

Health literacy measurement: Is consensus possible?

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Special thanks to:

- ◆ Julie McKinney, NIFL Health and Literacy list moderator
- ◆ Everyone at Canyon Ranch Institute
- ◆ All of the participants of the NIFL health literacy listserv (now LINCS) online discussion.
- ◆ Michael Villaire at Institute for Healthcare Advancement

Let me ask ...

- ◆ Why are you here?
- ◆ Is consensus possible ...
 - On health literacy?
 - On health literacy measurement?



The NIFL discussion

- ◆ March 8 - 12, 2010
- ◆ Over 200 messages
- ◆ Approximately 80 contributors
- ◆ The entire discussion is online at:

<http://lincs.ed.gov/pipermail/healthliteracy/2010/date.html>

- ◆ At that web page, scroll down to message #4148.

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

Proposed discussion questions

- ◆ What kinds of health literacy measures or screeners do you need in your work, and why?
- ◆ Who and what do we need to measure? (Just patients' abilities or also those of health professionals? How about systems?)
- ◆ Do we focus on specific skills - and if so which ones? Or, do we focus on the predicted outcomes of health literacy? (In both cases, are they the same for measuring patients vs. professionals?)
- ◆ What components would you include in an ideal measurement or screening tool - and why - and how?
- ◆ How can we create tools that work equally well across different contexts?
- ◆ How can we best continue to advance the field of health literacy given the disparate screening and measurement tools that exist?

Discussion themes

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

Discussion themes - 2

Number of messages	Theme
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

Criticism – an overarching theme

- ◆ “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.”

More criticism

- ◆ “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?”

And more ...

- ◆ “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.”

And ... some disagreements

- ◆ “I don’t agree that we are measuring health literacy when we consider the skill sets of practitioners. This usage bothers me.”
- ◆ “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.”

... and then – what people want

- ◆ “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.”

.. And more what people want ...

- ◆ “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 Andrew and Chris 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?”

(Trying to) define consensus: A first step

- ◆ At conclusion of the week long online discussion:
 - Created an online survey tool
 - 124 respondents
 - 4 day time frame to respond

Surprise – many areas of strong consensus (less than 10% disagreement)

	Strongly Disagree or Disagree	Strongly Agree or Agree	N
New measures of health literacy need to be developed.	9%	91%	123
New measures of health literacy need to be based on sound theory.	5%	95%	122
Theory of health literacy needs to be relevant to actual experiences.	3%	97%	121
Measurement of health literacy needs to be relevant to actual experiences.	2%	98%	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.	3%	97%	124

More strong consensus areas

	Strongly Disagree or Disagree	Strongly Agree or Agree	N
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.	9%	91%	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.	9%	91%	119

More strong consensus areas

	Strongly Disagree or Disagree	Strongly Agree or Agree	N
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.	9%	91%	119
A measure of health literacy needs to be validated with a broad population, not just a limited sample.	4%	96%	124

... and even more!

	Strongly Disagree or Disagree	Strongly Agree or Agree	N
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.	9%	91%	114
A measure of health literacy must allow comparison across contexts including culture, life course, population group, and research setting.	6%	94%	122
A measure of health literacy will be multi-dimensional, addressing both multiple conceptual domains and multiple skills.	5%	95%	120

Many areas of consensus (between 10 – 20% disagreement)

	Strongly Disagree or Disagree	Strongly Agree or 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.	13%	87%	119
Health literacy is a social determinant of health.	11%	89%	124
A measure of health literacy should include evaluation of spoken language skills.	20%	80%	121
A measure of health literacy should clearly distinguish health literacy from literacy.	15%	85%	120
A measure of health literacy that focuses solely on the clinical setting is inappropriate when researching public health behaviors and outcomes.	13%	87%	123

Areas lacking consensus (more than 20% disagreement)

	Strongly Disagree or Disagree	Strongly Agree or Agree	N
There is no utility in screening people in daily clinical practice. (Universal precautions should be taken.)	34%	66%	120
Health literacy measurement should not prioritize the clinical context.	25%	75%	112
A measure of health literacy should clearly distinguish health literacy from communication.	23%	77%	120

What to measure?

	Strongly Disagree or Disagree	Strongly Agree or Agree	N
Areas of strong consensus			
Finding/obtaining	7%	93%	122
Understanding	0%	100%	123
Evaluating/processing	2%	98%	121
Communicating/ Being able to communicate	0%	100%	124
Using information	3%	97%	121
Making informed choices	4%	96%	123
Areas lacking consensus			
Making appropriate choices	24%	76%	115

Which conceptual domains?

	Strongly Disagree or Disagree	Strongly Agree or Agree	N
Areas of strong consensus			
Fundamental/conceptual	5	95	108
Critical	10	90	107
Areas of consensus			
Cultural	11	89	109
Scientific	17	83	108
Areas lacking consensus			
Civic	31	69	104

Closing thoughts

- ◆ The broader conceptualization of health literacy has changed from its roots – which were to primarily blame patients for not complying with a health care professional's instructions.
- ◆ There is a strong consensus that the existing measures of health literacy are inadequate or incomplete.
- ◆ The lack of consensus about inclusion of a civic domain into a measure of health literacy is surprising. (Consider Freire)

Closing thoughts

- ◆ U.S. Institute of Medicine (IOM) Roundtable on Health Literacy 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 that an outcome of health literacy is an “appropriate decision.” (Versus an “informed decision”.)

Closing thoughts

- ◆ National and international health research funding organizations should support the development of a new approach to measuring health literacy that explicitly addresses a broader conceptualization and definition of health literacy.

Next steps

- ◆ More details available in a journal article in Nursing Outlook.
- ◆ We are planning a follow-up discussion on the LINCS health and literacy listserv – May 9 – 16, 2011.

Thanks!

- ◆ Thank you for your participation!!
- ◆ And again my thanks to Julie McKinney and to my colleagues at Canyon Ranch Institute for supporting this effort!!