an outcome of health literacy was an “appropriate decision.” Areas of strong consensus exactly duplicate other recent consensus processes, most specifically

the definition and conceptualization of health literacy as introduced by the Calgary Charter on Health Literacy.⁴⁹

Survey participants were offered an open-ended ‘Other’ category to respond to all questions, yet only five people replied to one opportunity and only 14 people replied to a second. The very low number of qualitative responses received to the ‘Other’ categories when offered is evidence that participants deemed the supplied conceptual domains sufficient and accurate. Participants were not supplied with definitions of these conceptual areas. Instead, they brought their existing understanding of health literacy to this process.

Summary of Key Findings

Comments on these results are welcomed from all health literacy professionals, whether they are researchers, practitioners, administrators, funders, policymakers, or a combination thereof. In the near future, a follow-up discussion will occur on the NIFL health and literacy listserv to further gauge consensus regarding how people understand the conceptual domains and skill sets. Doing so will help the field more precisely identify what and how health literacy professionals believe health literacy can and should be measured.

Additionally, further investigation into remaining areas of disagreement that arose during the online discussion and consensus-gauging process is warranted. For example, there is some disagreement about the importance of including outcomes in a

methodology/measure of health literacy. Additionally, there was some sense of disagreement about the relationship among culture, literacy, communication, and health literacy. Some participants in the online discussion seemed to indicate that culture and language could be separated while others strongly disagreed with this notion.

Discussion

There are two surprising findings worthy of note. One, a central debate ongoing in the field is whether health literacy is only a function of patients and the public, or whether the concept includes health professionals. During the online discussion, this theme repeatedly emerged. However, in the online survey of participants this became one of the strongest areas of consensus. Indeed, it seems the broader conceptualization of health literacy has indeed changed from its roots – which were to primarily blame patients for not complying with a health care professional’s instructions.

Secondly, the lack of consensus about inclusion of a civic domain into a measure of health literacy is surprising. Given the common appearance of references to Brazilian educator and internationally respected scholar Paulo Freire’s literacy work in the health literacy field in general, this result seems inconsistent with the widely accepted view of literacy as a tool of personal and societal empowerment. This finding is especially intriguing given the ongoing discussion about health care reform in the United States and the continuing need to increase prevention, especially of chronic disease, on the individual, community, national, and global levels. Health literacy is frequently cast as a

primary means to those ends, and a civic aspect to health literacy seems inherent to that process.

Overall, it is very safe to conclude from the analysis of the discussion and survey responses that there is a strong consensus that the existing measures of health literacy are inadequate or incomplete. This process identified many areas of consensus within the field about what should be included in a measure of health literacy.

Recommendations

This article's authors strongly suggest that national and international health research funding organizations support the development of a new approach to measuring health literacy that explicitly addresses a broader conceptualization and definition of health literacy, including the various domains indicated.

Further, this process found evidence indicating that the U.S. Institute of Medicine (IOM) should consider revisiting their core publication and definition on health literacy published in 2004. There was not consensus in regard to some elements of the current IOM definition of health literacy, a key example being the disagreement with the IOM definition that an outcome of health literacy is an "appropriate decision."

Health literacy has always been present, but only in the past 15 to 20 years has the idea started receiving the level of investigation and concern that is warranted. No one should

be surprised that a recently emerging field of study like health literacy experiences some growing pains in terms of developing and readjusting the core concepts. This is not a negative experience, but a positive learning process. This process of deliberation and consensus gauging has further advanced health literacy.

Table 1. Initial validation samples of selected health literacy screening tools

Measure	Exact description	General description
REALM	N=207; convenience sample; 54% black; 76% female; 42% dropped out of high school	Black women with less education
TOFHLA	N=403; app. 20% refusal; 11% failed screening; convenience sample, 45% African American “indigent”; 45% Hispanic; 58.5% less than high school graduate/GED.	Hispanic and African Americans with less education
Newest Vital Sign	N=500 (250 eng; 250 Spanish); 20% refusal; mean age 41; 21.5% white, 73% Hispanic; 84 men; 416 women	Hispanic women
Chew’s single item screener	N=332; 5% women; 81% white; 86% GED or higher; ambulatory pre-op clinic (excluded ‘worst’ cases)	White men with GED or higher
Wallace’s single item screener	N=305; 68% female; 81.3% insured by TennCare/Medicare; only English speaking; 85.2% White; 88% less than high school education	White women with less than high school education

Figure 1. How to join the Health Literacy discussion list

The purpose of this list is to provide an on-going professional development forum where literacy practitioners, healthcare providers, health educators, researchers, policy makers, and others can discuss health literacy needs, goals and strategies. These include: literacy and communication issues in health education programs and in health care settings; integrating health care access skills and basic health knowledge into literacy programs; collaborations between the fields of adult literacy, health care and other related agencies the readability of health materials; and the clarity and accessibility of oral and written health communication.

List members form an online community of practice dedicated to moving the field of health literacy forward, with the ultimate goal of improving health communication, access and outcomes for everyone.

You can read about it and join for free at the following link:

<http://lincs.ed.gov/mailman/listinfo/Healthliteracy>

At this link, you can also read the recently posted messages, as well as archived discussions from past years, and even search the archives for areas of interest. You can click on "Discussions" to see the other LINCS discussion list topics.

Table 2. Themes in the online discussion about health literacy measurement - arranged by number of messages

Number of messages	Theme
45	What measures are out there now and how do they work?
30	A disconnect between measures and definitions of health literacy
22	What and who should we measure?
19	Who measures and for what purpose?
10	Principles of health literacy and avoid labeling individuals as lacking
8	How to arrive at consensus?
6	Literacy vs. health literacy
5	The Calgary Charter – health literacy as a theory of behavior change
5	Spanish/English measures of health literacy
3	Any tool is better than none
3	The National Assessment of Adult Literacy (NAAL)
2	CAHPS item set on health literacy
2	Evaluating health literacy curricula
2	Measuring health literacy in Europe - the HLS-EU survey
2	NIH funding – What’s accepted as a measure of health literacy?
2	Public health literacy categories
2	Qualitative vs. quantitative measures of health literacy
2	Assessing readability

Table 3. Areas of strong consensus indicated by participant responses to the online survey about health literacy measurement

	Strongly Disagree	Disagree	Agree	Strongly Agree	N
New measures of health literacy need to be developed.	1%	8%	38%	53%	123
New measures of health literacy need to be based on sound theory.	0%	5%	44%	51%	122
Theory of health literacy needs to be relevant to actual experiences.	0%	3%	43%	54%	121
Measurement of health literacy needs to be relevant to actual experiences.	0%	2%	38%	60%	124
We need to be able to measure both sides of the health literacy equation - the health literacy of individuals and the health literacy of health systems and health professionals.	1%	2%	27%	70%	124
The field of health literacy is coming full circle from early depictions of it being the public's 'fault' to current work emphasizing the responsibility of the health system and health professionals.	0%	9%	51%	39%	117
No single methodological tool is up to the task of measuring health literacy, therefore a measure of health literacy must incorporate multiple methodologies. This may include both quantitative and qualitative methodologies.	1%	8%	44%	48%	119
A measure of health literacy needs to be validated with a broad population, not just a limited sample.	0%	4%	35%	61%	124
As you cannot 'see' health literacy, the measure must sample from all the conceptual domains outlined by the underlying theory or conceptual framework. The measure can be comprehensive but does not have to include everything.	1%	8%	68%	24%	114

A measure of health literacy must allow comparison across contexts including culture, life course, population group, and research setting.	3%	3%	44%	49%	122
A measure of health literacy will be multi-dimensional, addressing both multiple conceptual domains and multiple skills.	1%	4%	44%	51%	120

Table 4. Areas of consensus indicated by participant responses to the online survey about health literacy measurement

	Strongly Disagree	Disagree	Agree	Strongly Agree	N
Existing measures of health literacy, while important to the early development of the field, do not match the understanding of health literacy that has developed.	2%	11%	44%	44%	119
Health literacy is a social determinant of health.	2%	9%	37%	52%	124
A measure of health literacy should include evaluation of spoken language skills.	0%	20%	48%	32%	121
A measure of health literacy should clearly distinguish health literacy from literacy.	1%	14%	38%	48%	120
A measure of health literacy that focuses solely on the clinical setting is inappropriate when researching public health behaviors and outcomes.	2%	11%	43%	45%	123

Table 5. Areas lacking consensus indicated by participant responses to the online survey about health literacy measurement

	Strongly Disagree	Disagree	Agree	Strongly Agree	N
There is no utility in screening people in daily clinical practice. (Universal precautions should be taken)	5%	29%	23%	43%	120
Health literacy measurement should not prioritize the clinical context.	4%	21%	38%	38%	112
A measure of health literacy should clearly distinguish health literacy from communication.	3%	20%	39%	38%	120

Table 6. Which skill areas should be included in a measure of health literacy? (As indicated by participant responses to the online survey about health literacy measurement.)

	Strongly Disagree	Disagree	Agree	Strongly Agree	N
Areas of strong consensus					
Finding/obtaining	0%	7%	43%	51%	122
Understanding	0%	0%	22%	78%	123
Evaluating/processing	0%	2%	34%	64%	121
Communicating/ Being able to communicate	0%	0%	35%	65%	124
Using information	1%	2%	28%	69%	121
Making informed choices	1%	5%	26%	68%	123
Areas lacking consensus					
Making appropriate choices	7%	17%	28%	49%	115

Table 7. What conceptual domains (or literacies) should be included in a measure of health literacy? (As indicated by participant responses to the online survey about health literacy measurement.)

	Strongly Disagree	Disagree	Agree	Strongly Agree	N
Areas of strong consensus					
Fundamental/conceptual	0	4	47	57	108
Critical	1	9	47	50	107
Areas of consensus					
Cultural	2	9	43	55	109
Scientific	0	17	56	35	108
Areas lacking consensus					
Civic	0	31	50	23	104

Acknowledgements

The authors would like to express sincere gratitude and thanks to Jennifer Cabe,

Executive Director of Canyon Ranch Institute (CRI), and the entire CRI staff for supporting this process. We would also like to thank Michael Villaire, in particular, and the staff of the Institute for Healthcare Advancement (IHA) for hosting a series of important health literacy conferences and making this publication possible in so many ways. Sabrina Kurtz-Rossi receives our gratitude for graciously allowing us some of her time at the 2010 IHA health literacy conference, making a discussion of these results possible. We also would like to recognize the National Institute for Literacy for supporting the initial online discussion, the staff of World Education for supporting that effort, and most importantly, the participants in this online discussion and consensus-gauging process.

REFERENCES

1. Kuhn T. The structure of scientific revolutions. Chicago, IL: University of Chicago Press; 1962.
2. Ziman JM. Public knowledge: An essay concerning the social dimension of science. Cambridge: Cambridge University Press; 1968.
3. Shapin S, Schaffer S. Leviathan and the air-pump: Hobbs, Boyle and the experimental lifee. Princeton: Princeton University Press; 1985.
4. Latour B. Science in action: How to follow scientists and engineers through society. Cambridge, Mass.: Harvard University Press; 1987.
5. Ezrahi Y. The descent of Icarus. Cambridge, Massachusetts: Harvard University Press; 1990.
6. Pleasant A. Health literacy measurement: A brief review and proposal. In: Hernandez LM, editor. Measures of health literacy: Workshop summary. Washington, D.C.: National Academies Press; 2009. p. 17-21.
7. Breslow L. Health measurement in the third era of health. *American Journal of Public Health*. 2006;96(1):17-9.
8. Davis T, Crouch M, Long S, Jackson R, Bates P, George R, et al. Rapid assessment of literacy levels in adult primary care patients. *Family Medicine*. 1991 August;23(6):433-5.
9. Bass P, Wilson J, Griffith C. A shortened instrument for literacy screening. *Journal of General Internal Medicine*. 2003;18(12):1036-8.
10. Davis T, Wolf M, Arnold, CL, Byrd R, Long S, Springer T, et al. Development and validation of the Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen): a tool to screen adolescents for below-grade reading in health care settings. *Pediatrics*. 2006;118(6):1707-14.
11. Richman J, Lee J, Rozier R, Gong D, Pahel B, Jr VW. Evaluation of a word recognition instrument to test health literacy in dentistry: the REALD-99. *Journal of Public Health Dentistry*. 2007;67(2):99-104.
12. Parker R, Baker D, Williams M, Nurss J. The test of functional health literacy in adults: A new instrument for measuring patients' health literacy. *Journal of General Internal Medicine*. 1995;10:537-41.
13. Gong D, Lee J, Rozier R, Pahel B, Richman J, Jr. VW. Development and testing of the Test of Functional Health Literacy in Dentistry (TOFHLiD). *Journal of Public Health Dentistry*. 2007;67(2):105-12.
14. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Family Medicine*. 2004;36:588-94.
15. Wallace LS, Rogers ES, Roskos SE, Holiday DB, Weiss BD. Brief report: Screening items to identify patients with limited health literacy skills. *Journal of General Internal Medicine*. 2005;21:874-7.
16. Rudd R, Kirsch I, Yamamoto K. Literacy and health in America. Princeton, NJ: Educational Testing Service; 2004.
17. Weiss BD, Mays MZ, Martz W, Castro KM, DeWalt DA, Pignone MP, et al. Quick assessment of literacy in primary care: The newest vital sign. *Annals of Family Medicine*. 2005;3(6):514-22.

18. Agre P, Steiglitz E, Milstein G. The case for development of a new test of health literacy. *Oncology Nursing Forum*. 2006;33(2):283-89.
19. Hanson-Divers E. Developing a medical achievement reading test to evaluate patient literacy skills: A preliminary study. *Journal of Health Care for the Poor and Underserved*. 1997;8(1):56-69.
20. Nath C, Sylvester S, Yasek V, Gunel E. Development and validation of a literacy assessment tool for persons with diabetes. *The Diabetes Educator*. 2001;27(6):857-64.
21. Diamond J. Development of a reliable and construct valid measure of nutritional literacy in adults. *Nutrition Journal*. 2007;6(5).
22. Lee S, Bender D, Ruiz R, Cho Y. Development of an easy-to-use Spanish health literacy test. *Health Services Research*. 2006;4(1):1392-412.
23. Wu AD, Begoray DL, MacDonald M, Wharf Higgins J, Frankish J, Kwan B, et al. Developing and evaluating a relevant and feasible instrument for measuring health literacy of Canadian high school students. *Health Promotion International*. 2010.
24. Yost K, Webster K, Baker D, Choi S, Bode R, Hahn E. Bilingual health literacy assessment using the Talking Touchscreen/la Pantalla Parlanchina: Development and pilot testing. *Patient Education & Counseling*. 2009;75(3):295-301.
25. Kutner M, Greenberg E, Jin Y, Paulsen C, White S. *The health literacy of America's adults: Results from the 2003 National Assessment of adult literacy*. Washington, D.C.: National Center for Education Statistics; 2006.
26. Baker D. The meaning and the measure of health literacy. *Journal of General Internal Medicine*. 2006;21:878-83.
27. Buchbinder R, Hall S, Youd J. Functional health literacy of patients with rheumatoid arthritis attending a community-based rheumatology practice. *The Journal of Rheumatology*. 2006;33(5):879-86.
28. Morrow D, Clark D, Tu W, Wu J, Weiner M, Steinley D, et al. Correlates of health literacy in patients with chronic heart failure. *The Gerontologist*. 2006;46(5):669-76.
29. Zun L, Sadoun T, Downey L. English-language competency of self-declared English-speaking Hispanic patients using written tests of health literacy. *Journal of the National Medical Association*. 2006;98(6):912-7.
30. Friedman DB, Hoffman-Goetz L. A systematic review of readability and comprehension instruments used for print and web-based cancer information. *Health Education & Behavior*. 2006;33(3):352-73.
31. Zarcadoolas C, Pleasant A, Greer D. Understanding health literacy: An expanded model. *Health Promotion International*. 2005 June, 2005;20:195-203.
32. Zarcadoolas C, Pleasant A, Greer D. *Advancing health literacy: A framework for understanding and action*. San Francisco, CA: Jossey Bass; 2006.
33. Johnston M, Diab M, Kim S, Kirshblum S. Health literacy, morbidity, and quality of life among individuals with spinal cord injury. *The Journal of Spinal Cord Medicine*. 2005;28(3):230-40.
34. Aguirre A, Ebrahim N, Shea J. Performance of the English and Spanish S-TOFHLA among publicly insured Medicaid and Medicare patients. *Patient Education and Counseling*. 2005;56:332-9.

35. Kalichman S, Rompa D. Functional health literacy is associated with health status and health-related knowledge in people living with HIV-AIDS. *Journal of Acquired Immune Deficiency Syndromes*. 2000;24(4):337-44.
36. Pleasant A. A second look at the health literacy of American adults and the National Assessment of Adult Literacy. *Focus on Basics*. 2008;9B:46-52.
37. Easton P, Entwistle VA, Williams B. Health in the 'hidden population' of people with low literacy. A systematic review of the literature. *BMC Public Health*. 2010;10(459).
38. Kobylarz F, Pomidor A, Pleasant A. Health literacy as a tool to improve the public understanding of Alzheimer's disease. *Annals of Long-Term Care*. 2010;18(1):34-40.
39. Pardo R, Calvo F. Attitudes toward science among the European public: a methodological analysis. *Public Understanding of Science*. 2002;11:155-95.
40. Laugksch RC. Scientific literacy: A conceptual overview. *Science Education*. 2000;84(1):71-94.
41. Pleasant A, Kuruvilla S, Zarcadoolas C, Shanahan J, Lewenstein B. A framework for assessing public engagement with health research. Technical Report. Geneva, Switzerland: World Health Organization; 2003.
42. Street B, editor. *Cross-cultural approaches to literacy*. Cambridge, UK: Cambridge University Press; 1993.
43. Schillinger D, Davis T. A conceptual framework for the relationship between health literacy and healthcare outcomes: The chronic disease exemplar. In: Schwartzberg JG, VanGeest JB, Wang CC, editors. *Understanding health literacy: Implications for medicine and public health*. Chicago, IL: AMA Press; 2005. p. 181-204.
44. United States Department of Health and Human Services (USDHHS). *Healthy People 2010: Understanding and improving health and objectives for improving health*. Washington, D.C.: U.S. Department of Health and Human Services; 2000 November, 6.
45. Agency for Healthcare Research and Quality (AHRQ). CAHPS health literacy item set. [Website] 2007 Feb. 9, 2007 [cited 2007 July 16]; Available from: http://www.cahps.ahrq.gov/content/products/HL/PROD_HL_Intro.asp
46. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs AMA. Health literacy: Report of the Council on Scientific Affairs. *Journal of the American Medical Association*. 1999 February 10;281(6):552-7.
47. Kickbusch IS, Maag D. Health literacy: Towards active health citizenship. In: Sprenger M, editor. *Public health in Osterreich und Europa*. Graz, Austria: Festschrift Horst Noack; 2006. p. 151-8.
48. Kwan B, Frankish J, Rootman I. The development and validation of measures of "health literacy" in different populations. Vancouver: University of British Columbia Institute of Health Promotion Research & University of Victoria Centre for Community Health Promotion Research; 2006 November.
49. Coleman C, Kurtz-Rossi S, McKinney J, Pleasant A, Rootman I, Shohet L. *Calgary Charter on Health Literacy*. 2009 [cited 2010 7-13]; Available from: http://www.centreforliteracy.qc.ca/Healthlitinst/Calgary_Charter.htm

50. Schwartzberg J, VanGeest J, Wang C, editors. Understanding health literacy: Implications for medicine and public health. Chicago, IL: AMA Press; 2005.
51. Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. Health literacy: A prescription to end confusion. Washington, D.C.: Institute of Medicine of the National Academies; 2004.
52. Rogers EM, Ratzan SC, Payne JG. Health literacy: A nonissue in the 2000 Presidential election. *American Behavioral Scientist*. 2001;44(12):2172-95.
53. Simonds SK. Health education as social policy. *Health Education Monographs*. 1974;2(Supplement 1):1-10.
54. Kelly, P. A. (2004). Defining the state of health literacy research. Available at: <http://www.measurementexperts.org/news/>. Accessed June 9, 2005.
55. International Organization for Standardization. Stages of the development of international standards. n.d. [cited 2010 7-20]; Available from: http://www.iso.org/iso/standards_development/processes_and_procedures/stages_description.htm