My talk today is about engaging patients with low health literacy.
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.
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.
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.
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 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.
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 International 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.
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.
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.
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.
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.
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.
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.
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.
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.
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 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.
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 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.
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 an 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.
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.
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.
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.
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.
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.
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.
I’d like to acknowledge my colleagues for their input on these slides.