

THE JOHN M. EISENBERG CENTER FOR CLINICAL DECISIONS AND COMMUNICATIONS SCIENCE
at Baylor College of Medicine

EISENBERG CONFERENCE SERIES: 2015 MEETING

Engaging Patients in the Uptake, Understanding, and Use of Evidence: Addressing Barriers and Facilitators of Successful Engagement

Engaging Patients with Low Health Literacy

Lauren McCormack, PhD, MSPH

Director of the Center for Communication Science

RTI International, Research Triangle Park, NC

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Houston, Texas



My talk today is about engaging patients with low health literacy.

Presentation Overview:

Health Literacy

- What is it?
- The state of the field

A Socio-Ecological Approach

- Benefits of this strategy

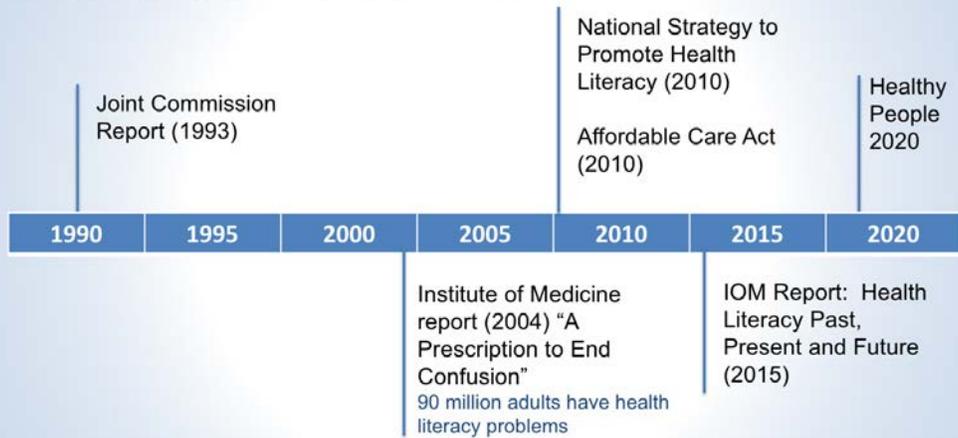
How to Engage Patients

(at all health literacy levels)

- Patient resources
- Clinician resources
- Organizational assessment and support
- Policy level initiatives and incentives

Health literacy is a key factor in securing access to healthcare services. So in my talk today, I'll talk a little bit about health literacy and what it is, how we measure health literacy and the state of the field right now. Then I'll talk about how to engage patients at various levels of health literacy because I think that's important. I'll also touch upon patient resources, clinician resources, and organizational assessment and support. Some of what we've been talking about this morning in terms of getting the environment right, is really critical for supporting health literacy. Also, I will touch on policy level initiatives and incentives. And then what I am going to talk about a social ecological approach as a strategy and its benefits.

History and Selected Policy Initiatives



Somers SA, Mahadevan R. Health literacy implications of the Affordable Care Act. Trenton (NJ): Center for Healthcare Strategies, Inc.; 2010.



Health literacy has come a really long way in the last 10 years. The seminal report in 2004, "Prescription to End Confusion" was really a catapult that launched health literacy onto the national scene. There have been a number of other key occurrences, for example, *Healthy People 2020*, the national strategy to promote health literacy. I also want to acknowledge the Institute of Medicine for their key role in helping to keep it on our radar screen, and also AHRQ and the CDC.

What Does Low Health Literacy Look Like?

Lack of confidence in health insurance costs and coverage

Difficulty understanding informed consent and role in a research study

Difficulty recalling medical instructions

Misinterpreting medication warning labels

Misunderstanding and/or incorrectly responding to clinicians' questions



With that kind of historical background, what exactly does health literacy look like? Health literacy can manifest in a number of different ways. We've been talking a little bit about it this morning - lack of confidence, difficulty reading instructions. But essentially, if people can't obtain, process, and understand information, they really can't be involved in their own care, they can't advocate for family members, and they are simply not able to make informed decisions. Health literacy is more than just reading; it involves understanding and acting upon that information.

What is Health Literacy?

No general consensus:

- 25 different definitions
- 6 conceptual frameworks
- Over 100 instruments to measure it

Reflects several dimensions:

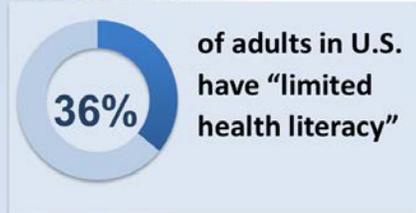
- Prose
- Document literacy
- Numeracy
- Communication
- Information seeking
- Application/function

Berkman ND, Davis T, McCormack, LA. Health literacy: What is it? *J Health Comm* 2010 Sep;15:9–19. PMID: 20845189
Sorensen K, Van den Broucke S, Fullam J, et al. A systematic review and integration of definitions and models. *BMC Public Health* 2012 Jan 25;12:80. PMID: 22276600.



There are more than 25 different definitions for health literacy, at least a half-dozen conceptual frameworks, and 100 instruments to measure health literacy. Broadly, it is processing understanding and acting upon that information. It involves prose or reading, document literacy. Some people like to include numeracy as a separate construct. Others include it in health literacy. Also, there is information seeking and applying the information gathered. So, that's the functional aspect of health literacy.

The Problem



***Elderly and chronically ill
are most at-risk, but...
all of us are at some risk***

Low health literacy is linked to:

- poorer overall health status and higher mortality
- poorer use of preventive health services
- poorer ability take medications appropriately
- more ER visits and hospitalizations
- \$106-\$238 billion in healthcare expenditures

Kutner M, Greenburg E, Ying J, et al. The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy. Washington (DC):National Center for Education Statistics; 2006.

AHRQ Systematic Review (2011). <http://archive.ahrq.gov/research/findings/evidence-based-reports/er199-abstract.html>



The problem of health literacy is demonstrated by a few statistics. Only twelve percent of individuals in the U.S. are deemed to have proficient health literacy. That leaves a whole lot of people that are non-proficient in varying levels of health literacy. The latest national survey, taken 10 years ago shows 36 percent of adults having limited health literacy. There is no specific plan regarding when health literacy will be measured nationally, again.

Those who have the lowest level of health literacy are our most vulnerable populations -- the elderly, chronically ill, and those with co-occurring conditions. But all of us are at risk of low health literacy at one time or another. The ramifications are widespread as there is an association between health literacy and lower health status, higher morbidity, mortality, higher healthcare costs, significant societal impact.

Health Literacy Tool Shed: A database of health literacy measures

Developed by Boston University, Communicate Health and RTI International. With funding from the National Library of Medicine.

The screenshot shows the homepage of the Health Literacy Tool Shed. At the top, there is a search bar labeled "Search by Name of Measure" with a "Go" button. Below the search bar is a navigation menu with links for "Home", "Find Measures", "Glossary", "Suggest a Measure", and "About". The main content area features a blue header with the text "Find the right health literacy measurement tool for your research." and a "Find Measures" button. To the right of this text is an illustration of a person pointing at a list of three items, each with a green checkmark. Below this is a section with a document icon and the text: "The Health Literacy Tool Shed is an online database of peer-reviewed measures of individual health literacy. Use the database to learn about health literacy measurement tools and find tools that meet your needs. [Learn more about the Tool Shed's goals and criteria.](#)" At the bottom of the page, there are logos for Boston University, AHRQ (Agency for Healthcare Research and Quality), and NIH/NLM. The footer also includes the text "Site Last Updated On: June 2, 2015" and "NLM Funder Acknowledgment".

With 100 measures of health literacy, how do you find the one that you need? In the fall of 2015, a health literacy tool shed will be available. The tool shed was worked on Boston University, Communicate Health, and RTI with funding from NLM. In the tool shed you will find information about validity, reliability, and whether the tool measures a specific health context or situation or disease.

A Broader Way to Think about Health Literacy



Parker, R. Measuring Health Literacy: What? So What? Now What? Measures of Health Literacy: Workshop Summary. Institute of Medicine (US) Roundtable on Health Literacy. Washington (DC): National Academies Press (US); 2009.

Koh HK, Rudd RE. The arc of health literacy. JAMA 2015 Aug. doi:10.1001/jama.2015.9978.



There has been a paradigm shift in terms of how people think about health literacy. For many years it was an individual's problem, something to do with their lack of skills, their lack of ability. There has been a shift towards recognizing the need for broader healthcare reforms and system wide thinking in terms of rectifying the issue of low health literacy and thinking about the demands and the complexity of the healthcare system. For that, I'd like to acknowledge Ruth Parker, Rima Rudd, and Howard Koh for their seminal work.

Ecological Approach to Engaging Patients



I would like to advocate for an ecological approach to engaging patients at all levels of health literacy and will use this approach to frame the rest of my presentation.

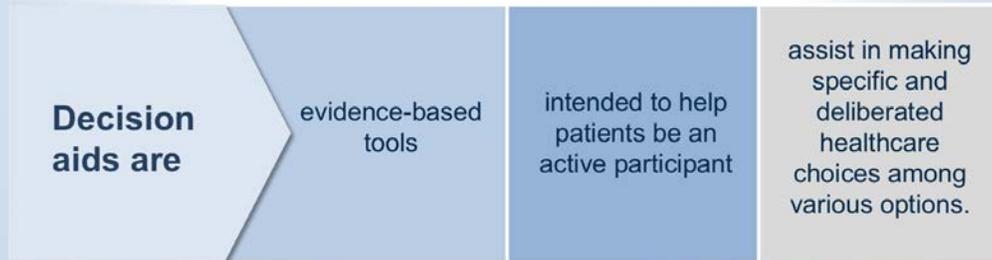
Social ecology involves thinking about multiple levels when it comes to health behavior because health behavior is affected by multiple levels of influence. Another important thing about social ecology is the reciprocal relationship between those levels of influence. So the first level is the intrapersonal level. So this is the skills and knowledge and ability that an individual brings to a certain situation, a clinical encounter, for example. Next is the interpersonal level of influence and behavior and this is relationships and communications that we have with our family, our friends, our clinician, and anyone involved in the healthcare process. Next, is institutions and organizations. This is when you are seeking care within a system.

I will focus my talk mostly on these three levels but I'll also hit on the next two to some extent. At the community level are the societal norms and influences that affect people as members of a community. That can be defined in a number of different ways because we are all part of different kinds of communities, including the public health community and the research community. Finally, there is public policy which includes the laws and regulations that can promote a health literate, healthcare system.

Decision Aids

“Decision aids differ from usual health education materials because decision aids make explicit the decision being considered, and provide detailed, specific, and personalized focus on options and outcomes for the purpose of preparing people for decision making.”

- Cochrane Review (2014)



Stacey D, Légaré F, Col NF, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews 2014; Issue 1. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub4.



At the individual level, I would like to first talk about decision aids. I do think that they are one way to help with low health literacy. They are not necessarily a panacea but they are a promising strategy, if done well.

Besides being evidence-based tools, particularly well suited for preference sensitive decisions I think one of the most valuable things they can do is help people -- particularly those who say, “Well, I just want my doctor to decide” – to recognize that they have a role to play. Not everyone might be ready to play that role right when they’re faced with a diagnosis but over time they may be able to engage in that role.

International Patient Decision Aid Standards (IPDAS)

Scoping	Describe the problem; state the decision that needs to be considered; specify target audience
Steering group	Team of stakeholders who advise on the development, evaluation, and implementation
Assess decisional needs	Elicit patients' and clinicians' views
Determine format & distribution plan	Choose media and format; timing of introduction into patient pathway; how and when decision aid will be distributed
Review evidence	Summarize clinical evidence relevant to decision and options
Prototype development	Draft storyboard, script, graphics, web design, video, etc.
Alpha and Beta testing	Test aid during development process, then externally with potential end users

Adapted from Coulter A, Stilwell D, Kryworuchko J, et al. A systematic development process for patient decision aids. *BMC Med Inform Decis Mak.* 2013;13(Suppl 2):S2. DOI: 10.1186/1472-6947-13-S2-S2. PMID: 24625093.



I wanted to mention with respect to IPDAS, the element related to user testing at the alpha and beta phases. There is so much of what we researchers and the clinical community can learn from patients to involve them in iterative rounds of user testing, and we need to engage with them throughout the process. PCORI is really doing a great job leading the way and requiring a lot of stakeholder engagement.

Communicating Uncertainties

Be clear about which aspects are supported by adequate evidence and are actionable

Empower patients to engage in decision making in areas with less certainty

Focus on both risks and harms of the intervention, coupled with a high-quality decision aid

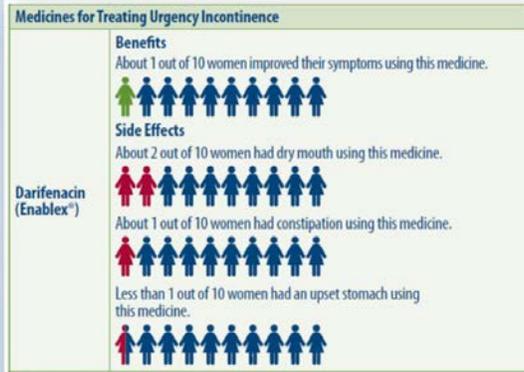
Focus on the outcome of making an informed decision, rather than a particular decision

Focus on key questions that have most direct relevance to patient

One challenge that we're going to see more and more of is how to effectively communicate uncertainties. More clinical conditions are becoming available online; more evidence is becoming contradictory, and new studies come out all of the time. We have got to be able to learn to communicate uncertainties more effectively particularly to low literacy audiences. I think this starts out with talking about presenting the benefits, and the risks, and doing that in a balanced way, and then acknowledging to patients that we really don't have all of the answers.

I was involved in a systematic review of the literature on communicating uncertainties -- it was work for AHRQ that we published in 2013 -- and the state of the science is very limited in terms of how to do this well. This is particularly important for low literacy individuals.

Best Practices for Patients with Low Health Literacy



Create tools and aids that:

Present essential information by itself or first

Visualize the data (particularly helpful for patients with limited numeracy)

Add video to verbal narratives

Sample icon array from The SHARE Approach: Putting shared decision making into practice: A user's guide for clinical teams. Rockville(MD): Agency for Healthcare Research and Quality; 2014.

Sheridan SL, Halpern DL, Viera AJ, et al. Interventions for individuals with low health literacy: A systematic review. J Health Commun 2011;16 Suppl 3:30-54. PMID: 21951242



Pictographs can be appropriate in many cases. We've also talked about presenting essential information first. Sometimes that is all you're going to get to convey to people with low health literacy. So that is a design strategy that one can consider. Also adding video and interactivity in decision aids is something to be cognizant of and try to work in.

Decision Aid Contents Example



Purpose of the study

What the study involves

How the study works

Benefits of participating

Risks of participating

Ability to withdraw

Storyboards courtesy of RTI International, Research Triangle Park, NC. All rights reserved.



So this is a decision aid that we are developing that focuses on promoting informed consent by individuals with developmental disabilities. The content includes what you would have in an IRB-required informed consent document, which is normally 16 to 20 pages long. We are looking at several different prototype strategies for benefits of participating, risks of participating, your ability to withdraw, and what's required of the patient, so they really have a better understanding of what they're getting themselves into before they sign up for this clinical trial. The interactivity helps a lot here; there's a sorting task to help them think about the pros/cons of going in the trial so that they can make a value-based decision.

Healthwise Shared Decision Points

Breast Cancer Risk: Should I Have a BRCA Gene Test?

1 Get the Facts 2 Compare Options **3 Your Feelings** 4 Your Decision 5 Quiz Yourself 6 Your Summary

What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and show how you feel about the following statements.

Reasons to have a breast cancer gene test	Reasons not to have a gene test
I want to let relatives know if I test positive so that they can think about having the test.	If I tested positive, I would not want to tell my relatives.
More important	More important
Equally important	Equally important
More important	More important
It's important for me to know whether or not I have inherited a BRCA gene defect.	I would rather take my chances than know for sure whether I carry the BRCA gene defect.
More important	More important
Equally important	Equally important
More important	More important

Screenshot taken from the Healthwise Knowledgebase. Breast cancer risk: should I have a BRCA gene test?
<https://www.ghc.org/kbase/topic.jhtml?docId=zx3000>. Accessed August 11, 2015.



Here is another example of a decision aid; this one showing along the top, the steps that a person needs to take. It helps them think through where they are in this process. of making a decision about getting a breast cancer test. It engages them effectively and lays out some options.

Making Tools Publicly Available to Clinicians

Advance Care Planning Decisions for end-of-life planning

Advance Care
Planning Decisions
for end-of-life planning

Mayo Clinic's Wisser
Choices for
chronic care

HealthWise Shared
Decision Points



CPR en Español: Enfermedades Graves Spanish

Spanish language edition, a general introduction to CPR for patients with a serious illness.

Login to Play

Advance Care Planning Decisions

Screenshot taken from Advance Care Planning Decisions video library. <http://www.acpdecisions.org/video-category/cpr/>. Accessed August 11, 2015.

Hostetter M, Klein S. Helping patients make better treatment choices with decision aids. New York(NY): The Commonwealth Fund; 2012 Oct/Nov.



It's just not sufficient to develop the decision aids and put them out there. Anything that is going to increase burden on the clinician time is not likely to be adopted. Anything that is going to disrupt the workflow or add to the workflow will be not that well received. So we need to work with dissemination research scientists in dealing with these practical challenges.

Patient-Centered Communication

Apply communications techniques known to enhance understanding among patients:

Use plain language	Use “teach back” and “show back” techniques to assess and ensure patient understanding	Limit information to 2-3 important points at a time, with most important information first
Use drawings, models, or devices to demonstrate points	Combine well-designed, personalized written information with oral consultation	Encourage patients to ask questions

“What did the doctor say?” Improving health literacy to protect patient safety. Washington(DC): The Joint Commission; 2007.



Patient-centered communication is one strategy for addressing low health literacy. The other presentations have talked a little bit about preventing information overload and resisting the challenge to convey all of those important points to a patient soon after diagnosis or in one visit. Combining written information with personalized oral communication, oftentimes one on one, tends to be more expensive, but it's critically important, particularly for low health literacy patients. Pausing, encouraging people to ask questions is also important; that moment of silence can help engage people.

Teach-Back Technique—Suggested Language

“Sometimes things in medicine aren’t as clear as most people think. Let’s work together so we can come up with the decision that’s right for you.”

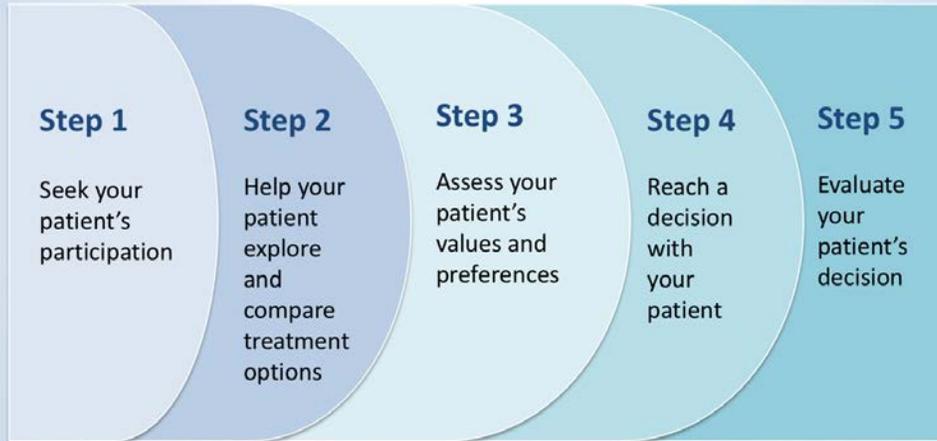
“I want to be sure I’ve explained things well. Please tell me what you heard”

“Do you want to think about this decision with anyone else? Someone who might be affected by the decision? Someone who might help sort things out?”

“People have different goals and concerns. As you think about your options, what’s important to you?”

I’m a pretty big fan of teach-back techniques. These are very easy to do, and easy to train clinicians to do they are easy talking points that they can use with patients, “So I want to be sure I’ve explained things well. Please tell me what you heard.” “Sometimes things in medicine aren’t as clear as most people think, so let’s work together so we can come up with a decision that’s right for you.” That suggests the importance of the partnership. Without training, clinicians are not necessarily going to have these hip-pocket ready.

Shared Decision Making (it doesn't always add time!)



The SHARE Approach: Putting shared decision making into practice: A user's guide for clinical teams. Rockville(MD): Agency for Healthcare Research and Quality; 2014.



Shared decision-making is getting a little more of the spotlight; for example, it is part of the national pain strategy because we are dealing with an opioid analgesic epidemic. It's also appearing in the Million Hearts national initiative to prevent a million heart attacks and strokes by the year 2017.

So, we need to be prepared to take shared decision making to a new level and think about how we can integrate it into the work that we're doing.

Making Effective Communication an Organizational Priority

Train all staff in the organization to recognize and respond appropriately to patients with literacy and language needs

Create patient-centered environments with clear communication from the reception desk to the examining room

Use well-trained medical **interpreters** for patients with low English proficiency

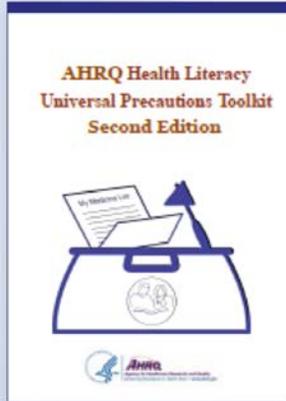
"What did the doctor say?" Improving health literacy to protect patient safety. Washington(DC): The Joint Commission; 2007.



Let's move onto the organization level. Here is where training for clinicians and staff is going to be not only really important for recognizing and responding appropriately to patients with literacy and language needs, but also for being sure that we do not do this in a way that creates stigmatization of individuals. I am a big advocate for objectively measuring health literacy as opposed to self-reported health literacy.

Speaking to the need to create a patient-centered environment, the environment can go a long way with terminology used in clinical settings, for example in signage, instead of saying hematology lab, what about bloodwork? In other words, if you can say it with a 25-cent word don't choose a 75-cent word. Simple changes like that can help with engaging individuals. And, of course, all other kinds of support with interpreters, involving family and friends, when the patient says that's okay.

AHRQ Health Literacy Universal Precautions Toolkit



Aimed at:

Simplifying communication and confirming comprehension for all patients

Making the office environment and health care system easier to navigate

Supporting patients' efforts to improve their health

Health Literacy Universal Precautions Toolkit, 2nd Edition. Rockville(MD): Agency for Healthcare Research and Quality; 2015. <http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlitoolkit2.html>. Accessed August 11, 2015.



This slide is a quick plug for the universal precautions toolkit on health literacy. It is a helpful resource for patients, clinicians, and the environment. I'm a big advocate for it.

“10 Attributes of a Health Literate Organization”

1 Has leadership that makes health literacy integral to its mission, structure, and operations.	6 Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
2 Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.	7 Provides easy access to health information and services and navigation assistance.
3 Prepares the workforce to be health literate and monitors progress.	8 Designs and distributes content that is easy to understand and act on.
4 Includes populations served in the design, implementation, and evaluation of health information and services.	9 Addresses health literacy in high-risk situations.
5 Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.	10 Communicates clearly what health plans cover and what individuals will have to pay.

Reprinted under terms of the Creative Commons Attribution License from Kowalski C, Lee SY, Schmidt A, et al. The health literate health care organization 10 item questionnaire (HLHO-10): development and validation. BMC Health Serv Res. 2015 Feb;15:47. PMID: 25638047.



We can also measure health literacy at the organizational level. This is a ten-item questionnaire that you can use to assess your organization’s health literacy status. It looks at the mission, structure, and the operation of the organization and how well it integrates health literacy into planning, evaluation measures, patient safety, quality improvement and workforce issues.

CDC Clear Communication Index

Research-based
tool **used to help**
plan, develop, and
assess public
communication
materials.

Part A: Core	
Items 2 and 6 have a "not applicable" (NA) option.	
Questions	Score (Check one per question)
Main Message and Call to Action	
1. Does the material contain one main message statement? <i>A main message is the one thing you want to communicate to a person or group that they must remember. A topic, such as heart disease or seasonal flu, isn't a main message statement. If the material contains several messages and no main message, answer no. (User Guide page 5)</i>	<input type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
2. Is the main message at the top, beginning, or front of the material? <i>The main message must be in the first paragraph or section. A section is a block of text between headings. (User Guide page 6)</i>	<input type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0 <input type="checkbox"/> NA
3. Does the material include one or more calls to action for the primary audience? <i>If the material includes a specific behavioral recommendation, a prompt to get more information, a request to share information with someone else, or a broad call for program or policy change, answer yes. If the call to action is for someone other than the primary audience, answer no. (User Guide page 10)</i>	<input type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0

Centers for Disease Control and Prevention (CDC). CDC Clear Communication Index Score Sheet.
<http://www.cdc.gov/ccindex/pdf/full-index-score-sheet.pdf>. Accessed August 11, 2015.



The public community has a role in improving the health literacy of patients. There are research-based tools like the DCD's Clear Communication Index, which assesses public communication materials produced by the CDC, but it has broader applicability for other Federal agencies and beyond. The index is a 22-item checklist that can be used to see if your communications messages are clear. It also includes tips that you can use to revise your materials before distributing them.

Communication Strategies to Inform Health Care Decisions

Researcher's role: Review comparing the effectiveness of:

Communicating evidence in various contents and formats that increase the likelihood that target audiences will both understand and use the information

Finding: investigators frequently blend more than one communication strategy in interventions

A variety of approaches for disseminating evidence from those who develop it to those who are expected to use it

Finding: multicomponent dissemination strategies are more effective at enhancing clinician behavior

Various ways of communicating uncertainty-associated health-related evidence to different target audiences

Finding: evidence on communicating overall strength of recommendation and precision was insufficient

There are a few different things that we, as researchers can do when reviewing the comparative effectiveness of different strategies for communicating information. There are communication science techniques, how the message is framed, the use of narratives, and tailoring and targeting the information. We looked at the comparative effectiveness of these in our AHRQ systematic review of the literature. When you take out all of the studies that looked at usual care, there were only about ten or so studies that looked at the comparative effectiveness of different strategies -- head to head. So we need more work in the area comparing strategies. There is more research when you're looking at comparative effectiveness of dissemination strategies. A key finding here is that multicomponent dissemination strategies, that is using more than just a decision aid, for example, is more effective at enhancing clinician behavior.

Addressing Literacy Needs Across Continuum of Care for All Patients

Eliminate “barriers to entry” in the care system by educating patients about when to seek care

Develop and provide plain language insurance enrollment forms, benefit explanations, and other insurance-related information

Emphasize learning of patient-centered communication skills in all health professional education and training.

Redesign the informed consent process to include forms written in simple sentences and in the language of the patient

Ensure written materials provided to patients are written at or below a 6th grade reading level.

“What did the doctor say?” Improving health literacy to protect patient safety. Washington(DC): The Joint Commission; 2007.



Then finally, at the public policy level, we have seen some changes in the last few years in terms of our health insurance system focusing on improving insurance enrollment forms and benefits. I think we’ve come a long way but there’s some more work to be done. This is a key part of health insurance literacy -- to really help address the needs of patients across the continuum.

An Ecological Approach to Engaging and Supporting Patients at *All Levels* of Health Literacy

- Make patient & family centered decision support tools widely available
- Provide training to clinicians so they can engage in shared decision making
- Upgrade our health care and insurance systems, community and public health infrastructure so patients can navigate them and be active participants
- Pass policy level initiatives and create incentives that enable reward clinicians for their time and effort spent engaging patients



To recap the ecological approach to engaging and supporting patients, there is something we can do for patients at all health literacy levels. These include making patient and family-centered decision support widely available; providing training to clinicians so they can engage in shared decision-making; upgrading our healthcare and health insurance systems, community and public health infrastructures so patients can navigate them and be more active participants; and finally passing policy level initiatives and creating incentives that reward practitioners for their time and effort in engaging patients.

Acknowledgements

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- Veronica Thomas, MPH
- Megan Lewis, PhD

I'd like to acknowledge my colleagues for their input on these slides.