

Building the Case for Health Literacy

PROCEEDINGS OF A WORKSHOP

Joe Alper, *Rapporteur*

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

Health and Medicine Division

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Acronyms and Abbreviations

ACA	Patient Protection and Affordable Care Act
ADH	Arkansas Department of Health
AHRQ	Agency for Healthcare Research and Quality
CANDOR	Communication and Optimal Resolution
CMS	Centers for Medicare & Medicaid Services
EHR	electronic health record
FQHC	federally qualified health center
HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
PCORI	Patient-Centered Outcomes Research Institute
VA	U.S. Department of Veterans Affairs
WIC	Special Supplemental Nutrition Program for Women, Infants, and Children

Introduction¹

The field of health literacy has evolved from one focused on individuals to one that recognizes that health literacy is multidimensional. Health literacy, explained Bernard Rosof, professor of medicine at the Zucker School of Medicine at Hofstra/Northwell and chief executive officer of the Quality HealthCare Advisory Group, includes both system demands and system complexities, as well as individual skills and abilities. While communicating in a health literate manner is important for everyone, it is particularly important when communicating with those with limited health literacy who also experience more serious medication errors, higher rates of hospitalization and use of the emergency room, poor health outcomes, and increased mortality. “Over the past decade, research has shown that health literacy interventions can significantly impact various areas including health care costs, outcomes, and health disparities,” said Rosof in his introductory remarks to the workshop. He continued:

It also has been noted that health literacy is key to delivering high-quality, person-centered care, health services, and programs. Both in the medical care system and for public health, it is critical that health literacy be considered when we are talking about person-centered care and involvement of the person and family.

¹ This section is based on the presentation by Bernard M. Rosof, chief executive officer, Quality HealthCare Advisory Group, LLC, and professor of medicine, Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, and his statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

BOX 1-1
Statement of Task

An ad hoc committee will plan and conduct a 1-day public workshop that will feature invited presentations and discussion on the impact of health literacy. A commissioned paper will be presented during the workshop. The workshop may include presentations and discussion of issues related to the effect of health literacy interventions on health and health care costs, quality, behaviors, outcomes, and other areas as appropriate. The committee will define the specific topics to be addressed, develop the agenda, select and invite speakers and other participants, and moderate the discussions.

To understand the extent to which health literacy has been shown to be effective at contributing to the Quadruple Aim of improving the health of communities, providing better care, providing affordable care, and improving the experience of the health care team, the Roundtable on Health Literacy established an ad hoc committee to plan and conduct a public workshop on building the case for health literacy (see Box 1-1).² The roundtable also commissioned a paper that would identify and describe peer-reviewed evidence of the effect of health literacy in a variety of areas.

ORGANIZATION OF THE PROCEEDINGS

An independent planning committee organized this workshop in accordance with the procedures of the National Academies of Sciences, Engineering, and Medicine. (See Appendix A for the agenda.) The planning committee's members were Susan Bockrath, Lori Hall, Stanton Hudson, Laurie Myers, Laura Noonan, Audrey Riffenburgh, Bernard Rosof, Steven Rush, and Michael Villaire. This publication summarizes the workshop's presentations and discussions, and it highlights important lessons about the role of health literacy in meeting the Quadruple Aim, case studies of organizations that have adopted health literacy, and discussions among the different stakeholders involved in making the case for health literacy. Chapter 2 provides a patient's perspective on the need for health literacy and Chapter 3 recounts

² The planning committee's role was limited to planning the workshop, and the Proceedings of a Workshop was prepared by the workshop rapporteur as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants, and are not necessarily endorsed or verified by the National Academies of Sciences, Engineering, and Medicine, and they should not be construed as reflecting any group consensus.

the discussion on the commissioned paper. Chapter 4 discusses why health literacy is important and Chapter 5 provides examples of how different organizations adopt health literacy. Chapter 6 recaps a moderated discussion on the future of the field of health literacy and Chapter 7 summarizes the roundtable members' reflections on the day's discussions.

In accordance with the policies of the National Academies of Sciences, Engineering, and Medicine, the workshop did not attempt to establish any conclusions or recommendations about needs and future directions, focusing instead on issues identified by the speakers and workshop participants.

The Patient Perspective on the Need for Health Literacy¹

To provide some context for the day's discussions on the importance of health literacy, the workshop began with two presentations: one by Martin Ratermann, a craftsman, cancer survivor, and advocate for patient safety and avoidance of medical errors, and one by Jennifer Pearce, who founded Plain Language Health after experiencing firsthand how poor communication can adversely affect health. An open discussion, moderated by Bernard Rosof, followed the two presentations.

Ratermann's less-than-satisfactory journey in the health care system began in 2001, when at age 49 he had his first colonoscopy at an academic teaching hospital and had a 1-inch malignant polyp removed from his rectum. At the time, nobody told him that he needed to be seen on a regular basis going forward, and even when his wife, who was employed at this same institution, asked if her husband should get a second opinion, she was told by the chief executive officer—a gastroenterologist—that he was in capable hands.

In September 2005, Ratermann noted some blood in his stool and mentioned that to his doctor, who had his medical history on hand. He was examined and told he had a hemorrhoid. He voiced the same complaint in late 2006, and again, nothing was done. "I felt assured. I did not think it was my place to question," said Ratermann. Referring to his physician,

¹ This chapter is based on the presentations and discussions of Martin Ratermann, a craftsman and cancer survivor, and Jennifer Pearce, founder of Plain Language Health. Their statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

he added, “She was the M.D., and I was the woodworker.” In mid-2007, when the bleeding got worse, he was reassured again that the cause was a hemorrhoid and not a cause for concern, until the following July when he was diagnosed with stage IV rectal cancer. “I now know rectal bleeding should be taken seriously. Mine was ignored,” he said. “What a hard lesson. A whole academic health care system failed, and I nearly died because I did not speak up and ask questions. Because I finally decided to ask questions and speak up, I find myself here today.” Ratermann recalled that when he began his career as a woodworker, a noted British furniture maker told him that a good and successful commission starts out with good conversation. “So does care of your health, and good conversation involves listening and paying attention,” he said.

When first diagnosed, Ratermann was determined to deal with his cancer with as much grit and integrity as possible, and he was bolstered by the care and respect he experienced from the technicians who administered the initial set of tests and imaging scans. However, he soon had two experiences a few days apart that sent him into a tailspin. The first was with a surgeon, who told him he had the worst case of rectal cancer she had ever seen, that she was not sure she could help him, and that he was going to have to wear a colostomy bag. “I felt embarrassed, and I was not certain that I even knew what she was talking about,” he said. He left that appointment convinced that he did not want her as his surgeon.

The second negative experience came at the hands of the oncologist he and his wife went to see. The oncologist talked too fast, was brusque, and would not look Ratermann in the eye. The oncologist pronounced that he was going to resect Ratermann’s liver in 2 days, and he and his wife left the appointment shaken. When a nurse practitioner called the next day to schedule surgery, Ratermann told her he would not be coming back. “I was discouraged,” he said. “I knew I was in over my eyeballs, and I was ready to give up, but my wife disagreed. She decided to ask for some help.” A phone call to a close friend and physician in Kansas City led to an appointment 48 hours later with a specialist at the Siteman Cancer Center in St. Louis, who told Ratermann that his initial polyp removal had not been complete and that his cancer was actually a recurrence. “He pointed us in a very different direction, and everything changed after that,” Ratermann said.

Ratermann’s new surgeon explained things well and reassured Ratermann that this was not the worst case he had ever seen. The surgeon also commented that Ratermann asked many questions that most patients never posed, and as Ratermann recalled, he seemed pleased to answer them and even drew a picture of what was going to occur during surgery. Fortunately, the surgery revealed that the tumor had not spread to his liver and that the pathology reports were “the best we could have asked for.” His subsequent therapy at Missouri Cancer Associates was superb, he said, and even when he

was worn down and confused, the staff there were compassionate and caring, even proactively asking him and his wife about their concerns and worries. Communication, he said, was excellent. Even later, when he developed a fever and had to go to a wound center, the nurses and doctors there were caring. The first thing the doctor who saw him did was sit next to him, put her hand on his arm, and let him know that she and her colleagues were there to help him. “The touch of the human hand, and the tone of voice, I assure you, can have a positive effect on the process we call healing,” said Ratermann.

His family, he said, has learned that there is no such thing as false hope, and he credited the remarkable care he received from many dedicated caregivers, particularly his wife. When he recovered his strength, he obtained his medical records, wrote to the academic medical center where he was first seen, and outlined the errors in care he had experienced with the hope of preventing others from the same fate. Two months later, he met with the vice chancellor of medical sciences whose response was that it was hard to pay a primary care physician \$150,000 per year.

Shortly thereafter, Ratermann received a call from the director of clinical effectiveness, who incidentally had been his primary care physician before receiving a promotion, and she invited him to bring his concerns to a meeting at the hospital. After outlining what he had experienced and what went wrong with his initial care, the head of risk management dismissed it all by calling what Ratermann experienced a complication. “I was taken aback,” he said. “I politely disagreed, everything remained cordial, and before I left, I asked if anyone says they are sorry. I did not get an apology, so even communication about how we deal with medical errors failed.”

That was not the end of his story, however. Six months later, he learned that an entry was made in his medical record showing that he had normal colonoscopy results in 2003 and 2005, neither of which took place. “A thoughtful person would ask questions about ethics,” he said. “How do you make corrections in a climate like this? We are human, and things do go wrong, and how we deal with error and mistakes is the real measure of who we are as human beings.” Noting that he has seen both the finest in health care and some things that are unacceptable, he wondered how different his family’s life would have been had his doctors taken a little more time and focused less on the bill.

“Change has to come from the top, but the catalyst for change has to come from the bottom,” he said, referring to his new and reluctant role as an advocate for patient safety. “The loss of personal privacy is now part of who I am, and I do not want to let it define me. I want to be remembered for my workmanship,” Ratermann explained. “I feel like I have achieved my goal of doing this with integrity, and mentally, spiritually, and emotionally, I have done well. This has allowed me to forgive and to harbor no hard feelings, forgiveness beyond what I was taught, but forgiveness that

sets me free.” He also recalled something that an executive of a health care system said at a conference: “Just because we know the right thing does not mean we always do it.”

Ratermann said he does his best with the physical issues he deals with now, but he feels disheartened by the medical system’s response to what he experienced. Noting that he was not looking for sympathy, he said, “I came here to be your partner, and it takes determination and spine.” He also pointed out that his current caregivers have a keen sense of what the error in his diagnosis cost him and seem determined to do everything they can to support him going forward.

Regarding the prevention of medical errors, he noted the work of Sorrel King, whose 18-month-old daughter died because of a medical error, as well as Atul Gawande, and others, who repeatedly point out that the most common cause of error is a breakdown in communication. “Why would we work so hard to be good at what we do and allow ourselves to fail because we do not communicate effectively?” asked Ratermann. “It seems senseless. It is costly to insurance companies, to business owners, and to families.” What troubles him the most, he added, is the thought that others might have done without because of what was spent on his care. “It should trouble you, too,” he said.

In closing, Ratermann said that one lesson he learned from his experience is that medicine is a healing art as well as a science. “St. Francis tells us that if you work with your hands, you are a laborer. If you work with your hands and your mind, you are a craftsman, and if you work with your hands, your mind, and your heart, you are an artist,” he said. “A number of times, I have given this talk to the medical schools, and I leave them with this thought: please do not lose your heart in your goal to heal.”

Jennifer Pearce began her story by noting that the worst part of it is that it is not unique. “Details aside, it could be anyone’s story, and I know this because I make my living talking with people just like me—regular folks with no medical training,” she said. “What we all have in common is being hurt by the very system that is designed to care for you, and I am not talking about major medical errors. It is a hurt that comes from a slow, steady erosion of confidence in people and organizations.” The one thing that makes her story different, she said, is that she has spent the past 18 years working inside health systems to remedy the problems she experienced as a patient. It is a process she likened to digging a tunnel with a tablespoon. “I think everyone in this room understands,” she added.

Over those 18 years, Pearce has learned three lessons. The first, she said, is that efficiency has been allowed to supplant empathy, something she learned in the summer of 1991 when she was battling what had been initially diagnosed as whooping cough and syphilis, then a blood cancer, and finally systemic lupus. She recalled asking the nurse who phoned her

at work on a Friday afternoon with the final diagnosis if she was going to die. The nurse did not know, but she did say that she had an elevated risk of stroke and likely would not be able to have children. Pearce then asked what she was supposed to do next, and the nurse told her that the doctor was away until Tuesday and that she should make an appointment with a rheumatologist. “The next available appointment was 3 months away,” said Pearce.

That first lesson was reinforced 10 years later after she had given premature birth to twin girls and developed serious complications. At some point, she said, staff wheeled her in her hospital bed into the neonatal intensive care unit, where the doctor began educating her about her girls, a process a family member captured on video. “He delivered the requisite detailed education directly to me, and at the end he asked if I had any questions. I looked back at him and blinked slowly, once or twice I nodded my head, and I said no,” she recounted, noting she had no memory of the episode. “In both cases, the providers had news to deliver, and each delivered it efficiently. Both got to check the box. The problem was they did so without showing empathy for their audience.” These examples and others like them, she said, have made it hard for her to trust that people in the health care system would do right by her.

The second lesson she learned is that information silos continue to stymie the continuity of care. While she accepts responsibility for managing her chronic illness every day, doing so has been made more difficult by the inability for information about her care to flow smoothly among providers, particularly on the occasions when she has had to switch doctors. “My doctors’ efforts to find vital details in my previous records become time-consuming hunts during my already too-short appointments,” she said, an experience that seems the same today in the era of electronic health records (EHRs) as it did when her records were all on paper. The result is that the burden of tracking what tests and medications she needs falls on her shoulders, and that lab result trend lines start over with each new provider, a situation she called unacceptable. “While medical record portability and meaningful use requirements could have significantly relieved patients of the burden of having to remember all the details, their promise has been hampered by the silos they were designed to bridge,” said Pearce. “These experiences made me feel like my care, past and future, was less important than the integrity of these systems’ EHRs.” What is particularly galling, she said, is that EHRs have the capability of integrating information from other systems, but that they do not appears largely to be a business decision.

Pearce called lesson three “labeling at the expense of connecting.” “Every organization I have worked in has a unique vocabulary, and health care is no different.” What labels such as “noncompliant” and “frequent flyer,” and medical acronyms such as “DVT” (a blood clot) or “OFI”

(opportunity for improvement), do is dehumanize a person and their situation, she said, which gets in the way of expressing empathy. In her case, she was labeled as high risk when it came to pregnancy, and one obstetrician said he would not touch her with a 10-foot pole. “He dehumanized my situation and made it about liability,” said Pearce. Another obstetrician, in contrast, called her situation high risk but said he was willing to try. “The risk was on me, and I accepted it,” she said, noting that her premature twins just got their driver’s licenses.

In her mind, health literacy is not just about words but about the experience of health care, raising the question of how health literacy can infuse humanity into health care. “I am talking about creating health literate health care experiences, ones where people feel better when they come out instead of worse,” said Pearce, who offered three steps for how health literacy can lead to better care. First, she said, it is necessary to align care with a patient’s needs, design workflows that revolve around the people being served, and work with patients to find the best time and place to deliver information. For example, the best time to have a patient consent to anesthesia is not when the patient is on a gurney being wheeled into surgery. “That may be the most convenient time for the anesthesiologist, but how is that benefitting the patient?” asked Pearce.

Second, the health system must shift the burden of communication from the patient to the system whenever possible, Pearce said. This requires using EHRs to their full potential and using the Health Insurance Portability and Accountability Act (HIPAA) and meaningful use requirement in the Patient Protection and Affordable Care Act (ACA) to benefit patients, as these laws intended. Information silos and an overemphasis on privacy create roadblocks. Third, it is imperative to translate labels into dialogues that reveal truth rather than obscure it, she said. As an example, Pearce said that labeling someone “noncompliant” is a shortcut that leads to a dead end, while inviting someone to share why they have chosen to not take medication starts a dialogue. “Words matter,” said Pearce. She said:

Efficiency, information silos, acronyms, and labels are things we associate with business. Empathy, continuity, connection are things we want in health care. Health care is a business, but it is the business of caring for human beings, and it cannot be successful without humanity at its core.

Concluding her remarks, Pearce acknowledged that none of what she suggests is easy and that it takes time and effort, but the evidence shows that doing so leads to a more human system. “Most importantly,” she said, “a humanity-driven system minimizes the harm, the burden, and the shame that too often characterizes the status quo, leaving both patients and our providers dissatisfied.”

DISCUSSION

Before opening the floor to questions, Rosof described a phenomenon he calls the “hand on the doorknob syndrome,” which is when a patient, after spending 30 to 40 minutes going through a physical examination and discussion, gets up and does not exactly leave the room, but rather lingers for a few moments with a hand on the doorknob. “If you notice this and ask the patient if there was something you missed, you find out the true reason for the patient’s visit, which you missed in the previous 45 minutes,” said Rosof. “That hand on the doorknob, the ability to communicate, is something that becomes innate for people who want to learn the methods of communication.”

Catina O’Leary from Health Literacy Media asked Pearce for her thoughts on how to stop thoughtless and lazy communication, given that the health literacy field has been trying to accomplish that task for 20 years or so. Pearce replied that in working with providers, they all say they want to adopt innovations to improve communication, but only if they do not affect their workflow. This attitude should not be surprising, she said, given that physician incentives and performance metrics are about efficiency and time spent using the EHR. “The EHRs run health care at this point, so I think the patient is an afterthought,” said Pearce. What must happen, she said, is for physician incentives to be based instead on how well they communicate with patients, which would not only benefit patients but ease the burdens physicians are experiencing from spending so much time working with EHRs.

Stacey Rosen from Northwell Health noted that there were two stories in *The New York Times* on the day of the workshop discussing those burdens and their effect on clinician wellness. Pearce replied that Donald Berwick, the Institute for Healthcare Improvement’s founder and current Senior Fellow, has written about the three eras of health care, starting with the paternalistic era that is ending, albeit slowly. The second era, which represents today’s health care, measures everything, regardless of whether it needs to be measured. The third, which is in its nascent stage, would create a more health literate experience. Rosof recounted another story in which Berwick was addressing his daughter’s medical school graduation class. After giving his usual commencement speech, he told the new doctors that the best thing they could do was to take off their white coats, sit with their patients, and really learn what it takes to be a physician and how to communicate with their patients.

Andrew Pleasant from Health Literacy Media asked Pearce and Ratermann how medical education should be changed so that patients do not have to experience what they went through because of poor communication. Ratermann said he did not know how to teach effective communication

skills other than to start in kindergarten and work from there. He added, though, that listening and asking questions is a key piece of being a good communicator, and being curious about the patient and putting them in the center of the conversation is a good place to start. Pearce said she would have medical schools pay attention to the work of Clifford Coleman at Oregon Health and Science University, who has developed a health training intervention for medical students (Coleman and Appy, 2012; Coleman and Fromer, 2015; Coleman et al., 2013, 2016a,b). She also recommended that physicians-in-training who are poor communicators should become specialists in a field that does not require contact with patients, such as radiology.

Cindy Brach from the Agency for Healthcare Research and Quality (AHRQ) noted that research shows that people are more likely to sue their physicians after a medical error when there is poor communication (Kachalia et al., 2010; Robbennolt, 2009) and that her agency has developed the Communication and Optimal Resolution (CANDOR) toolkit to help physicians develop apologies for errors and learn from their mistakes.² Given that there are institutions that have not adopted this type of technique, Brach asked if an apology would have made a difference to the two speakers in terms of whether they sued for malpractice. Ratermann said that he asked for an apology several times, and if there had been one, “we could have started down a totally different road.” He said that physician friends of his have told him that he would have been a model for a different approach to dealing with a series of mistakes, but instead, there was constant finger pointing and denial. As he pointed out, it is hard to correct a mistake when nobody will admit to making one. He noted, too, that when he tried to get his medical records, he had to pay \$100 to obtain them, which in his opinion was an intentional barrier erected to discourage him from having those records. He also said that when he received the right diagnosis, he called his primary care doctor, who responded that he had been focusing on Ratermann’s diabetes. Ratermann is not diabetic.

In the spirit of the moment, Suzanne Bakken from Columbia University commented that as a biomedical informatician, she wanted to offer an apology for her field’s failure to develop an informatics solution that is truly more patient-centered. “We know that our current situation certainly makes it very difficult for both the patients and the providers,” said Bakken. She then asked the speakers if they had any experience with the OpenNotes movement in health care (Leveille et al., 2012; Trossman, 2013),³ and if they did, if they would comment on its implications for a health literacy agenda. Pearce said she is familiar with it and is all for anything that allows

² See <https://www.ahrq.gov/professionals/quality-patient-safety/patient-safety-resources/resources/candor/introduction.html> (accessed December 24, 2017).

³ See <https://www.opennotes.org> (accessed December 24, 2017).

medical records to be more portable. One of the great frustrations for patients, she said, is that patient portals do not allow patients to feed information into their EHR because health systems do not trust patients to enter accurate information, even for something as simple as getting their flu shot at the grocery store. “I think anything that circumvents these ‘nervous nelly’ health systems and their data integrity issues is a positive,” said Pearce, who reiterated the common knowledge that EHRs are built as billing platforms. “Every health system in the country is trying to put lipstick on a pig and turn these EHRs into patient engagement tools, and that is not what they are built for,” she added.

Pearce then suggested that there is a huge opportunity for the health information technology field to develop proprietary or open-source products to fill that gap. One big issue, responded Bakken, is that she and many of her colleagues work at institutions that had developed home-grown EHRs with increased functionality, but that these institutions are now adopting one of the large commercial products that in almost all instances results in decreased functionality. Ratermann commented that he is the last person to talk to about EHRs and that he is a word-of-mouth person. In his case, he was fortunate that his wife knew someone who knew someone who referred him to Missouri Cancer Associates for his treatment. Pearce remarked that the health care system can and needs to do better than “care by accident.”

Earnestine Willis from the Medical College of Wisconsin thanked the two speakers for “letting us as physicians see a mirror of our system and the consequences of what can happen with these errors.” She then commented on the fact that Ratermann’s wife was his strongest advocate at a pivotal time in his journey and the importance of patients having an advocate when receiving critical information at times when it may be hard to comprehend or even hear that information. Her question to Pearce was whether the institution she worked at before becoming a consultant had a system for incorporating advocacy for patients at critical times in their care when it is easy to miss some of the finer pieces of information that are critical for making good medical decisions. Pearce said that at the time she left that institution in January 2017 there was no formal effort beyond encouraging people to bring someone with them to their appointments. In fact, the lack of such a system is why she emphasizes the after-visit summary in her health literacy work. “For those of us who cannot bring someone with us, it is the only record of what you may have missed,” said Pearce.

In her opinion, producing a health literate after-visit summary is supposed to be one of the meaningful use requirements, yet in her experience, most after-visit summaries are useless. “I think that is an area where our field can effect some change,” she said, noting that she tried hard in her previous position to get one of the major EHR vendors to add tools that

would produce better after-visit summaries only to be told that her system was the only one asking for such tools. “I think we can exert some pressure there as a profession,” said Pearce. Brach noted that the roundtable held a workshop in March 2014 on after-visit summaries and discharge instructions (IOM, 2014) and that AHRQ has funded research that will be published soon on after-visit summaries. As part of that project, the researchers did qualitative work with patients regarding what they want to see in a more understandable, actionable after-visit summary and found that there was little flexibility in the common EHR platforms to produce that type of information.

Wilma Alvarado-Little from the New York State Department of Health noted that Ratermann’s wife worked for the organization that misdiagnosed him and commented that just because someone works for a health care organization does not mean that they are going to be getting honest responses. If that is true, she said, it makes one wonder what messages people not associated with a health care organization are getting. Gwen Ratermann, Martin’s wife, pointed out that for someone like her husband or her 87-year-old mother, both of whom are computer illiterate, the idea of being able to access their own EHRs means nothing, which in her mind reinforces the importance of teaching physicians how to be good communicators.

Sochan Laltoo, a public health instructor from Trinidad and Tobago, remarked that in impoverished countries or countries where people may not feel empowered to access their own medical records, people may not be health literate enough to ask questions of their doctors and understand the answers. Given the prevalence of health illiteracy, he asked if there were any international efforts to promote health literacy. Pearce said there are, and Rosof suggested that Laltoo pick up a copy of the summary from a 2012 workshop the roundtable conducted on health literacy around the world (IOM, 2013).

Improving Health and the Bottom Line: The Case for Health Literacy

The workshop's second session featured presentations by two of the four authors of the paper commissioned for the workshop: Stanton Hudson, associate director of the Center for Health Policy at the University of Missouri, and R. V. Rikard, senior research associate in the Department of Media and Information at Michigan State University. An open discussion followed their presentation.

PRESENTATION OF THE COMMISSIONED PAPER¹

Before discussing the commissioned paper, Hudson told the workshop attendees that he and his colleagues also created a series of fact sheets that can be used to present information on the impact of health literacy. He also noted that his team's plain language specialist revised the paper's executive summary so it could be understood by people outside of the field, and he thanked the more than 50 people he and his colleagues spoke with to find out what new evidence was available and identify best and promising practices that have not been published in the peer-reviewed literature. He

¹ This section draws on a paper commissioned by the Roundtable on Health Literacy, *Improving Health and the Bottom Line: The Case for Health Literacy*, by Stanton Hudson, R. V. Rikard, Ioana Staiculescu, and Karen Edison (see Appendix C) and is based on the presentation by Stanton Hudson, associate director of the Center for Health Policy at the University of Missouri, and R. V. Rikard, senior research associate in the Department of Media and Information at Michigan State University, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

explained that there is a great deal of quality improvement work underway in hospitals that has not yet appeared in the peer-reviewed literature.

At the start of their work on the commissioned paper, Hudson and his colleagues realized that there are several challenges to making the case for health literacy, and even with a compelling case, there are aspects of the U.S. health care system that hinder the argument. Volume-based reimbursement incentives, for example, are an impediment, although the ongoing transition to value-based reimbursement should ease that barrier.

A second challenge is the overall lack of transparency in the U.S. health care system. “We want people to be active, engaged health consumers, health customers, but if you cannot shop around for price, or you cannot tell the quality of the products you are buying, then it makes it virtually impossible,” said Hudson. Quoting James Duesenberry, Hudson said, “Economics is all about how people make choices. Sociology is all about why they don’t have any choices to make.” The goal may be to empower patients to make choices, he said, but they are trying to work within systems and against policies and structures that limit patient choice at almost every level. He stated that until the health care system and policies that govern it change, it will be challenging for well-intentioned patients to make well-informed choices even when presented with health literate information.

A third challenge to making the case for health literacy is that the legal profession has not yet embraced the literacy movement and can function as a barrier. As an example, Hudson recounted how frequently he and his colleagues have reworked documents, often with the help of patients, for Missouri’s Medicaid program only to have lawyers reject the changes. He did note that some of the younger lawyers are starting to get that plain language can reduce, not increase, liability, but until the legal profession is convinced about the importance of plain language, the legal profession will continue to be a challenge.

Rikard then discussed the fourth challenge, which is the need for research to support the efficacy of health literacy interventions. Most of the research that has been done, he said, has looked at short-term outcomes. There have been no longitudinal studies involving health literacy that examine long-term outcomes related to cost, quality, satisfaction, and effects of broad-based health literacy initiatives and interventions, which makes it difficult to identify causal relationships between health literacy and improved outcomes. Rikard conceded that there could be useful evidence in the literature that does not turn up in a search using the term “health literacy.” He also noted that Hudson heard in informal conversations with researchers that when an intervention does not work, it is difficult to get funding to try a different approach.

To prepare the case for health literacy, Hudson and his colleagues first looked at what they called the business case, which he explained speaks



FIGURE 3-1 Health literacy and the bottom line.

SOURCE: As presented by Stanton Hudson and R. V. Rikard at Building the Case for Health Literacy: A Workshop on November 15, 2017.

to the factors that go into the Quadruple Aim and is aimed primarily at hospitals. They then looked at the ethical case. There are areas of overlap between the two, he said, given that health literacy can affect behavior change and patient experience as well as cost, quality, and access.

When the authors of the commissioned paper looked at the business case (see Figure 3-1) they started by looking for recent studies on cost that had not been included in a systematic review published in 2011 (Berkman et al., 2011a,b) and identified quite a few ways in which health literacy can improve the bottom line. For example, one health literacy intervention found that some 18 percent of individuals who received an automated phone call to remind them to have a cancer screening did, in fact, get screened, generating nearly \$700,000 in additional income for the health system in 2 months. When Massachusetts General Hospital hired a community resource specialist, emergency department visits fell by 13 percent and realized a net annual savings of 7 percent, generating a return on investment of \$2.65 for each \$1.00 spent on the community resource specialist.² Even something simple, such as giving parents the book *What to Do When Your Child Gets Sick*, produced savings of \$1.50 for every \$1.00 spent by giving parents easy-to-understand information on how to deal with their child's

² Information available at <http://www.partners.org/Innovation-And-Leadership/Population-Health-Management/Current-Activities/Integrated-Care-Management-Program.aspx> (accessed December 24, 2017) and <https://www.advisory.com/research/market-innovation-center/the-growth-channel/2017/04/health-disparities> (accessed December 24, 2017).

health care at home. Another study found that using the teach-back method at the appointment desk reduced no-shows by 15 percent. In short, said Hudson, while health literacy is not a magic bullet for controlling health care costs in the United States, there are many health literacy interventions that can produce significant cost savings.

Behavior change is also part of the business case, and Rikard discussed several examples that were not in the peer-reviewed literature. One study found that when new mothers-to-be received *What to Do When Your Child Gets Sick*, they used the emergency department less frequently because they had an understandable resource at hand that they could use when their children were sick. In another study, heart failure patients received phone calls asking patients to call in and report their weight. Over the first 2 weeks, the percentage of patients who reported their weight daily increased from 28 percent to 36 percent, and more importantly, these patients who called in lost weight. A third study found that when an adult education class added health literacy into the curriculum, the adult learners increased their knowledge about health and what they needed to do regarding prevention. “These are one-off studies, but we see that there are these behavioral changes that happen as a result of maintaining a health literacy practice,” said Rikard.

When Hudson and his colleagues looked at health outcomes, one of the promising new developments they found was the increased use of multimedia programs and associated YouTube videos as mechanisms to provide information to people in forms they can understand. One study, for example, found that individuals who used a video education program were more likely to have controlled blood pressure, regardless of their blood pressure control status, than were those who relied on written information. Similarly, video education programs benefitted individuals with other chronic conditions, such as producing improvements in glycemic control in patients with diabetes. Combining online interactive media with automated phone calls produced a 15-day delay in readmission for chronic obstructive pulmonary disease and a 69 percent reduction in length of stay when patients did have to be readmitted to the hospital. Another study found that a patient navigator program for individuals with heart failure produced a 15.8 percent decrease in unplanned readmissions. Hudson noted that the Centers for Medicare & Medicaid Services (CMS) is now penalizing health systems for readmissions and that private insurers are likely to follow suit, so hospitals are desperate for approaches to reduce readmissions, such as Project RED (Re-Engineered Discharge), which increases support for people upon discharge from the hospital.

In some cases, said Hudson, realizing improvement can require some unexpected interventions. His hospital, for example, has been struggling with getting its congestive heart failure patients to report their daily weights.

The first issue, it turns out, was that many of these patients did not have a scale at home or know how to use it. Even after providing a scale and testing their knowledge about how to use it, the hospital staff was still having trouble getting them to report their daily weight, which turned out to be because they were being asked to report daily weight *change*, which required them to do math. When the patients were asked to report daily weight instead, compliance improved by 18 percent. Understanding these little challenges and being able to put supports in place, said Hudson, can help patients overcome these challenges.

Hudson said he was surprised how little literature there was that tries to understand the causal relationship between health literacy and medical errors. Perhaps the one exception is there have been quite a few studies showing that health literacy improves medication adherence and reduces medication errors (NASEM, 2017). There are clear guidelines, for example, to use milliliters instead of teaspoons and tablespoons to stop people from using kitchen cutlery to measure liquid medication, and these guidelines have made a difference as far as reducing dosing errors. Hudson noted that the U.S. Department of Veterans Affairs (VA) developed and adopted a patient-centered medication label format to improve the quality of care for veterans.

One of the statistics that Hudson quotes whenever talking about health literacy is that patients forget between 40 and 80 percent of what the doctor tells them as soon as they leave the doctor's office. More worrisome, though, is the fact that half of what patients do remember, they remember incorrectly (Kessels, 2003). "That is where those mistakes are going to be made that are really going to impact not only the health system and cost, but the lives and quality of life of those patients," said Hudson. He also commented that the United States has a mixture of health care systems. "We have socialized medicine in the VA and the Indian Health Service. We have employer-sponsored health plans. We have a national health insurance, Medicare, like they have in Canada, and trying to make these all work can be very challenging," he said.

In his opinion, the VA is leading the way when it comes to improving the quality of care, and while the VA has its own challenges and issues, one big advantage is that its EHR can communicate across the entire VA system. As an aside, Hudson noted his hospital uses one vendor's system and the other hospital in town uses a second system, and the result is that the two hospitals must fax patient information between them. Referring to the VA's patient-centered medication label, he said the label is currently being tested and he is curious about whether it will make a difference in reducing medication errors. He also noted that the one study he found that looked at the relationship between health literacy and costs was conducted at the VA (Haun et al., 2015). That study found that in a population of

Regulations play a significant role in making the ethical case, as well as the business case, Hudson explained. CMS regulations for home health agencies and long-term care facilities, for example, require that information be provided in ways the patient can understand and in culturally appropriate forms. A bigger factor, however, will be the requirement in the Medicare Access and CHIP (Children's Health Insurance Program) Reauthorization Act that states that half of all reimbursement for those two programs will be through value-based payment arrangements, either through the merit-based incentive payment system or one of several alternative payment models. One aspect of these new reimbursement models is that they will pay for health literacy activities, which Hudson called a promising development. For Hudson, one of more interesting demonstration projects enabled by the ACA bases physician bonuses on HCAHPS scores, which means the consumer has a voice in how much the doctor and the health system get paid. Another promising development is that most state Medicaid programs—42 by his count—are using an alternative payment model, such as medical homes, to reimburse physicians and incentivize effective quality care. One effect of these policy changes, said Hudson, is that they will force hospitals to switch from a model that tries to keep beds filled to one that has to keep people out of the hospital, which helps create a true health care system rather than the current sick care system.

Health equity is another aspect of the ethical case, explained Rikard, and from a health literacy perspective, health equity means that everyone has equal access to health information on which they can act. In many cases, he said, people who do not have health information also lack access to health care services, and even if they have access, the information might be understandable by some, but not all. In addition, he added, the 2016 CMS Quality Strategy includes two goals related to health literacy and health equity.³ Goal 1 calls for improving safety and reducing unnecessary and inappropriate care by teaching health care professionals how to better communicate with people who have low health literacy and by more effectively linking health care decisions to person-centered goals. Goal 3 calls for enabling effective health care system navigation by empowering individuals and families through educational and outreach strategies that are culturally, linguistically, and health literacy appropriate

In Hudson's opinion, the implications of health literacy for health policy and practice are best laid out in the 2012 Institute of Medicine discussion paper *Ten Attributes of Health Literate Health Care Organizations* (Brach et al., 2012). Once the case for health literacy is made, he said, this

³ See <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Quality-Strategy.pdf> (accessed December 24, 2017).

paper, “lays out the road map for what facilities can do to really address that case and make a difference.” It is his hope, he said, that someday everything measured in health care around health literacy will be based on these 10 attributes, and that the health care enterprise will come to realize that these 10 attributes speak to the provider experience as much as the patient experience. As an example, he recalled hearing a presentation several years ago by Laura Noonan from the Carolinas HealthCare System showing that physicians who integrate the teach-back method into their practice had to spend less time with patients because they were using less jargon that needed to be reexplained.

Rikard and Hudson concluded their summary of the commissioned paper by listing recommended areas for future research. These included

- Assess the savings from long-term outcomes and behavior change, conduct longitudinal studies of broad-based health literacy activities.
- Change health behaviors and health outcomes, study whether public health literacy provides an upstream payoff.
- Ensure that information and communication technologies translate into better health outcomes, examine the effect of eHealth literacy interventions on health outcomes.
- Understand the direct relationship between health literacy and medical errors, examine the causal link between health literacy and adverse events.
- Examine the link between health literate organizations and provider–patient communication, develop evidence on the direct relationship between health literacy and provider satisfaction.
- Achieve health equity, focus on the effect of the health care power dynamic on health equity and opportunities for people to achieve a healthy life.

In thinking about health equity, which is where Hudson said his interests lie, he referred to the illustration showing the difference between equality and equity (see Figure 3-3). “Equality is where we give everyone the same box to see over the fence, and equity is where we provide different supports to patients,” he explained. “That is where we are now, identifying our patients that struggle and trying to give them a little extra support.” Where he would like to see the health care system move to is a place that recognizes the structures and policies that create inequity, Hudson said:

It is the fact that we do not have EHR interoperability, so we have to rely on patients for their information. It is the fact that we have siloed and disjointed health care, which is something that stares patients in the face. It is the fact that we do not have transparency of information. We need to

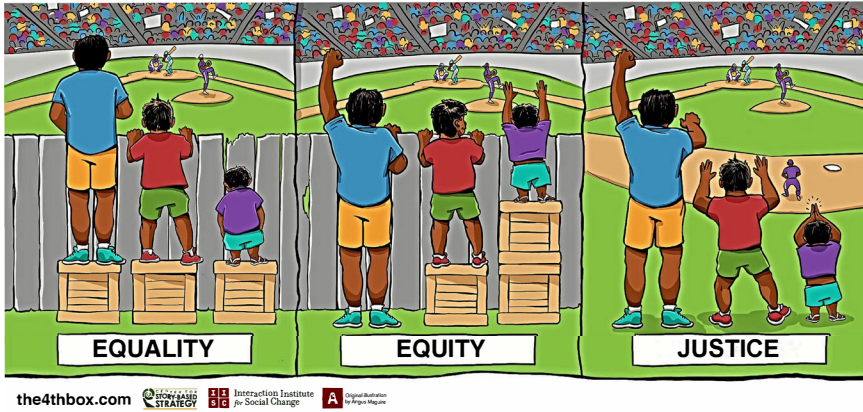


FIGURE 3-3 The difference between equality (left), equity (center), and eliminating the structures and policies that contribute to inequity. **SOURCES:** Image presented by Stan Hudson and R. V. Rikard at the Building the Case for Health Literacy workshop, adapted from Angus Maguire, Interaction Institute for Social Change, and from Craig Froehle.

tear down those systems and recreate them so that people can see through that fence. Then we do not have to worry about providing special support, and we create an equitable system for everybody to be able to navigate and get in the game, so to speak.

DISCUSSION

Terry Davis from the Louisiana State University Health Sciences Center in Shreveport opened the discussion by commenting on the use of automated call prompting. In her recent experience, automated text messages are producing better responses from patients because so many people have stopped answering their phones when they do not recognize the phone number that is calling them. She also remarked that while research has largely focused on what the system must do and some on what the patient must do, there is little in the literature about family caregivers; but as society ages, family caregivers are going to play an increasingly vital role in health literacy.

Lawrence Smith from Northwell Health stated that the health care system needs to teach patients two things: enough information about their illnesses so they can be legitimate partners with the health care system in the appropriate management of their illness, and equally important, how the health care system works. “In fact, if the patients don’t under-

stand how the health system works,” said Smith, they will be “endlessly surprised” by the “traps” they will encounter. He expressed concern about the suggestion that the language of imaging reports and the like should be changed so patients can understand them, when in fact, the precision of medical terminology in a report intended to go from one expert to another should not be diluted to the level of a lay person. “I would strongly object to someone changing the way a neuroradiologist reports findings on an MRI [magnetic resonance imaging] scan to a physician who ordered it looking for specific things,” said Smith. Perhaps what is needed, he suggested, is a summary that provides the take-home message for the patient who is going to look at the medical record. He noted that this would require “a tremendous culture change, and I do not know whether medicine is ready or not.”

Smith then commented that patients who are mad at the health care system need to realize that the physicians working in that system are also unhappy. Each year, he said, Northwell Health surveys its 18,000 physicians and asks if they think about leaving the practice of medicine, and if so, why. Every year, the top reason why physicians think about giving up their practices is frustration with the EHR. In fact, said Smith, the level of patient dissatisfaction with the health care system pales in comparison to the dissatisfaction physicians express about the EHR. He reminded the audience that the EHR was designed for chief financial officers, not physicians, and relayed the cynical message he got from the vice president of one of the major EHR vendors, which was his company did not care about doctors or patients, because if the finance department was happy, they would keep buying this vendor’s products for their hospitals. “We are talking about an entire system that was designed to make everyone miserable except a very select few people,” said Smith.

As a final comment, Smith said that in his opinion, efforts to conduct randomized trials on interventions that involve partnering with patients and caregivers to reconstruct the health care system are perhaps misplaced. His suggestion was to find the natural experiments that have already take place and to identify the physicians who are already great communicators and health literacy teachers and find out how their patients have done.

Hudson responded to those observations with one of his own, which is that the system largely blames the patient for being health illiterate. “We expect individuals to have these skills, but we do not teach them,” he said. “If we truly wanted to teach health literacy, we would teach it in elementary and secondary school along with reading, writing, and math as a life skill everyone needs.” In fact, when someone asked him the night before the workshop for the most innovative study he found, he singled out a study in which the researchers were “democratizing medical education” by taking what medical students would learn and including it in elementary and sec-

ondary education. Until that happens on a large scale, however, patients are not going to have the necessary health literacy skills. “When you are learning on the fly, when you are sick, in pain, or worried about a family member, that is not the most conducive learning environment,” said Hudson.

Regarding Smith’s concern about rewording imaging reports, Hudson clarified that the idea is not to reword those reports but to provide a translation into a more understandable form for patients. The challenge will be to develop the necessary translation tools that will take the report designed to convey information from one expert to another into language suitable for the patient who is going to look at their medical record or use OpenNotes. The crucial step in developing such tools will be to involve patients in end-user testing. “The golden rule of health literacy is to know your audience and to test and develop with your audience,” said Hudson. “That is something the health system does not do like other industries.”

Kim Parson from Humana reiterated Hudson’s message that the health care system must stop blaming patients for what they do not know and take responsibility for conveying information in a way that is suitable for patients. “In my organization, we like to say, ‘It is not my fault, but it is my problem,’ and I think that is how we have to approach things.” She also agreed with Smith that it is right for two experts to use language that conveys information precisely when communicating between themselves and that it is just as right to recognize that not everyone is going to understand that language. “Therefore, it is incumbent upon the system to design and co-create with the people who are going to be the receivers of this information, and for those that are going to be navigating the system,” said Parson. “End-user testing is great, but I think we should start with the user at the beginning.”

Terri Ann Parnell from Health Literacy Partners asked Hudson if the videos used in the video-based interventions all came from the same company, which they did. Hudson noted that one thing this company does better than others is that they partner with researchers to make sure they get good evaluation data. This company also provides fact sheets and reports that document the effectiveness of its products, and it also reports when the videos have no effect and need further work. Parnell added that the videos that she has used from this company are also noteworthy in that they use language that is culturally appropriate.

In response to Parnell’s subsequent comment that medical schools are now doing better at teaching health literacy skills to medical students, Hudson said the problem is that similar efforts are not being made with attending staff and preceptors. “Students come out all gung-ho to use the teach-back method and they immediately get shut down by a doctor not understanding what they are doing, saying they do not have time for it,” said Hudson.

Laurie Francis from the Partnership Health Center remarked that the United States does not have a true health system because every organization and every state is different, which creates challenges. She also noted that the discussion about health literacy does not include team-based care as often as it should. Today, with patient-driven, patient-centered, team-based care, the doctor does not have to do everything, and since most doctors are not great communicators, perhaps more effort should be spent identifying those team members who are good communicators and training them in health literacy techniques. She then noted that teaching physicians motivational interviewing, health literacy, and power-sharing skills is an effective way of retaining physicians. "Physicians really enjoy it once they learn how to ask questions," said Francis. She then asked if the VA studies that Hudson and Rikard found look at whether the cost savings were associated with health literacy alone or if the culture of the VA had an effect as well. Hudson replied that the VA study he cited was a 3-year retrospective study in which patients took a test to quantify their health literacy level and then the patients' records were examined retrospectively to look at direct medical costs. "They did not extrapolate as much on other factors that could be playing out, and they were just trying to tie it to health literacy," said Hudson.

Commenting on the idea of bringing a family member to medical appointments, Wilma Alvarado-Little from the New York State Department of Health pointed out that family members should not serve as interpreters because that robs the family member of their primary purpose, which is to provide support. She also reminded the workshop that doctors and nurses are not the only providers who see patients. Physical therapists, speech therapists, and other health care professionals who enter a patient's room can be a provider who can be tapped to provide health literate information. She then asked the two speakers if any of the studies looking at performance measures did so through the lens of community-based organizations that do not provide specific direct services but do affect patients and the partners of those organizations. Hudson replied that the commissioned paper does include studies that looked at public health literacy interventions. He also noted that the Canyon Ranch Institute is using quality-adjusted life-years and similar measures to measure the effectiveness of interventions on cost and can identify extensive cost savings in that manner. One challenge, said Hudson, is that most of the research is focused on direct costs. "What we need is a longitudinal study that not only looks at multiple interventions at once, because we usually do not do health literacy one thing at a time, but also looks at indirect cost savings," he said. "We do not talk about the lost years of productivity that result from medical errors and the people who die from them, and that is a huge cost to society."

Stacey Rosen from Northwell Health asked the speakers if they found any pilot studies or reports on bringing health literacy education to elemen-

tary, middle, and high schools. Hudson replied that he and his colleagues only found one study, but they were not looking for them either since their focus was on the business case. Rikard mentioned there are studies of that type underway in Europe. Health Literacy Europe, he said, is implementing health literacy curricula in Europe's primary and secondary schools and studying what happens to those children over time.⁴

Audrey Riffenburgh from Health Literacy Connections noted that she recently met a professor at the Colorado State University College of Veterinary Medicine and Biological Sciences who told her that the veterinary students all receive 50 hours of health communication skills as part of the standard curriculum. This faculty member told Riffenburgh that she and her colleagues have made two observations regarding this training. The first was that the clients of the veterinarians who had received this training were more likely to be repeat clients because they felt good about the communications they had with the veterinarian (Shaw et al., 2012). The second observation was that the clients were more likely to be compliant with treatment recommendations for their animals (Kanji et al., 2012).

Jay Duhig from AbbVie Inc. asked the speakers to discuss the barriers to conducting the future research they suggested. Rikard replied that the main barrier is there are no incentives for people, particularly from different fields, to work together on long-term projects. The National Institutes of Health, for example, does not have grant mechanisms to fund cross-discipline, long-term projects. Pleasant then asked what funders could do to address this barrier. Hudson replied that one challenge specific to health literacy studies is that many are funded by the Patient-Centered Outcomes Research Institute (PCORI), and the legislation authorizing PCORI does not allow it to fund cost-effectiveness research. While that may be a special case because that funder was created by Congress, Hudson said that giving more latitude to researchers to explore the breadth of the issue would be a key first step. Rikard added that he would start approaching large nonprofit institutions and foundations to interest them in the importance of health literacy in improving the health of the nation.

Casey Quinlan from ThinkProgress asked how much of a barrier is created by the status quo in a \$3.5 trillion industry with little incentive to change and if it would be possible to make faster progress by involving patient communities in reform efforts. Hudson replied that he would like to see more funding for projects that bring in community investigators as equal members of the team and that involve the community in the planning process for these projects. In his opinion, doing so would save time and money by skipping the need for a redesign phase when a poststudy end-user group finds a problem with an intervention. He noted that the field is

⁴ See <https://www.healthliteracyeurope.net/hl-and-eu-policy> (accessed February 15, 2018).

getting better at engaging with the community and valuing the knowledge that community members bring to studies when they are involved at the beginning rather than the end of a project. Rikard added that a study he is working on regarding the water crisis in Flint, Michigan, is using paid community investigators who have made important contributions to the study design.

With the last comment of the discussion period, Cindy Brach from AHRQ commended the speakers for including the ethical case for health literacy in their paper because even if an intervention does not save money, patients have a right to communicate with and understand their health care providers. One part of the business case that was not mentioned, she said, concerns market share and patient loyalty. She suggested that these should be included in the business case because patients are more likely to return to a health care organization that communicates clearly. She also noted that changes in payment policies are providing new incentives that reward outcomes and positive patient experiences; these changes should become important pieces of the business case.

Why Health Literacy?

The third session of the workshop featured two presentations on why health literacy is important to the health care enterprise's stakeholders. Cathryn Gunther, vice president for global population health at Merck Sharp & Dohme Corp. (Merck), spoke about the importance of health literacy from the perspective of a pharmaceutical company, and Bernard Rosof, chief executive officer of the Quality HealthCare Advisory Group, discussed the role of health literacy in achieving the Quadruple Aim. An open discussion with the panelists followed the two presentations.

A PHARMACEUTICAL COMPANY PERSPECTIVE ON WHY HEALTH LITERACY MATTERS¹

One piece of good news about health literacy, said Gunther, is it is getting increasing attention around the globe. Several European countries, for example, found they were not getting the degree of comprehension about health topics that they had anticipated and are now starting to address this problem. Asian countries are also starting to address health literacy for the first time. "There is enormous opportunity around the globe to improve comprehension, and I would suggest all of us as key stakeholders in the health industry have a responsibility to address it," said Gunther.

¹ This section is based on the presentation by Cathryn Gunther, vice president for global population health, Merck Sharp & Dohme Corp., and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

Why is health literacy so important to Merck? The reason, said Gunther, is that the number one goal of a pharmaceutical company is to get the right medication to the right individual in a way that is comprehensible, that fits into the total care plan, and that helps the patient feel empowered regarding his or her health care. Reflecting on the health literacy experiences she has had during her career, both within the pharmaceutical industry and outside of it as a consultant, she said they all come back to appreciating the context of a patient's life—where they are, where they are coming from, and the environment in which they live—and meeting them where they are.

The late George Merck, son of the company founder and company president, embedded the patient experience into the center of the company's philosophy when he said, "We try never to forget that medicine is for the people; it's not for the profits. The profits follow, and if we've remembered that, they have never failed to appear," explained Gunther before listing some of the ways in which the pharmaceutical industry has contributed to society—the development of medications that turned HIV/AIDS from a death sentence to a treatable chronic illness; vaccinations for measles, mumps, rubella, diphtheria, polio, and other childhood diseases; and more recently, immunotherapies that are changing the prognosis for many cancers. Gunther said it is important to appreciate that Merck is a research-intensive biopharmaceutical company, one that understands that a new drug has no real value unless the person taking that drug understands what that medication is going to do for them so they can take ownership of their own care and adhere to the appropriate medication schedule. Health literacy, she added, is a big part of realizing that value, and the current objective at Merck is to focus a collaborative effort across the organization—research, manufacturing, and sales and marketing—to ensure that health literacy is an embedded theme throughout the company.

From that perspective, patients must be treated as partners in efforts to help them gain the knowledge they need to take their medications properly. Better yet, everyone, not just those who have a health issue, need to be partners in the effort to expand health literacy to make it part of learning to live a healthy life. As a sponsor for global population health efforts, Gunther says she is interested in health creation, health promotion, and prevention; to achieve those, health literacy should start at home. Often, she said, health literacy starts with the women who are health providers for the family, and sometimes the community and schools as well.

She then asked the workshop participants to imagine a person who, along with 70 percent of the American population, is either overweight or obese, and who is among the close to 6 percent of the population that has diabetes and three or more other medical conditions, such as hypertension, high cholesterol, sleep apnea, joint issues, and depression. That person, she said, may be taking as many as 12 different medications, and it is nearly

impossible to achieve what used to be called “compliance” and has now been softened to “adherence.” “It is difficult for any individual to comprehend that and take all those medications as prescribed, assuming the prescription and diagnoses are accurate,” said Gunther.

Many opportunities exist for communicating with patients and maximizing their comprehension about a medication, Gunther said. These opportunities arise as early as the start of a clinical trial when patients are given consent to join the trial, as well as when the company creates materials about dosing that are provided to individuals enrolled in trials, conducts targeted messaging to underrepresented populations as a means of recruiting trial participants from those populations, and posts lay summaries of each trial on a public website.² One emerging area of contact occurs when the company solicits patient input into trial design and outcomes.

Opportunities for engagement continue after a product is approved. For example, when the company drafts the product label—the information that accompanies every medication when a patient picks it up from the pharmacy—it works with focus groups comprising individuals from the lay community who help refine the label’s language. The company also tests comprehension with panels of lay individuals, at least 25 percent of whom are on the lower end of the health literacy scale. “We consistently achieve about 90 percent comprehension across all levels of health literacy,” said Gunther, who described this approach as a new paradigm for designing patient inserts. She noted, too, that Merck has engaged in its own internal health literacy activities to make sure its 65,000 employees can understand the health-related benefits the company provides.

Antibiotic resistance is an important public threat that results, in part, from patients failing to understand the importance of adhering to the prescribed medication regimen. Gunther said that some patients believe they become resistant to the antibiotics, not that the bacteria do, because of inappropriate use of the drug. Patient comprehension, she said, plays a critical role in managing antimicrobial resistance and improving stewardship. Zika is another area in which the company recently engaged in a health literacy effort. In this case, Gunther and her colleagues worked with the Centers for Disease Control and Prevention Foundation to ensure that women of childbearing age in Puerto Rico had the necessary information to make an educated decision about the types of birth control they would choose to delay having a child during the Zika outbreak there.

Lastly, Gunther said:

From a global policy perspective, working with countries and policy makers around the world, we have made significant contributions to the

² The website is anticipated to be operational in Europe in early 2019.

research that's being done in Europe as well as in the United States, because we feel that health literacy is an incredibly important issue and one worth investing in.

ACHIEVING THE QUADRUPLE AIM: HEALTH LITERACY INTERVENTIONS AS AN ESSENTIAL COMPONENT³

In delivering health care, communication is a key ingredient, said Rosof, and achieving the Quadruple Aim of better care, improving the health of the community and population, affordable care, and patient and health care team satisfaction is not possible without a health literate population. As the delivery of health care continues to evolve in the United States, he said, health literacy can serve as an innovative and disruptive force that creates a new value equation for health care that includes the Quadruple Aim. “Let us think about health literacy that way, as a really disruptive technology to achieve our goal,” said Rosof, “one supported by science and patient experience and one designed to disrupt the old habits and existing ways of thinking that get in the way of making progress.”

The current design of today's health care system requires patients and families to possess and demonstrate multiple skills, including understanding and giving consent, interacting with health professionals, and applying health information to different situations in a variety of life events. In that context, health literacy is the degree to which individuals have the capacity to obtain, process, and understand the health information needed to make appropriate health decisions. Health literacy, said Rosof, can only occur when system demands and complexities align with individual skills and abilities.

Two Institute of Medicine reports—*To Err Is Human: Building a Safer Health System* (IOM, 2000) and *Crossing the Quality Chasm: A New Health System for the 21st Century* (IOM, 2001)—detailed why health literacy is important, said Rosof. He noted that the only population-level study of health literacy skills conducted to date, the U.S. Department of Education's National Assessment of Adult Literacy,⁴ found that only 12 percent of U.S. adults are health literate enough to understand and use health information effectively. “They may fail to understand critically important warnings on the label of over-the-counter medications or find it difficult to define a medical term, let alone negotiate the payer system and try to understand insurance,” said Rosof. In addition, some 24 million Americans, or nearly 9 percent of the U.S. population, are not proficient in English.

³ This section is based on the presentation by Bernard Rosof, professor of medicine, Zucker School of Medicine, Hofstra/Northwell, and chief executive officer, Quality HealthCare Advisory Group, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

⁴ See <https://nces.ed.gov/naal> (accessed December 25, 2017).

Regarding the priority areas for national action identified in *Crossing the Quality Chasm* to transform health care quality in the United States (see Figure 4-1), Rosof said quality is clearly a systems property. He noted that the priority areas did not focus on improving treatments through biomedical research or technological innovation, but instead focused on ways to improve the delivery of treatments and align system demands and priorities with individual skills and capabilities, the true definition of health literacy. He noted that the priority areas include acute care, preventive care, palliative care, and chronic care, all areas that should be familiar to the health literacy community, as well as cross-cutting systems interventions such as care coordination, self-management, and patient and family engagement that all require the presence of a health literate population.

The cycle of crisis that characterizes health care delivery today (see Figure 4-2) is all too familiar, said Rosof. One of the drivers of this cycle is health illiteracy, which leads to patients taking their medications incorrectly or not understanding the importance of follow-up appointments. In a

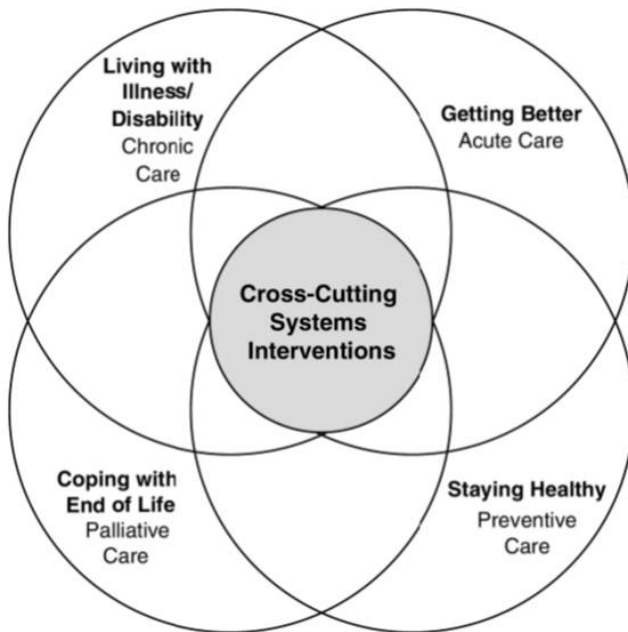


FIGURE 4-1 Priority areas for national action to transform health care quality in the United States.

SOURCE: As presented by Bernard Rosof at Building the Case for Health Literacy: A Workshop on November 15, 2017.

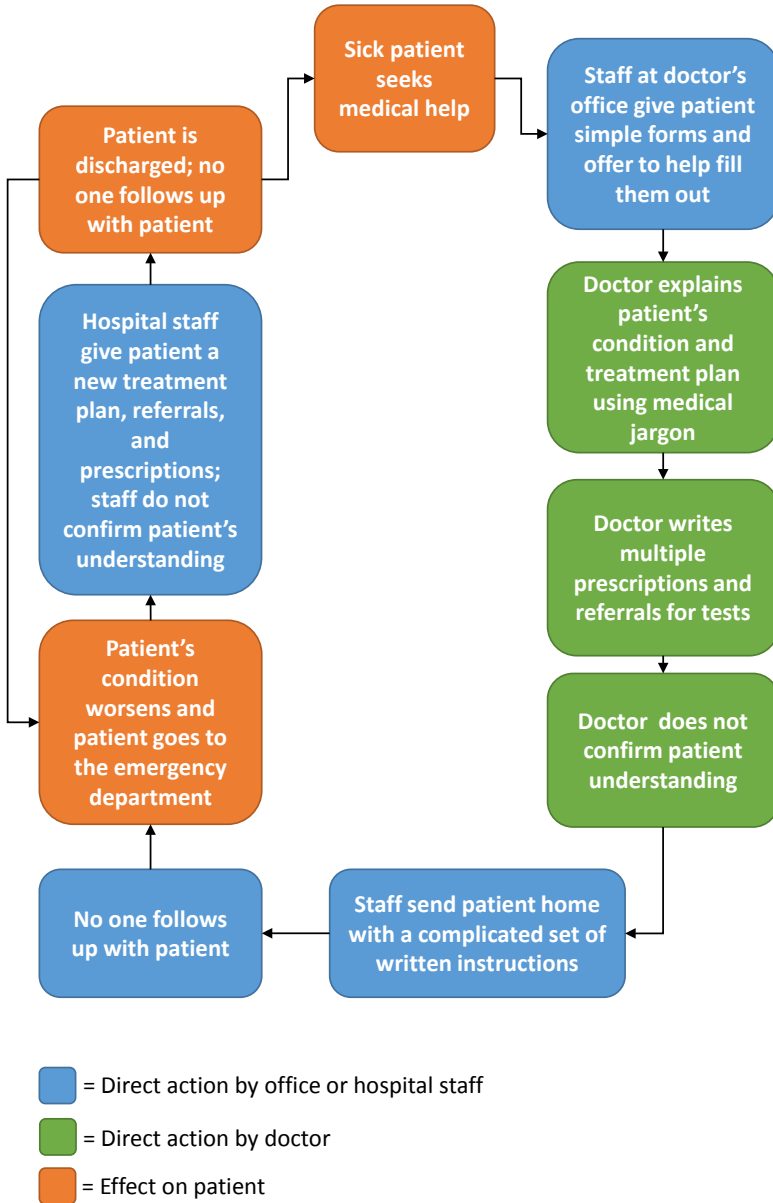


FIGURE 4-2 A patient's experience of the cycle of crisis care in the absence of health literacy.

SOURCE: Adapted from a presentation by Bernard Rosof at Building the Case for Health Literacy: A Workshop on November 15, 2017.

health literate patient experience (see Figure 4-3), the scheduler reminds the patient about coming back to the office, the physician and other members of the medical team explain things in a way that leads to comprehension, discharge information and medication instructions are easy to understand; and the result is a well-managed patient who does not need to return to the emergency department and is not readmitted to the hospital. Rosof noted that the way a team functions in the medical office is important in delivering health literate care.

Health literacy arrived at a tipping point, said Rosof, with the development of several new federal policies, including the ACA, the U.S. Department of Health and Human Services' (HHS's) National Action Plan to Improve Health Literacy, and the Plain Writing Act of 2010. It was then that health literacy was ready to move from the margins to the mainstream of health care, and become a national priority for the U.S. population to become health literate as a means of improving health care and health for all, Rosof said. The National Action Plan to Improve Health Literacy (ODPHP, 2010) is based on two principles: that everyone has the right to health information that helps them make informed decisions, and that health services should be delivered in ways that are understandable and lead to health, longevity, and good quality of life. The Plain Writing Act of 2010 requires federal agencies to write documents clearly so the public can understand and use them. "I'll leave that to your judgement as to whether that has actually occurred," said Rosof.

One component of the ACA is that it required the Secretary of HHS to establish a national quality strategy that would achieve what was then called the Triple Aim, before the provision to improve patient and health care team satisfaction was added. The National Quality Strategy is an iterative, transparent, consultative, and consensus-building process that continues to be updated on a regular basis. The six priorities of the National Quality Strategy include health and well-being; prevention and treatment of the leading causes of mortality; providing person- and family-centered care; improving patient safety; engaging in effective communication and care coordination; and making care affordable. "If I had known enough about health literacy when we wrote the National Quality Strategy, I would have changed effective communication to health literacy," said Rosof, who at the time chaired the committee that drafted the National Quality Strategy.

As far as who is at risk for low health literacy, Rosof said that men are at greater risk than women and that African Americans and Native Americans are at greater risk than whites and Asian Americans. Hispanics have the lowest skills among minority populations, and people 65 years and older have the lowest level of health literacy overall. As was discussed earlier in the workshop, patients with limited health literacy experience

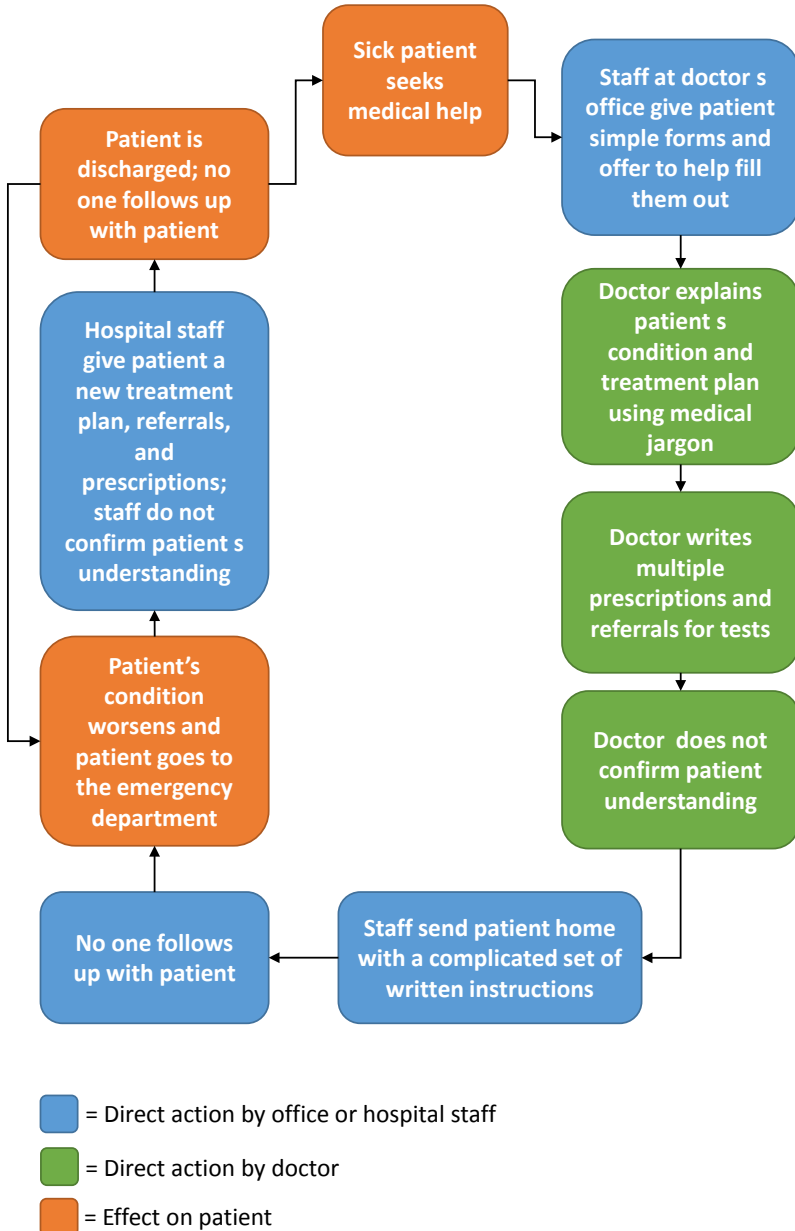


FIGURE 4-3 A patient's experience with health literate care.

SOURCE: As presented by Bernard Rosof at Building the Case for Health Literacy: A Workshop on November 15, 2017.

lower-quality communication, increased confusion regarding medical terminology, and insufficient time to express concerns. They fail to receive clear explanation and are less likely than others to use preventive services, all of which, Rosof explained, translates to poor outcomes. “When you begin to discuss social determinants of health associated with health literacy, you see that there are some areas of the United States where mortality and expectation for life may be 20 years less,” said Rosof.

A learning health system to better inform health literate practices and achieve the Quadruple Aim could improve this situation. A learning health system is one in which progress in science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience, and seamlessly refines and delivers best practices for continuous improvement in health and health care (IOM, 2007). “Building a learning health system around the concept of health literacy will enable an environment that has rapid-cycle learning and knowledge dissemination in which health literate research is continuously translated into practice and the care experience,” said Rosof. In simpler language, he explained, the health care system must take advantage of going digital and use the data available to compare outcomes, learn, and improve those outcomes. The key, he said, is to figure out how to do this routinely to create a learning health system. “Building a learning health system around the concept of health literacy will enable us to do this more efficiently,” he added.

Among the principles of health literacy that need to be articulated and emphasized is that of universal precautions (see Figure 4-4). Just as hand-washing has become a universal precaution in infection control based on the assumption that every person in a health care setting is carrying a potentially dangerous microorganism with them, so too should it be assumed that every patient may have limited health literacy. “Health literacy is a state, not a trait, and everyone benefits from clear communication,” said Rosof. He explained that if there is a prepared, proactive, health literate health care team and an informed, health literate, activated patient and family, the result is a productive interaction and improved outcome.

AHRQ has developed a universal precautions toolkit.⁵ The 20-tool toolkit, said Rosof, includes a quick start guide, a path to improvement, sample forms, PowerPoint presentations, and worksheets. It also includes tips for communicating clearly, lessons on the teach-back method, and the brown bag medication review, which encourages patients to bring all of their medications, including over-the-counter medications, to the doctor’s office. None of this happens, however, in the absence of putting the patient

⁵ See <https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html> (accessed December 25, 2017).

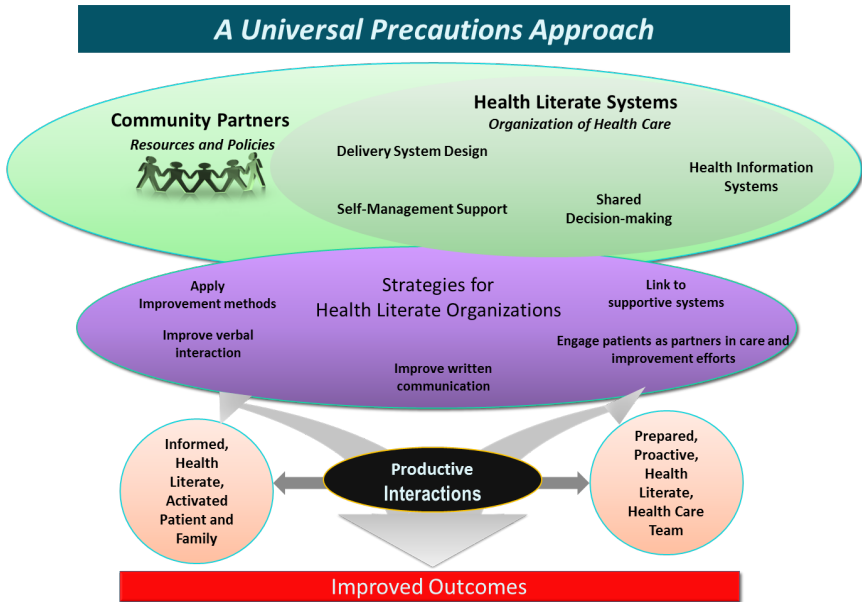


FIGURE 4-4 A universal precautions approach in a health literate care model.
SOURCE: As presented by Bernard Rosof at Building the Case for Health Literacy: A Workshop on November 15, 2017.

first and remembering that patient feedback is important to make the process work. The Joint Commission has weighed in, Rosof added, by stating the safety of patients cannot be assured without mitigating the negative effects of low health literacy and ineffective communication on patient care.

The 10 attributes of a health literate health care organization (Brach et al., 2012) are critical to creating a health literate health care organization, which makes it easier for people to navigate, understand, and use information to take care of their health, but it requires a charter for organizational professionalism (Egener et al., 2017) in order to develop, said Rosof. The charter for professional organizations includes four domains: patient partnership, organization of culture, community partnership, and operations and business practices. These domains, said Rosof, require communication in a health literate manner.

Rosof then noted 2 of the 10 attributes. Attribute 1 states that a health literate organization has leadership that makes health literacy integral to its mission, structure, and operations by not only making clear and effective communication a priority, but assigns responsibility for health literacy

oversight, sets goals for health literacy improvement, and allocates fiscal and human resources to that effort.

Attribute 2 characterizes a health literate organization as one that integrates health literacy into planning, evaluation measures, patient safety, and quality improvement. “Health literacy and communication have to be measured to be certain that it is happening in the organization,” said Rosof. “It has to be integral to your quality improvement program, to your performance improvement program, and to the efforts on patient safety.”

The commissioned paper presented at the workshop, said Rosof, included published outcomes, all of which demonstrate clear improvements in a health literate organization. These included

- A congestive heart failure self-management program, which reduced hospitalization rates and mortality by 35 percent (Berkman et al., 2011a);
- A diabetes self-management program using health literacy strategies in patients with limited literacy achieved success of 42 percent versus 15 percent without such strategies (Rothman et al., 2004);
- A randomized controlled trial of the “reengineered discharge” reduced rehospitalization by 30 percent (Jack et al., 2009);
- Plain language, pictogram-based medication counseling produced fewer medication errors (5.4 percent versus 47.8 percent) and greater adherence (38 percent versus 9.3 percent) (Yin et al., 2008); and
- Improving providers’ communication skills resulted in patients having higher colon cancer screening rates than a control group (55.7 percent versus 30 percent) (Ferreira et al., 2005).

Rosof noted that many members of the American Hospital Insurance Plan have undertaken explicit health literacy initiatives to improve patient outcomes. One such study, for example, estimated the effect of health literacy on selected health outcomes, controlling for education, income, race, and language, and found significant improvements in patient outcomes (see Table 4-1), all of which should translate into greater income for a health care institution. Rosof ended his presentation by drawing the following conclusions:

- Best care and improved population health requires adherence to health literate principles.
- Cross-cutting interventions to achieve the quality goals of the National Academy of Medicine and the National Quality Strategy require bilateral health literate communication and an alignment of system demands and complexities with individual skills and capabilities.

TABLE 4-1 Estimated Effect of Health Literacy on Selected Health Outcomes, Controlling for Education, Income, Race, and Language

Outcome	Population	Population Average (County Level)	Impact of Moving from Low- to High-Literacy Community
Avoidable ED visit rate	Commercial UHC	44.1 per 1,000	Reduction of 4.3 per 1,000 (-10.1%)
Avoidable hospitalization rate	Commercial UHC	5.4 per 1,000	Reduction of 1.0 per 1,000 (-18%)
Medication adherence rate	Commercial DM	81.4% adherent*	Increase of 2.4 percentage points in adherence (+3.1%)
Readmission rate	FFS Medicare	17.7%	Decrease of 1.2 percentage points (-7%)
ED visit rate	FFS Medicare	645.8 per 1,000	Reduction of 100.5 visits per 1,000 (-15%)

NOTES: * = adherence rate is lower than 81.4 percent in a general population; DM = diabetes medication; ED = emergency department; FFS = fee-for-service; UHC = UnitedHealthcare.

SOURCE: Adapted from a presentation by Bernard Rosof at Building the Case for Health Literacy: A Workshop on November 15, 2017.

- Efficiency in the delivery of health care, particularly in the treatment of chronic disease, requires health literate skills.
- Enhancing patient and health care team satisfaction and mutual trust, improving adherence, and diminishing burnout requires optimum communication skills.

DISCUSSION

Jay Duhig from AbbVie Inc. began the discussion by asking if it is possible to make the process of creating health literate materials open source, that is, could the process of creating those materials be transparent and available for others to use to create their own materials? He noted that his efforts, for example, benefitted from Laurie Myers at Merck sharing best practices with him. In his mind, a mechanism like ClinicalTrials.gov, where organizations would publish their materials, the goals of and processes for developing those materials, and any outcomes data associated with the use of the materials, would accelerate progress and address systemwide needs.

Gunther replied that she and her colleagues are starting to publish some of their results. “My preference is always to elevate all the boats in the ocean and share those because this is not a problem that just resides with the one drug’s manufacturer, but it is a systemic opportunity,” she said. She noted that the Food and Drug Administration has expressed interest in

Merck's work and believes it is a result of the agency recognizing the importance of health literate labeling. "Perhaps we can provide insights such that they will start to create some best practices that they would encourage all device manufacturers, as well as diagnostics and pharmaceutical companies, to abide by," said Gunther. In her mind, that would be just one example of the opportunities all stakeholders have to create a learning health care system. Rosof agreed that total transparency would drive performance improvement because there would be more shared data and more metrics to demonstrate what improvement looks like.

Linda Harris from the Office of Disease Prevention and Health Promotion at HHS noted that the commissioned paper and many of the comments at the workshop have assumed that health literacy will thrive in a value-based system of care, but given the current political climate, she wondered about the prospects of getting to such a system in the absence of federal leadership. Rosof said that he does not believe this transformation depends on a federal initiative, but rather on local initiatives. In his experience and from what he sees happening, he believes that most health systems are prepared to move from a fee-for-service environment to a value-based environment. He believes, in fact, that it is already embedded in daily activities and discussed at the level of health system boards, medical staff meetings, and even in medical schools.

Harris then asked if anyone has built a case for health literacy to be a driver of value-based organizations, rather than being dependent on the existence of a value-based care. Rosof replied that if the assumption is that consumer-based care needs to be health literate, then the evidence makes that argument clearly because health literate care produces better outcomes, reduces mortality, and saves money. "I do not see how we can ask for anything more," said Rosof. Christopher Dezii from Bristol-Myers Squibb, commenting on Rosof's remark that health literacy is essential for meeting the four aims, added that without health literacy, patient engagement will not happen, and neither will shared decision making or informed consent. After reading the commissioned paper and hearing the authors' presentation at the workshop, Dezii said he is convinced the case for health literacy has been built. He suggested that the patient engagement literature would be another place to look for research on the effectiveness of health literacy interventions and future research should take the form of quality improvement work as a means of generating the measures that matter. Rosof noted that a newly published book on health literacy by Robert Logan (Logan and Siegel, 2017) will help spread the word.

Katherine Atchison from the University of California, Los Angeles, remarked that effective communication among the entire health care team, not just the physicians and nurses, is imperative for achieving a health literate health care organization. Rosof agreed completely, noting that the

health care team is not restricted to the team that sits within the hospital or within the ambulatory care setting; it can also include community resources and social services. Wilma Alvarado-Little from the New York State Department of Health said she would include someone from the spiritual community and mental health community as part of the health care team when appropriate, as well as interpreters for those who are visually or physically challenged. Gunther added that there are other individuals on the payer side who are also part of the care team, including case navigators and case managers who work with insurance companies to help patients navigate their care. In her opinion, there are opportunities for working with employers to enhance wellness and health literacy. "I think there are many strange bedfellows we could tap to increase communication and education needed to improve health literacy," she said.

Sochan Laltoo, a public health instructor from Trinidad and Tobago, asked Gunther to comment on how health literacy plays into the growing acceptance of so-called natural remedies as replacements for pharmaceuticals when there is little or no evidence for the efficacy of those natural remedies. He also asked how increasing health literacy might reduce the inappropriate use of antibiotics. On the antibiotic issue, Gunther said the pharmaceutical industry is doing a great deal of work to (1) educate both the public and the medical profession, including dentists, veterinarians, and others, and (2) establish better guidelines on antimicrobial stewardship. Regarding natural remedies, Gunther said her company's responsibility is to invent medications that prove effective in the clinic and provide as much information as possible to regulators, so they can decide whether those medications are safe and effective. It then becomes her company's responsibility to provide balanced marketing information about that new drug. In her opinion, it is important for patients to take responsibility when they are given a prescription to ask what the medication is, why they are taking it, and if there are alternatives. "We have to appreciate, though, that not every human being is equipped to ask those questions in that moment, and that is where health literacy and improved communication skills from physicians comes in," said Gunther. "I think there are benefits to both of those types of holistic, herbal, and medicinal drugs, but the risks and benefits should be carefully weighed for each individual and it needs to fit their cultural predisposition as well."

Adopting Health Literacy in an Organization

The workshop's fourth panel featured three speakers and focused on how different organizations can adopt health literacy effectively. Audrey Riffenburgh, president of Health Literacy Connections, continued the discussion on the research base regarding adoption of health literacy. Chris Carlson, senior vice president for consumer and customer experience at UnitedHealthcare Shared Service Operations, then spoke about his organization's experience with developing and adopting a health literacy plan. Jennifer Dillaha, medical director for immunizations and medical advisor for health literacy and communication at the Arkansas Department of Health, described how her organization adopted health literacy as part of the department's strategic plan. An open discussion followed the three presentations.

WHAT RESEARCH SHOWS ABOUT ADOPTING AND IMPLEMENTING HEALTH LITERACY IN A HEALTH ORGANIZATION¹

To start her presentation, Riffenburgh noted that she would be sharing the findings of her dissertation research, which she completed in 2017. Her research focused on the early phases of adoption and implementation of health literacy initiatives. In particular, she looked for factors

¹ This section is based on the presentation by Audrey Riffenburgh, president, Health Literacy Connections, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

that advance or impede implementation of health literacy initiatives. Her research involved in-depth qualitative interviews with individuals in charge of advancing health literacy in health care organizations around the country. In some cases, these individuals were employed as full-time health literacy change leaders, while others spent half or less of their time on health literacy after somewhat grudgingly being given permission to do so. The organizations varied in size, how long they had been working on and had a person in charge of health literacy, and the populations they served. She cautioned that while her research identified some important themes, the findings are not generalizable to the entire U.S. health care system.

As with any study, Riffenburgh's first step was to review the literature. She reviewed three different areas of research: organizational theory, organizational change theory, and what she characterized as an interesting and rich field called dissemination and implementation. (This last field is the source of the often-repeated finding that it takes 17 years for 14 percent of medical research to lead to care that benefits patients.) Riffenburgh's study found many of the facilitators and barriers to implementation of new initiatives previously identified in the literature, such as the importance of leadership support; making the initiative a strategic priority; having executive sponsors, champions, and a task force; dedicating full-time employees, a budget, and an office; and having policies that support or mandate the initiative. "When these were present, they were facilitative, and when they were not present, it created all kinds of barriers," said Riffenburgh. "It all centered on leadership support. If the leadership support was not there, then the things that flowed out from the leadership support were not there, and progress was going to be tough."

In addition to the findings related to factors previously identified in the literature, there were findings and themes specifically related to health literacy initiatives. First, two distinct types of organizations emerged in the findings. In one type, advancing health literacy was so slow and difficult that one of the interviewees described it as "digging a tunnel with a tablespoon." In the other type of organization, advancing health literacy was much faster and easier. In contrast to "digging with a tablespoon," the second type of organization could be described as "creating a path with a backhoe." In a "tablespoon" organization, people lack tools and resources, and they labor away largely hidden from the view of the rest of the organization. In a "backhoe" organization, people have enough resources to metaphorically "buy a backhoe instead of going to the thrift store to buy a tablespoon," Riffenburgh explained. "They're out there making a path, and it's noisy, and everybody sees it. It's clearly important to the organization because they're blasting away, and things are happening." One interesting finding, she said, was that the participating organizations were split almost equally into the two types, with only one or two somewhere between these

two types. She noted, however, that Brach conducted a similar study and found more of a continuum between these two types (Brach, 2017).

Riffenburgh then presented a composite case study involving Carol, a fictional health literacy leader. Carol has a “backhoe” at her disposal because the leaders of her organization have made health literacy a priority: they named an executive sponsor and champion, created a taskforce, ensured she has access to senior leaders, developed supportive policies and mandates, allocated resources, and created a health literacy office with organization-wide reach. As a result, Carol has been able to make widespread progress in spreading and embedding health literacy through the organization. When Riffenburgh asked one of the interviewees in this type of organization what it was like being the change leader, the person replied, “I’ve loved it. It’s significantly easier if leadership is on board. Without that, change is not likely.” In Riffenburgh’s opinion, that was an understatement because change is definitely not likely.

Jamie, another fictional health literacy leader, works in a “tablespoon” organization, where she has little or no leadership support, no sponsor, no resources, no mandates, and little access to leaders at any level. Health literacy is not a priority at her organization, and she is only allowed to work on it part time. She has managed to find some allies in her organization, but they are working mostly under the radar on small projects. Despite having little in the way of resources or help, she and her team of volunteers keep “digging with their tablespoons.” When Riffenburgh asked one of the interviewees in this type of organization what it was like being the health literacy change leader, the person replied, “We feel like our hands are tied. We don’t have a voice or the attention of leadership.” The contrast between the frustration this person expressed and the joy of the person working in the “backhoe” organization was profound in Riffenburgh’s opinion.

A second theme the research identified was the significance of who was bringing health literacy into an organization and where in the organizational structure they worked. If awareness of health literacy came from a senior leader who had heard about health literacy at a conference or from a colleague, for example, that person was in a position to start moving things, Riffenburgh said. In contrast, health literacy initiatives that started from the bottom up had a much harder time gaining traction. In many cases, they not only did not have adequate access to organizational leaders, but they could not even get the leadership’s attention. “Without awareness and access, it was difficult to build support, but with both of those in place, it was much easier,” said Riffenburgh.

Riffenburgh’s research showed that the location of health literacy initiatives within an organization was a third theme that seemed to influence the level of success. Health literacy initiatives placed where they would have organization-wide reach and authority, such as part of quality improve-

ment, patient experience, population health, or care coordination, were more successful than initiatives situated in one area or service line, such as in nursing education, the medical library, patient education, or marketing. “If the initiatives were under the chief quality officer or chief experience officer, things were going to be much easier,” said Riffenburgh. She added that being placed in a silo, such as under the chief nursing officer, made it easy for people in other parts of the organization to ignore health literacy. It was often seen as irrelevant to their work unless it was led by a leader with authority over their area or department.

The fourth theme identified in the study was the health literacy change leader’s level of experience within their organization. The research suggested that longevity in the position was a factor for success, as was the health literacy leader’s passion and commitment to keep going despite setbacks. “I would hear stories of incredible frustration, yet they were persistent. That was remarkable,” said Riffenburgh. She noted, however, that there was a “vast gap” between the background and training these individuals had and the demands of their job. It was not surprising that almost none of the health literacy leaders she spoke with had training in health literacy. However, it was surprising how little training they had in areas such as making persuasive presentations to senior leadership, catalyzing organizational change, and creating easy-to-read text-based information for their organizations.

The fifth theme that emerged related to how health literacy change leaders made the case for health literacy to their organization’s leadership. The majority of participants were unsure how to begin making the case. They described somewhat randomly choosing a strategy and trying it out. The strategies they most commonly tried included linking health literacy to other initiatives, focusing on cost savings and return on investment, presenting statistics on health literacy, and relaying stories of patient experiences to engage both the hearts and heads of organizational leaders. Of note, only one interviewee mentioned using important legal, regulatory, and compliance issues to justify addressing health literacy to leaders.

Based on her findings, Riffenburgh offered two sets of recommendations: one for the health literacy field and perhaps funders, and the other for health literacy change leaders. For the field, her first recommendation was to develop and implement strategies to increase health system leaders’ awareness of health literacy, perhaps by targeting the conferences they attend or the publications they read. The challenge is to learn how to make the case to health system leaders so they take the lead in starting health literacy initiatives. Her second recommendation to the field was to identify the most effective locations in an organization to establish health literacy initiatives and then develop best practice guidelines for health care organizations on locating their initiatives. Her third recommendation was for the field to produce one or two current films with patient stories highlighting

their experiences in health care, because the films used now are quite old. For health literacy change leaders, she recommended building their skills for leading organizational change by learning their organization's change process. This might include talking to others who have had success at creating change both within and outside of the organization. She also recommended that they learn how to better make the case for health literacy, be persistent and patient, and, just as importantly, honor the struggle. Making organizational change takes time, she said, but it is the best struggle to be engaged in because it is so important.

A CASE STUDY: ADOPTING HEALTH LITERACY IN A HEALTH PLAN²

“Ultimately, getting any initiative adopted by an organization is about trust, and trust is a function of credibility, reliability, and intimacy,” said Carlson. “Do you believe the source? Is it credible? Consistent?” he asked. “When you have a conversation, when you interact, do you feel like they are actually engaging with you, or are they saying something they have been told to say or that is generic?” Earning and establishing trust unlocks the potential of technology to enable a more human experience. In short, said Carlson, trust begets engagement, and in the same way, health literacy equals engagement when it is done right. The unique thing about health care, he added, is that no matter what part of the health care system someone interacts with, the experience of health care is emotional, which makes establishing trust even more important.

Carlson noted that the technological aspects of how people interact with the health care system are getting more complex. Today, there is virtual care delivery and virtual service processes. Chatbots may be replying to questions online, but chatbots are not appropriate for all questions. When a man calls in and says in a flat tone that he just got out of the hospital and his wife just died and does not know what to do, responding to him with a chatbot is not the way to go. “We want somebody to listen to him, understand how unique his situation is, and then do whatever it takes to offer assistance,” said Carlson. Technology alone, he added, does not help when it comes to dealing with the complexity of health care. It can be a tremendous burden or tremendously enabling.

Turning to the value of a health literacy intervention from UnitedHealthcare's perspective, Carlson explained that his organization

² This section is based on the presentation by Chris Carlson, senior vice president for consumer and customer experience, UnitedHealthcare Shared Service Operations, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

insures some 14 percent of the U.S. population. If the cost to the nation resulting from poor health literacy is \$240 billion annually, UnitedHealthcare has the potential to save 14 percent of that total, or approximately \$34 billion per year, if it could eliminate the waste resulting from inadequate health literacy (see Figure 5-1). That is money, said Carlson, that the company could use more effectively to improve the health system. The company's internal research estimates that transforming a low health literacy community to a higher literacy level would affect medical costs, including an estimated 10 percent drop in emergency department visits and 18 percent decrease in hospitalizations.

As an example of the type of educational work his team does internally, he explained how UnitedHealthcare trains its pharmacy advisors who work with a Medicare population by putting them in real-life situations. "We give them big, thick cotton gloves and ask them to open a pill bottle, or we take glasses and scratch them, so you cannot really see through them and have them try to read the label on the pill bottle," said Carlson. "That is the reality of the individuals they will talk to on the phone." This type of approach puts people in the shoes of those they will be serving.

One of the first big transformations at UnitedHealthcare was its Advocate4Me initiative, which transformed how the company deliv-



FIGURE 5-1 Building the case for health literacy interventions.

SOURCE: As presented by Chris Carlson at Building the Case for Health Literacy: A Workshop on November 15, 2017.

ered health care services across roughly 30 million members in less than 18 months. The first steps in that initiative involved teaching everyone in the organization who answered the phone to listen. He and his team then built technology and analytic tools so that the person answering the phone listens actively and positively, thereby placing the conversation in context and engaging the caller. “If you do that, you can help keep people out of the emergency department and you may keep people out of the hospital,” said Carlson. Another component of that initiative improved adherence to treatment plans by offering clear directions in simple language both in direct conversation on the phone or in the service environment or via digital tools such as a mobile app or patient portal. These tools helped the company’s advocates talk to members using plain language, not the benefit structure language that exists in some health industry documents.

There are many things going on in a person’s world when calling in to a member advocate, logging onto the patient website, or using a mobile app (see Figure 5-2). Many individuals with chronic illness, for example, have comorbidities, depression, and other behavioral issues that affect their ability to comprehend information. In a health literate world, every individual gets to participate in the decision-making process and will feel empowered

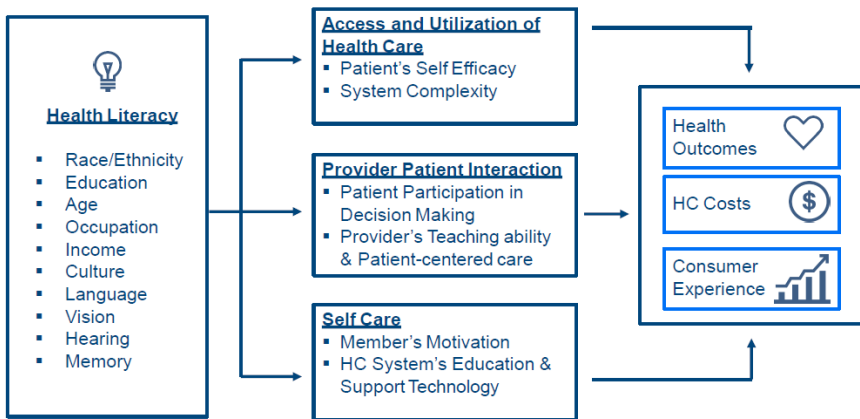


FIGURE 5-2 The inputs and outputs of health literacy at the moment of interacting with the health care system.

NOTE: HC = health care.

SOURCES: Adapted from Paasche-Orlow and Wolf (2007), as presented by Chris Carlson at Building the Case for Health Literacy: A Workshop on November 15, 2017. Reprinted with permission from PNG Publications, publisher of *American Journal of Health Behavior*. Adaptation provided to Chris Carlson via personal communication with K. Ellingworth, K. Froeber, D. Goldstein, S. Kibler, and S. Tai, Optum Health, 2017.

to do so. They will have access to their own medical information, and they will come into their appointments having done some research and being prepared with questions. “That future state, I believe, is going to be accelerated by our ability to incorporate literacy and engagement tools into every interaction we have,” said Carlson.

Ultimately, though, patient motivation is critical for successfully engaging with the health care system, because if a person is not motivated to care for himself or herself, health literacy is irrelevant. However, Carlson noted, “If someone has been frustrated by a system that they do not understand, that is going to affect their motivation. That is a literacy issue, not a motivation issue.” In fact, when individuals feel there are barriers and complications that they cannot understand, they become demotivated.

For Carlson, there are two ways to look at the function of health literacy and engagement (see Figure 5-3). One way is through the interaction points an individual has on the journey through the health care system. When patients are “prospecting,” for example, they may be looking at the options covered by various health plans to fit their current life situation. “Onboarding” is when a new member registers for a plan or states their preferences, and Carlson said there are too few tools available to help members use their plans better. The other way to look at health literacy and engagement is through the patient’s entire ecosystem at home.



FIGURE 5-3 The two components of the consumer’s journey in the health care system.

SOURCE: As presented by Chris Carlson at Building the Case for Health Literacy: A Workshop on November 15, 2017.

UnitedHealthcare's approach of advancing health literacy has been to work on simplicity, accessibility, and developing understandable and relevant content that is actionable. "Consumers do not want to engage unless there is an action," said Carlson. "Sometimes that action is to do nothing but stop worrying." One area of focus has been on readability and relevance, and Carlson's team developed a writer's guide of internal language that he called the Blue Book, which lists 10 big ideas for creating clearer documents. They also developed an English-Spanish-Portuguese glossary and the Just Plain Clear scorecard. Other areas of focus included ensuring clarity on actions, using appropriate tone and personalization, employing simplicity in messaging, changing burdensome processes, working to minimize member anxiety during conversations, and listening when conversations do occur. This initiative, said Carlson, created a foundational set of change actions that got people in the organization galvanized to embrace health literacy as a necessity for driving the organization forward.

Carlson then listed a set of purposeful actions the company had taken since 2012 to build health literacy best practices and standards into every touchpoint and program across all business lines and functional areas. These included establishing a top-down approach to communication directed by a chief consumer officer. This effort includes rewriting every one of the company's 3,700 templates, affecting more than 100 million touchpoints and eliminating those that were unnecessary. In 2017, for example, 690 templates were reworked and 44 were eliminated, producing a savings of \$217,000. Carlson's team created health literacy trainings that more than 200,000 UnitedHealthcare employees have taken, and the company established a center of excellence with professionally trained writers to support the company's functional team. The Just Plain Clear tools were made publicly accessible and more than 150,000 people have accessed them in just the past year. Usage of the Just Plain Clear glossary, which currently has more than 12,000 terms, has tripled every year since the company published it, said Carlson, and people from 68 countries accessed this tool within 2017. The company, he added, tracks the top subjects, clinical, and nonclinical words that users search.

Service agents have been trained in spoken word health literacy and changing the way they listen to and talk with consumers to provide positive, clear, personal, and compassionate messages. Introduction of financial literacy practices are helping consumers understand cost and benefit options, including proactive alerts and personalized videos, and the company now solicits communication preferences to help address personal situations, such as the need for documents in large print or in alternate languages. "We took very deliberate and actionable steps to incorporate change, not just in what we did, but what we sent our consumers and our members," said Carlson.

As an example, Carlson described what happened in 2012 when the DC Department of Health mandated that all health plans send every member who was a DC resident a letter about a preferred service to use when fulfilling HIV/AIDS-related prescriptions, regardless if there was an HIV diagnosis in the household. The letter had to (1) use wording provided by the federal regulators; (2) be on company letterhead; and (3) be signed by the chief executive officer or medical director. Of the more than 36,430 members who received the letter, about 15,300 telephoned the company's service center wanting to know why they got this letter. Nearly 40 percent of the people who called had never called the service center before, while 54 percent called at least twice, and nearly 30 percent called three or more times. As evidenced by the content of the calls and the repeated phone calls from people who had never called before, the wording in the letters made them nervous that they were infected with HIV. "That costs money," said Carlson. "Every time somebody calls us, it costs us \$15 and it takes time out of the caller's day." Because of this incident, UnitedHealthcare has now instituted a health literacy control point and includes a plain language explanation via a cover letter, as well as a Web link to more information, that can help reduce member anxiety and increase understanding. The company also started an effort to help state partners and regulators become aware of how difficult content can be to understand and how it can affect its members adversely.

Another case study Carlson presented involved a survey of the company's Medicare Part D and Medicare Advantage group members. This survey asked members how they felt about their understanding of the materials they received and their medications. Part D members who rated their understanding of their benefits from 0 to 4 called the service center three times more frequently than did those who rated their understanding between 9 and 10. That ratio was even higher among Medicare Advantage members. At \$15 per call, there was a clear incentive for the company to rewrite its plan materials to reduce complexity and increase understandability. Carlson placed the estimated cost savings at \$4 million or more annually for its Part D and Medicare Advantage populations.

In closing, Carlson said he wanted to underscore the importance of engagement and trust developed through a series of positive experiences that result from the simplicity, relevance, and actionable nature of the conversations between members and the company. Those conversations, he said, can be verbal, digital, and written. He referred to the people who received the HIV letter and noted how it was irrelevant to most of them, but sending it created relevance, which led to frustration, fear, confusion, and a struggle to understand; this produced anxiety and problems those individuals did not need. "At the end of the day, simple, clear, relevant, and focused conversations, digital or otherwise, is what it is all about,"

said Carlson. “Ultimately, engagement and trust are based on literacy and simplicity in the experiences we have with our consumers every day.”

A CASE STUDY: ADOPTING HEALTH LITERACY IN A PUBLIC HEALTH SYSTEM³

Arkansas, explained Dillaha, has a unified health department, which means the state agency she works for operates all 94 local health units in the state’s 75 counties. Almost 3 million people live in Arkansas, with 19 percent of the population living in poverty and 17 percent living with a disability. Only 14 percent of the state’s residents older than age 25 graduated college, and only 64 percent of the state’s households have a broadband Internet subscription, which is the second lowest in the nation. In addition, the state was 48 out of 50 states in the 2016 America’s Health ranking, and 37 percent of the state’s population—about 820,000 people—have low health literacy (see Figure 5-4). Dillaha noted that the counties with the lowest health literacy tend to have the lowest life expectancy in the state. She also explained that at least one-quarter of the population struggles with low health literacy even in counties with the highest level of health literacy.

Not long after Dillaha had read the 2004 Institute of Medicine report *Health Literacy: A Prescription to End Confusion* (IOM, 2004)—which was her “Aha!” experience—she was appointed director of the Arkansas Department of Health’s (ADH’s) Center for Health Advancement and became aware that people in Arkansas struggled with grasping the information made available to them and using it to make decisions about their health. She and a local pediatrician who had gone through the American Medical Association’s health literacy training gave a joint presentation to the weekly grand rounds at the health department on health literacy. “You would have thought we had set off a bomb,” said Dillaha. “It resonated, and the ripple effects have continued even to this day.”

Dillaha and her colleagues at the health department spent the next couple of years talking about health literacy to everyone they knew, and on July 24, 2009, the ADH, Arkansas Literacy Councils, University of Arkansas Cooperative Extension, and Arkansas Children’s Hospital held a joint meeting to which they invited everyone they could find who was working on health literacy. Out of that meeting came the Partnership for Health Literacy in Arkansas, which became the health literacy section of the

³ This section is based on the presentation by Jennifer Dillaha, medical director for immunizations and medical advisory for health literacy and communication, Arkansas Department of Health, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

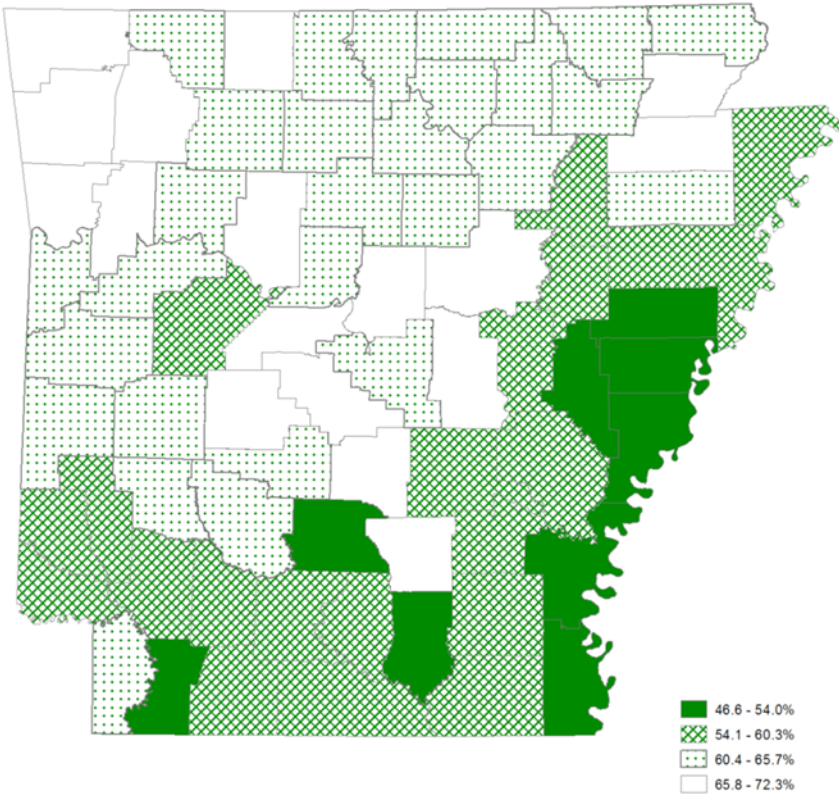


FIGURE 5-4 RAND health literacy estimates by Arkansas County.
 SOURCE: As presented by Jennifer Dillaha at Building the Case for Health Literacy: A Workshop on November 15, 2017.

Arkansas Public Health Association, a broad-based coalition of individuals, agencies, and organizations committed to improving health literacy among all Arkansans. The coalition has had its ups and downs over the years, said Dillaha, and it became somewhat dormant over the past few years, although it is now taking off again.

What the coalition discovered over time was that low health literacy is more than a literacy problem and that it cannot be solved with more health information. They also learned that individual patients are not the only ones with low health literacy—the health care system, including the public health system, has a health literacy problem, too. By 2011, when the ADH had developed a strategic plan there was a broad consensus within the agency to add strengthening and integrating health literacy strategies into

its overall plan for addressing high-burden health issues and strengthening and expanding the clinical services that it offered through its 94 local health units. Today, the health department's 2016–2019 strategic plan infuses health literacy into every one of its goals on childhood obesity, teen pregnancy, mental and community wellness, hypertension, immunizations, and tobacco use. Every objective related to each of these goals now includes a health literacy component, Dillaha explained.

"This was made possible because we had support from the highest levels at the health department to make health literacy an important part of what we do," said Dillaha, echoing what Riffenburgh and Carlson said about the importance of having support from the highest levels of an organization. In Arkansas's case, the director of the Office of Health Communications (who has since retired) was an early participant in the partnership and an avid supporter of the health literacy strategy. At the time of the initial strategic plan, that office provided the staff support needed to address health literacy in the agency, although there were no staff dedicated to this effort. "All of the health literacy goals and interventions have been added on to what people have already been trying to do," she said. "That adds to their workload, and sometimes we have competing priorities that caused health literacy and our capacity building to be put on the back burner."

To build capacity, Dillaha and her colleagues started a plain language learning community. All four of the department's centers, as well as the state laboratory and department administration, sent representatives, some of whom Dillaha refers to as the "voluntolds," because they were volunteered by others to participate. "It is one of those things in an agency or an organization where you have some people who have a vision and understand it and others who are not quite there yet, and they struggle with why it is important," she said. "That became the voluntold component." However, all of the voluntolds had their "Aha!" moments, came to understand why health literacy was important, and were able to take that perspective and what they learned back to their part of the organization and encourage others to have that perspective.

This was such an important experience that even after the project ended in the spring of 2012, this group met with agency leadership and came up with some plans to implement more plain language. "That was what we really needed to take steps to integrate this with all that we were doing in the health department and that we needed ongoing training opportunities," said Dillaha. The vision they developed was that people would rotate into the plain language learning community for 6 months, but making this happen proved challenging because of the struggle to get a funded position to oversee the learning community. However, reported Dillaha, the current director of the Office of Health Communication is supportive and now has funding to recruit and hire such a person.

The ADH did receive a grant from the Centers for Disease Control and Prevention's National Public Health Improvement Initiative to improve the communications that the department issues, including the state health assessment and health improvement plan the department published in 2013. This document, which identified Arkansas's big health problems and how the department planned to solve them, was written using plain language principles and has been extremely popular, according to Dillaha. She noted that Nathaniel Smith, the department director and state health officer, has called this the most important document the health department produced over the past 5 years because it represents a paradigm shift in terms of serving as a model for what the state needs to do going forward. She added that in the past producing documents in plain language was challenging because many of the contributors were epidemiologists who did not have plain language skills. "We relied on our partner, the University of Arkansas for Medical Sciences," she explained. "They have helped with training, but we would like to develop in-house capacity to provide that training to our staff."

The ADH has also received funding for several other projects, including one focused on maternal, infant, and early childhood home visiting that at its core is a health literacy intervention. Currently, the program serves 53 counties using one of five models implemented through the department's local health units and partners. The idea behind these programs, said Dillaha, is to provide individually tailored, evidence-based education and information as well as resources and support to expectant parents and families. In a 2001 report, The Pew Charitable Trusts found that well-designed and implemented home visiting programs show a \$5.70 return on investment for every taxpayer dollar that is used for these programs (PHVC, 2001).

One of the models, Baby Back Home, works on improving adherence to medical appointments and immunizations, facilitates coordination of health care, monitors a child's growth and development, identifies local resources to meet the needs of the family and infants, and promotes parent education. "Does that sound like a health literacy intervention to you?" asked Dillaha. "It does to me." For babies in this program who weighed less than 2,500 grams when they were born, the infant mortality rate has been 8 per 1,000 compared to the infant mortality rate of 52 per 1,000 for similar babies in the state who are not part of that program. In addition, for children from 0 to 18 months in this program, the immunization series completion rate is 94 percent, compared to approximately 50 percent for the state overall. Sisters United, a program developed by the ADH's Office of Minority Health and Health Disparities and supported by the Region VI Southwest Regional Health Equity Council, is another successful infant mortality reduction program. Sisters United trains members of African American sororities to go into the communities and use health literacy

principles to talk to African American women about taking folic acid before they are pregnant, getting flu shots when they are pregnant, breastfeeding, and following safe sleep practices as a means of reducing infant mortality.

Dillaha said she did not have time in the presentation to do justice to the many activities the ADH has undertaken through its local health units. For example, the local health units have learned to use the teach-back method in the state's HIV program, and the state's Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) program provides children's books so parents can read to their children about some of the health lessons they are learning through the WIC program.

Dillaha concluded her presentation with some lessons learned. One lesson is that in terms of organizational capacity, increased awareness of low health literacy is not sufficient to improve health literacy. Awareness must be accompanied by increased capacity for addressing low health literacy. Another lesson is that efforts to change health behaviors that do not address health literacy will be confounded. Dillaha said she recognizes the ADH is not likely to get many additional resources to conduct health literacy activities, so efforts to improve health literacy must be implemented by using current resources differently. Perhaps the biggest challenge she has faced has been acquiring funding for staff with time dedicated to working on increasing health literacy capacity throughout the health department.

DISCUSSION

To begin the discussion, Brach commented that given the importance of leadership and remembering that leadership can change, it is critical to institutional health literacy practices to establish a health literacy infrastructure even in a "backhoe" organization because subsequent leadership may be less supportive. She also noted that just as there can be physician burnout, health literacy champion burnout is a concern in "tunnel and teaspoon" organizations. To help prevent champion burnout, Brach suggested that the International Health Literacy Association should consider developing a mentoring program to support those individuals. Riffenburgh noted that three of the champions she interviewed have left their positions in the past year because of burnout.

Brach then asked Carlson if there is a case for UnitedHealthcare to invest in full-time staff to engage in health literacy activities to reap the potential billions of dollars that the company could save. Carlson replied by clarifying that the \$34 billion figure he cited represents potential value to members, which is different from savings. Having said that, he noted that Steven Rush, the director of the health literacy innovations program at the company, has full access to and is a consultant for his entire team, much of which focuses on simplicity, relevance, and engagement. He explained

that where he sits in the organization allows him to build and implement programs across the entire enterprise, whereas Rush sits in a policy-oriented part of the company. At UnitedHealthcare, it is his team's job to provide Rush with enough capacity to create, administer, and direct policy and then leverage his group to build systems that make that policy real for consumers and for people in the organization.

Smith commented that he has seen many initiatives start in his health system and eventually fade away because they are not solving a problem that keeps company executives awake at night. Making that case, he said, requires metrics that correlate with something that concerns those executives. In that context, he asked Riffenburgh if any of the organizations she interacted with spent much energy producing robust, reliable metrics that answer questions important to organizational leadership. "Very few," said Riffenburgh, even though there are multiple instruments that those organizations could be using. One issue for many "tunnel and teaspoon" organizations, she said, is that it is hard to know what the issues are that most concern leadership if there is no access to leadership. Carlson suggested focusing on loyalty measures, which are a concern for every health system today. His organization, for example, has spent the past 2 years focusing on net promoter score, a management tool that can be used to gauge the loyalty of a firm's customer relationships. In his opinion, measuring health literacy itself is missing the mark because that is not the direct issue that concerns most health system leaders.

Michael Villaire from the Institute for Healthcare Advancement asked Riffenburgh how the health literacy leaders in "tunnel and teaspoon" organizations evaluated themselves and their activities to even maintain the little support they received from their health systems. Riffenburgh said that she did not delve into that issue in the limited time she had with the people she interviewed. She did observe that in low-support organizations, the expectations of the champions were unclear. "When the people above you do not really know what health literacy is, and you do not have a way to tell them, it is hard to figure out how your progress should be measured, or even what you or they are doing, or if the people above you even know or care what you should be doing," she said. In those organizations, there was a great deal of "stabbing in the dark and just starting," she explained, with no strategic plan. Rather, it was grabbing the low-hanging fruit of finding a document that could be revised to be easier to read. In fact, she added, one of her findings was that in "tunnel and teaspoon" organizations, the health literacy champions did not even know if there was an organizational change model in place, making it difficult to know what would be possible to accomplish in those organizations.

Linda Harris from the Office of Disease Prevention and Health Promotion asked Carlson if UnitedHealthcare believes that the health literacy

work at the company, which includes the larger issue of improving customer experience, is something the company can use to increase market share and to promote and differentiate UnitedHealthcare from its competition. “Yes,” replied Carlson. “We feel strongly that our ability to engage will absolutely be a differentiator and create a distinctive relationship between our organization, our brand, and the members and the providers with whom we work. There is no doubt that we are spending time and resources to build foundational capabilities and a strategy around that specific focal point. It is our intention to differentiate on patient experience.”

Earnestine Willis from the Medical College of Wisconsin asked Riffenburgh if she had any insights into why placing health literacy in the nursing department resulted in it being siloed compared to putting it under quality improvement, which led to wider dissemination in an organization. Riffenburgh replied that those she interviewed said that it had to do with perception—when put under the director of nursing, the attitude at those organizations was that health literacy was only important to nurses, for example. In contrast, when placed in an area that everyone in the organization was supposed to pay attention to, such as quality improvement or patient experience, that sent a loud signal that health literacy was an organization-wide priority. That attitude might be different, she said, in a nurse-run organization, such as a magnet hospital. In fact, her professional experience before starting her doctoral program was that she worked in an organization dominated by nurses, and since her health literacy initiative was in a different area, the nurses were not interested, and she could not get any traction for her program.

Jennifer Pearce asked Carlson if UnitedHealthcare had plans to use health literacy interventions to bridge the divide between insurer and provider. Carlson replied that the plan is to extend their work outside of the company. “Our focus on experience and relationships inside the company is on its way outside with the consumer as well as with the provider,” he explained, saying:

We are starting to work with the provider systems across the country, globally actually, around experiential attributes, ease of information exchange between systems, elimination of processes that are required based on data we might already have, and simplifying everything we can do to automate and accelerate the access to care when it is required and certainly not create hassles and barriers based on complexity and challenges with literacy.

Helen Osborne from Health Literacy Consulting commented that the hospital she worked for 20 years ago did not even have a teaspoon, but more of a medicine dropper. In fact, the hospital president had no understanding or tolerance for any health literacy activities. The lesson she

learned was the importance of having an entrepreneurial spirit and seeking alternative paths to make a difference, often going outside an organization. Riffenburgh agreed that it is sometimes more effective to come from outside an organization because leaders often listen more carefully to outside voices. She then recounted that three of the people she interviewed from “tunnel and teaspoon” organizations said their organizational leaders had each called health literacy “fluff.” With leadership like that, it is not hard to see why people experience burnout, she added.

Ruth Parker from the Emory University School of Medicine commented that using health literacy to drive retention as an outcome makes good sense, and she asked Carlson how the company sees health literacy relating to consumer health activation and engagement, which could also be used to build the case for health literacy. Carlson said patient engagement is critically important to UnitedHealthcare and the organization uses a tool—the activation index—to measure it. In his view, if members do not understand, they will not adhere, and if they do not adhere, they will not engage and be activated. “Activation is a critical output and a function of interacting in a way that enables simplicity, relevance, action, and literacy,” he said. “I see a deliberate linkage between activation and literacy at the individual level.”

At the organizational level, he continued, the ability to engage and activate communities differently or provider delivery systems differently is critical to the overall health and well-being of the population, the family, and the individual. Many of his organization’s interventions are now focusing on activating the family unit as a means of providing more effective care for a family member. Carlson added that in his opinion, effective activation will strengthen and accelerate the case for democratizing the health care system, to which Parker added that democratization will not happen without health literacy.

Where Do We Go from Here?

The final panel session of the workshop featured a moderated discussion in which the panelists, each representing a different sector of the health care enterprise, responded to specific questions developed by the workshop planning committee and posed by moderator Laura Noonan, director of the Center for Advancing Pediatric Excellence at Levine Children's Hospital. The panelists were Christopher Trudeau, assistant professor in the University of Arkansas for Medical Sciences' Center for Health Literacy, representing the legal sector; Lori Hall, director of health literacy at Eli Lilly and Company (Lilly), providing a pharmaceutical industry perspective; Thomas Bauer, senior director of patient and family education at Johns Hopkins Health Centers, providing insights from the health care system perspective; Laurie Francis, executive director of Partnership Health Center, representing the federally qualified health center sector; and Lawrence Smith, dean of the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, providing insights from the education and training sector. An open discussion followed the moderated panel discussion.

MODERATED PANEL DISCUSSION¹

The first question Noonan posed to the panel was to ask them to think about how to increase the company leadership's awareness of health

¹ This section is based on the moderated discussion among Laura Noonan, director of the Center for Advancing Pediatric Excellence, Levine Children's Hospital; Christopher Trudeau, assistant professor, University of Arkansas for Medical Sciences' Center for Health Literacy;

literacy and its benefits. Smith said that if he was speaking with the chief executive officer of Northwell Health, he would say that chronic disease cannot be managed without health literacy. “We are now in the chronic disease management business full-time,” said Smith, who noted that at least half of his organization’s efforts focus on prevention. “You cannot do prevention without health literacy because nobody will come for preventive interventions. You will not have a patient base that thinks you treat them respectfully without health literacy and interventions to assure that. I think I could make a very strong business case on a moral, ethical, and medical quality basis.”

Bauer said he agreed with Smith, and that his argument has always been based on the quality and satisfaction aspects of the Quadruple Aim. “What has worked more effectively for me is one-on-one meetings with key leaders throughout the organization and finding those that also will support the message,” said Bauer. The purpose of those meetings, he explained, is to have advocates in the executive suite who engage in the critical conversations that take place throughout the organization and to which he is not a participant. From his experience in two organizations, he learned the importance of first making the case in small demonstrations, celebrating and sharing those victories, and then allowing them to grow organically. “When that happens, the word spreads through the organization and that organic growth becomes fire and fire then leads to the spread,” said Bauer.

From her perspective as the executive director of a federally qualified health center (FQHC), Laurie Francis said she feels certain that “health literacy will only find purchase if we build it into quality, cost, access, and equity. For those of us in health centers, it is absolutely about value and value-based care, not just cost.” In her opinion, the field needs to do more with metrics to better understand why a health literacy intervention will improve control of hypertension. One action her organization in Montana is doing is disaggregating populations to look just at those who are currently in control of their chronic disease and better understand that population using a social determinants screening tool. Francis also recommended an article on organizational transformation (Halfon et al., 2014) that her former health center in Oregon used to guide its efforts and to help her understand the language that would resonate with leadership.

Trudeau, referring to Smith’s comment about the importance of understanding the critical issues for executives, noted that compliance and risk

Lori Hall, director of health literacy, Eli Lilly and Company; Thomas Bauer, senior director of patient and family education, Johns Hopkins Health Centers; Laurie Francis, executive director, Partnership Health Center; and Lawrence Smith, dean, Donald and Barbara Zucker School of Medicine, Hofstra/Northwell, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

are major concerns among health system executives. Explanation of benefits, informed consent, and patient care plans all have a compliance aspect to them, and so from his perspective, tying health literacy to legal concerns could make a compelling case in the executive suite. He considers health literacy to be both sword and shield. The shield is the compelling evidence laid out in the commissioned paper showing that health literate communication must be the standard of care. “We are starting to get information on what type of interventions work and what interventions may not work so well. That is the shield. Those organizations that adopt those principles now are going over and above the standard of care. And those that do not, they are subject to the sword,” said Trudeau. In his opinion, combining return on investment and compliance makes a compelling argument to move any type of organization toward a patient-centered approach and having activated members.

Considering the question through a pharmaceutical industry lens, Hall said that while a pharmaceutical company is full of people who care deeply about patients, there is no one-size-fits-all message to deliver across an entire organization. She reminded the room full of health literacy ambassadors that they each had their moment when they realized how important health literacy is, and the challenge is to find the message that will make the light bulb go on for people with different roles and agendas in an organization as large and diverse as a pharmaceutical company. What appeals to a scientist in the organization will be different from what interests someone in the marketing department. “By customizing the message and breaking through the noise, we allow people to have the ‘Aha!’ moment first before they are ready to hear and listen to supporting data,” said Hall. She has had a great deal of success in taking this approach and acknowledged that it takes work to customize a message for each new group in the organization. In her mind, helping people in the organization feel they can become heroes in their own story is the best path forward. “You have to do your homework and have real insight into the one or two or three things that they are working on and your message should start with ‘I understand that you are focused on these three things in the next quarter. Here is how health literacy can help you get there.’”

In a follow-up question, Noonan asked the panelists how the health literacy community can get invited to speak at the meetings that executives, legal staff, or pharmaceutical company representatives attend, knowing that those people are not likely to attend a health literacy conference. Smith said that at his medical school, the definition of a good doctor is someone who creates a positive effect in the patients they treat. “Once you decide that that is what a great doctor is, then health literacy and communication skills and empathy and all those other things become tools for effectiveness, not nice things to do to a patient,” said Smith.

One thing Bauer did when he was first starting a health literacy effort in his organization was to send emails on a regular basis to key decision makers relaying the results of studies he would hear about at health literacy conferences. Eventually, those emails got through. “It was a powerful way to get that message to a group of individuals who are too busy to go to a conference on health literacy alone,” said Bauer. Francis suggested that titling meetings or conferences, “the role of health literacy in improving health equity,” would draw a wider audience, particularly from FQHCs, as would “the role of health literacy in containing costs.”

Trudeau said that he had to break down two sets of walls in the health care system and in the legal world. He noted that in 2016, he sent a proposal to the Michigan Bar Association’s health law section for a conference session on health literacy and why it matters to lawyers. Within hours, the conference organizer called him and said she had been practicing health law for 15 years and had never considered the relationship between health literacy and her field. Since then, he has written articles for the *Michigan Bar Journal* and similar publications. “We have to start targeting these new markets that we do not often think of because we have to make the people who do not hear our message or who are not predisposed to our message have that ‘Aha!’ moment, then they can start making the connections themselves rather than having us do it for them,” said Trudeau.

When asked if she was seeing health literacy sessions at pharmaceutical meetings, Hall said not as much as required, but health literacy is appearing as a topic at conferences on medication adherence and patient experience. She noted that in preparing for this workshop, she used her participation as an opportunity to get in front of the senior executives at Lilly and get their input. The answers, she said, were compelling. One leader acknowledged that they have so many competing priorities that they do not even know what they do not know, which in this case means they may not even know that the field of health literacy exists. Another executive told her that the field needs to make more noise and engage in more promotion with quick, repeatable messages that break through the existing noise using creativity, humor, and alternative media. A third executive, who is engaged with health literacy as a critical issue and is one of her supporters at the company, suggested that the field organize a health literacy forum for the pharmaceutical industry that would exist in the noncompetitive space to share ideas and data and stimulate research.

Noonan, commenting on advertising that tells people who have taken a particular drug to call a legal team pursuing a class-action claim, asked Trudeau if the day was coming when a commercial would tell people who received a particular piece of patient education material that they could not understand or act on to call a law office. “You raise an interesting point, and I think that is the next frontier,” said Trudeau. “Now that we know

what we know regarding health literacy and what patients understand and do not understand, that can guide our future development of the regulations.” He predicted, however, that this would take time because laws generally take time to change.

Before moving on to the second question, Noonan challenged the panelists to advocate for a session or workshop on health literacy at all of the professional conferences they attend. “Maybe that will also raise awareness,” she said. She then posed the second question to the panel: “What are the selling points or data that will move leadership in your specific industry to take action?”

Bauer says he goes about tackling this problem differently. When he is with a group of people from the health care industry, he asks them if they are the health care experts in their family, and almost universally, everyone raises their hand. Then he asks if anyone has taken a call from a friend or family member and started shaking their heads because what they are hearing is not true. Somebody in the group usually smiles at that point and he asks them to share a story. “The reason this is so powerful is that health literacy is about everyone,” said Bauer. “It is not about a group of individuals that you could label. It affects everyone.” These stories, he said, become powerful because they open the door to head and heart, and then it is possible to share statistics and talk about readmission rates, patient satisfaction, and reduced emergency department visit.

Francis responded with an admission. “I am still not a convert to health literacy as a stand-alone entity,” she said. “I always use the term patient-centered communication. Health literacy is a critical piece of that, but as a pull-out, it does not work for me.” For the population she serves through an FQHC, she is more concerned about literacy in general than health literacy and more concerned about how people can become owners of their own lives and not as much about keeping people with congestive heart failure out of the hospital. “I think about power and equity and access to the information that patients want to improve their lives, which does have a health literacy piece, but I want it to be the information they want, not the information we want them to have,” said Francis. For her, health literacy, patient-centered communication, motivational interviewing, and trauma-informed care together make a difference in creating vibrant organizations that serve people well, and that translates into improved quality and contained costs.

Trudeau noted that a survey conducted several years ago by ProAssurance Corp. found that 4 of the top 10 reasons for malpractice suits had to do with weak patient education or a breakdown in communication between provider and patient. In addition, one study found that the average 250-bed hospital spends between \$300,000 and \$1 million annually defending medical malpractice claims. “This is not for paying the claims. This is for paying the

lawyers,” said Trudeau. A rough back-of-the-envelope calculation suggests that U.S. hospitals spend between \$173 million and \$624 million annually on legal fees associated with poor communication. “We need more focus on this,” said Trudeau, suggesting it could be a powerful selling point to health system executives.

Hall, who describes health literacy as a problem hiding in plain sight, liked leveraging the idea that implementing health literacy practices would allow health systems to stretch their dollars further. For pharmaceutical industry executives, a message that would resonate with them would be that health literacy could improve clinical trial awareness, increase enrollment of diverse populations in clinical trials, reduce adverse events, and improve medication adherence. At a more basic level, Hall has found that she needs to be an excellent communicator with her colleagues and company leaders and make sure she pays attention to the details, such as how she writes and formats her emails to ensure the recipient can quickly scan, process, and act upon a given request. “Make it as easy as possible for them to say ‘Yes!’” she said. Often, creating an effective, repeatable message that connects health literacy to something important to the executive suite works well. “There is a lot of strategy and psychology around what is successful,” she said.

Bauer added that the executive suite is not homogenous, and chief medical and chief nursing officers are going to need a different message than the chief financial officer. “Understanding the pain points and addressing a message to those pain points is the key,” said Bauer. He recalled that early in his career, he was spreading the message to his organization’s physicians and felt that while the message was getting across, he was not engaging or activating them. Then he started talking to the providers and was able to identify their pain point, which was that despite all their work in the office, they were having to spend additional time answering emails and call backs from patients and families seeking clarification of what they had heard in the office. “When I started to address those things and how health literacy might be a solution to that pain point, things started to change,” said Bauer. He noted one study done at the Cleveland Clinic showing that the teach-back method reduces the clinical encounter by 2 minutes, in addition to preventing another call. After getting that type of information to physicians and having them experience their own successes, the message spread quickly.

Working in Queens, New York, where the residents speak more than 100 different languages and live largely in tight-knit communities, Smith explained that delivering culturally sensitive care can win an entire community, not just the patients coming in for care. From a business model, Northwell Health is now recognizing the power of becoming the preferred provider for the Korean community, the Sikh community, the Russian-

Jewish community, and the hundreds of others spread throughout Queens. “The payoff is tremendous, both in terms of loyalty and business,” said Smith.

Taking off from that comment, Noonan asked the panel if there is a business case for becoming the destination for medical care based on patient experience rather than on offering robotic surgery or other technology. Smith said absolutely, and his experience as a physician was that his practice increased during his 25 years as a primary care doctor because someone walked out of his office satisfied. “When I got the next-door neighbor and the uncles and aunts and cousins of the patient I saw that day, that is how my practice grew,” he said. Francis agreed as well, although she extended the idea to the entire health care team needing to be good at listening and communicating to their patients. This is particularly true at an FQHC, where the clients are often not heard in many aspects of their lives.

Noonan then posed the final question: “What do people who lead this work in your organizations need to do to advance adoption of this work if it is not already a highly reliable process in your organization or your industry?” Francis replied that building leadership support is critical, as is designing materials around both the internal customer and external customers, patients, and staff members. Also needed are metrics that reflect the incorporation of changes in health literacy at the care team level and with respect to quality of care.

Bauer joked that he is often asked how big his team is, and his answer is, “You are looking at it.” In fact, though, he has an army working for him, a group of people who do a little bit across the organization, such as patient education teams at each of his health care system’s hospitals and in each of its home health entities. He has people on the payer side and community physician side at Johns Hopkins Health System who devote a little of their time to this work because it has become their passion as a result of leadership support and understanding that it is a vital component of delivering good care. In fact, he said, leadership support has enabled him to create a small amount of capacity for many people to spread the word about health literacy, which is why he would reiterate what others have said about the importance of cultivating leadership support as a first step.

In addition, Bauer said he would build strong partnerships with the people who manage the organization’s EHR. Integrating health literacy work into the EHR so it is easy for patients and the health care team to access is essential to the work he is doing, said Bauer. Similarly, he would establish a partnership with the quality assurance teams to create opportunities to improve patient participation and satisfaction. He noted that in an environment where finances are tight, he does not expect to get more money or more people to drive his programs. “What becomes most incumbent upon me is to share that message with passion, patience, and persistence to

continue that focus so in a time when there are so many conflicting priorities, this remains one of them,” said Bauer.

Smith seconded the importance of building leadership support and recruiting an army. His favorite tactic for recruiting that army is to collect enough data to convince everyone there is a real problem. “Once everyone believes we have a problem that has to be fixed, all of a sudden people get activated,” said Smith. “It is very hard to ram a solution down someone’s throat when they think you are trying to solve a non-issue.” Given the pervasiveness of the problem, he said it should not be hard to find supporting data in any organization.

One takeaway Hall recognized in trying to activate the leaders in her company is that there is much to borrow from the principles of health literacy. This starts, she said, with understanding what leaders need, meeting them where they are, and customizing the message according to what is important to them, not what is important to her as the health literacy director. It goes a long way, she said, when leaders feel understood regarding the pressures they are under and the competing priorities they deal with every day.

From a legal perspective, Trudeau would emphasize some of the ways in which health literacy can advance the mission of risk compliance managers and the legal staff. For the legal staff, it is important to get the message across that health literacy and the law are not mutually exclusive. “I always talk about law and health literacy,” said Trudeau. “It is a win-win, not one or the other.” When Trudeau speaks to lawyers and risk compliance managers, he mentions the regulations that support patient understanding, including the caregiver acts that AARP has been advancing in some states. Delaware’s regulation, for example, requires notice and training to the caregiver in ways that they can understand, he explained. Another area he emphasizes is how health literacy relates to organizational strategic priorities and regulations about patient engagement, patient-centered care, and patient understanding. At academic medical centers, regulations on informed consent are a big issue with a tie-in to health literacy. The common rule, for example, focuses on patient understanding of informed consent, and Trudeau believes it provides a legal construct for arguing about the importance of health literacy.

All of those activities, said Trudeau, are just the first step. The second step is training legal staff members and risk compliance managers on how to weave health literacy principles into what they do. Picking up on Trudeau’s last comment about training, Noonan equated the current situation for health literacy to that which existed earlier when quality improvement was introduced to health care and tens of thousands of physicians had no idea what to do because they had not been trained. As the dean of a medical school, she asked the panelists to address the challenge of how she is going to train medical students and faculty in the principles of health literacy.

Smith said that he would start with medical students because they are “infinitely easier to train than faculty.” Medical education at his institution uses a problem-based learning curriculum, and communication skills and patient exposure are part of that curriculum from the first day of school. “This is a very different, radically student-centered curriculum,” said Smith. From day one, students engage in elaborate exercises involving complex cases for which the students learn both the biologic science that underpins the case and the social determinants of illness, health literacy issues, and compliance with medication challenges. “We throw other things into those cases, so they understand that effectiveness is never just knowing the [material]. It is also turning your knowledge of the [material] into effective action,” said Smith. What the medical school has learned is that segregating the nonbiologic aspects into separate exercises relegated them to the “touchy-feely stuff.” “But when we incorporate them into the solution to the patient’s problem, suddenly they became as important as understanding the biochemistry and physiology of the patient,” Smith said.

Smith acknowledged that while this approach works well with students, he does not think it would work at all with the attending staff. “I am not sure what would, except pointing out to them that when they are misunderstood with what they think are crystal clear patient conversations, bad things happen to the patient,” he said.

Trudeau recounted a story about an emergency department physician whose patient satisfaction levels were very low. At the time, he was experimenting with the idea of using Ask Me 3 as the framework to present information and teach-back to verify knowledge transfer. When Trudeau went back to talk to this physician a month later, the physician said his experience was humbling because he had just learned that his patients had never understood him completely. As a result, that physician began using those methods as his own quality assurance mechanism. Trudeau added that in that emergency department, patient satisfaction scores rose 40 percent and the staff became one of the most powerful proponents for his work. He noted that his current institution includes exposure to health literacy, social determinants of health, and health equity in the interprofessional training that all health professionals must take. Francis said that in her work at an FQHC, she disaggregates the population and does subpopulation management as a way of creating health equity and bringing health literacy principles into play.

Hall said that health literacy is still in its infancy in her organization, and her challenge is to continue building awareness and break through the noise. “People have to buy in to the problem before they are ready to think about solutions,” she said. One approach she has been doing is collecting myths and misconceptions about health literacy that exist in her company and is creating an on-demand eLearning experience around myth

busters. She is using this approach to address the misconception that health literacy applies only to the work of a few groups in the company, or that this is a “government-manufactured health crisis,” or something that only applies to certain vulnerable populations—not the rest of us. “I am hoping that this myth busters approach will challenge people’s assumptions about what this really is and who it applies to,” said Hall.

Noonan concluded the panel discussion with her reflections. Her first was wondering how to pay for educating the entire medical profession about how to use health literacy principles. Just training all of the nurses at her institution on teach-back and Ask Me 3 cost \$4 million. “How do we get somebody to write the check?” she asked. “How do we get somebody to say this is a line item just like the electric bill?” In her opinion, this is the cost of doing business well for patients. Her second comment concerned the concept of coproduction, which means involving the patient in the design process, whether it is of a letter, a bill, or a process. To her, that gets to the heart of a patient-centered approach.

DISCUSSION

Alicia Fernandez from the University of California, San Francisco, remarked that she works with language barriers and the law has been a wonderful sword and something of a shield, with most of the big advances resulting from lawsuits brought by patients. From her understanding, language barrier work is an affirmative case through the Civil Rights Act, but to her knowledge, there is no equivalent to Title VI for the right to understand, or at least attempt to understand, one’s physician. In her mind, this diminishes the sword, and she asked Trudeau if there have been discussions about creating an affirmative standard to move this field forward. Trudeau agreed that the sword is dull regarding health literacy and said data are needed to promote the case for an affirmative standard. There is the Plain Language Act of 2010, he noted, but it lacks teeth and is more of a guideline for agencies, not for hospitals. One avenue for sharpening the sword might be through Joint Commission standards.

Terry Davis from the Louisiana State University Health Sciences Center commented that, like Francis, she does not use the term “health literacy,” believing it to be jargon just like “health activation,” “health engagement,” and “patient engagement.” “I am not sure this is a term we want to ride on from now on,” she said. Francis said that all this discussion is about improved health outcomes, maybe safety and equity, and about patient-centered, team-based care, where there is a natural role for health literacy to meet patients around their priorities. Bernard Rosof from the Quality HealthCare Advisory Group and Donald and Barbara Zucker School of Medicine at Hofstra/Northwell pushed back on the idea that health literacy

and the like are jargon. “But team-based care, patient-centered care, family and patient engagement and health literacy have all focused on the patient at the center of our activity. If you lose that perspective that the patient is the center of our activities, then you have lost what we are trying to accomplish,” said Rosof. “I would not like to lose the phrase ‘health literacy’ in what we are talking about going forward. That seems to me to be a step backward.”

Sochan Laltoo, a public health instructor from Trinidad and Tobago, offered his opinion: health literacy is based more on solutions rather than on problems, and to him, he sees it as a proactive approach to try to prevent health crises from arising and that it should be applied at the population level as part of disease prevention. “We should not have to deal with patients,” he said. “We should be focusing on the population.” Trudeau agreed with this idea and said that if the nation were designing a health care system from the ground up from a policy perspective, health literacy would be a population-based approach. He commended Jennifer Dillaha and her colleagues in Arkansas for taking that approach and wondered if that approach would benefit everyone.

Jay Duhig from AbbVie Inc. asked the panel for ideas on how to integrate health literacy into mHealth, digital health, and other technological developments that are making rapid inroads into the health care system. “To me, it is frightening that we would import the same problems that we have now when we shift to tools that could potentially address them,” said Duhig. Bauer replied that he did a survey in 2016 with more than 1,000 health care professionals in his organization. “What we found when you start talking of integration of health literacy into the electronic world is that our staff did not know what educational materials were approved to use and what was not approved, how to find approved materials, and which documents are the right ones to use,” said Bauer. For example, a search of his organization’s EHR for diabetes turns up 236 documents. “Which is the right one to give to patients?” he asked.

One lesson Bauer learned was that it was harder to work in the EHR than it is to go to Google and pull information, which is not the ideal situation, and as a result, he has been working to make it easier to work in the EHR rather than going to Google for information. Today, when a health care professional activates a care plan, the EHR deploys a teaching plan with teaching points using health literate materials that support the patient. The next step will be to make it easier for patients to access that information themselves through the patient portal.

One concern going forward, he said, is the proliferation of health-related apps for smart phones. “Are they good? How vetted are they? How are they maintained?” he asked. His hope is to not end up where every patient has a different app with no single source of vetted information. As

a model for what he hopes will develop, Bauer noted the learning process that bariatric surgery patients go through before their surgery. There is a 6-month minimum educational period preceding surgery, and there are apps built to support the patient that allow them to report to and interact with their medical team.

Regarding mHealth, Trudeau is worried that the technologies being developed are following the same path as EHRs, which is that they are being developed with the goal of saving chief financial officers money and not for the benefit of patients. In his opinion, the developers of these technologies need awareness training and should be encouraged to design their technologies from the ground up rather than to be compatible with the leading EHR products. It may be necessary, he said, to incentivize that type of development through regulations or grants.

Stanton Hudson from the University of Missouri noted that the discussion has not included the patient as a member of the health care team, and he wondered if any of the panelists had success partnering with patients to strengthen the case for health literacy. Bauer replied that he had just had his second meeting with his patient and family advisory council dedicated to health literacy. “One thing they will tell you is to involve them at the beginning,” said Bauer. His plan going forward is to have this group review the strategic plan he developed to make sure the members’ perspective is included in the plan to ensure that efforts going forward are driven by a true partnership with the members of his health care organization.

Francis wondered if the field should start asking what the role of health literacy is in health care and helping individuals improve their health and well-being, listening to the answers, and then identifying natural insertion points for health literacy. She noted that she uses a technique known as empathic inquiry. The doctors and nurses found that once they started asking different questions that helped them better understand their patients’ lives and how they could help, they started getting completely different answers. Smith added that his institution has experienced what he calls sentinel events in which well-informed patients who understood their illnesses warned their health care teams that something bad was going on, and instead of being listened to, they were labeled as aggressive, disruptive patients. “If we are going to educate and empower our patients, we have a lot of work to do on the culture of the care team to have care teams actually listen to the patient,” said Smith.

Reflections on the Day

As is customary at a Roundtable on Health Literacy workshop, the final session was devoted to roundtable members' reflections on the day's presentations and discussions. Catina O'Leary from Health Literacy Media began the session by commenting that much of the discussion during the day focused on patients and the care team, with only a slight nod to communities and health literacy at the population level. The field needs to think bigger and stop doing the same things that it has been doing for the past 20 years, she said. In the same vein, she agreed with comments made by Partnership Federally Qualified Health Center's Laurie Francis about the terms the field uses. This struck her as highly relevant, given that health literacy now sits under a bigger tent with more stakeholders and requires different solutions and strategies that are more inclusive. She then referred to observations made by the Hofstra/Northwell Zucker School of Medicine's dean, Lawrence Smith, about changing the culture of the care team; O'Leary wondered how health care can create a culture that changes how it thinks about power and privilege and decision making. She also voiced the need to stop blaming the patient and for the health care system to adopt the attitude that health literacy is not its fault, but it is now the system's problem to solve from the perspective of the patient.

Kim Parson from Humana focused on improvements she heard that the health care profession needs to make time for, including eliminating silos within and between organizations, eliminating the check box mentality of an after-visit summary, making health records portable, developing health literacy metrics that measure health outcomes, and designing and co-creating policies, processes, and communications with its patients, caregivers, payers,

and policy makers. Parson said she heard the need for focusing on teaching wellness and how to engage with the health industry from an early age, to accept responsibility for mistakes and be held accountable for making things right, to encourage patients to take an advocate or caregiver to all physician visits to record instructions and ensure the patient gets all questions answered, and to rethink using the term “health literacy.” Also needed is more effort incorporating health literacy into the solutions for a patient’s problems, busting myths, and most importantly, finding time to listen.

Steven Rush from the UnitedHealth Group appreciated that the day’s discussions moved out of the patient–clinician environment to hear what pharmaceutical companies, health insurers, and others are talking about regarding health literacy. He agreed that there may need to be new terms to talk about health literacy with certain target audiences, and that it is important to ask how a health literate communication solution will address a specific problem. Rush also appreciated the idea that the National Committee for Quality Assurance is talking about creating communications in clear, understandable, everyday language.

One message that Christopher Dezii from Bristol-Myers Squibb heard was the need to recognize in building the case for health literacy that it inextricably links to many other concepts. For example, he works on disparity issues, which at their core contain a health literacy issue. Referring to the hurricanes that struck the United States and its territories in the Caribbean, he said it would be important and reasonable to declare the situation with health disparities a national disaster, given what those events revealed. That, he said, might mobilize action.

Michael Villaire from the Institute for Healthcare Advancement commended the authors of the commissioned paper for assembling the evidence supporting the case for health literacy and the ensuing discussions on how to develop convincing arguments using that evidence to sway the people who still think of health literacy as fluff, as a nice but not essential thing to do. He then challenged everyone attending the workshop who provided good examples of what they are doing in their organizations to “identify a peer organization and ask them to step up to the plate and do the very same thing so that we can start to spread this out,” said Villaire. “We need to get outside of this room, have action, and start to have a domino effect out there.” He voiced concern about the challenge of disseminating the good programs that the authors found in the grey literature, rather than in the peer-reviewed literature, and encouraged those who develop those programs to talk about them with their peers.

Lori Hall from Eli Lilly and Company said an important message she heard is that empathy cannot be outsourced, automated, digitized, or operationalized. Empathy, she said, emphasizes the power of human touch and a kind, caring approach to change everything for a patient, including the

trajectory to meaningful conversation and an engaged, empowered patient and family. She also encouraged the roundtable to include the patient voice in its work going forward.

Cindy Brach from AHRQ heard that there is no single case for health literacy, and that the argument depends on the audience. She was struck by the importance of creating arguments based on solving problems that are important to an organization's leadership and suggested enlarging that idea to issues that are important to an organization's priorities. "Is it patient safety? Is it patient engagement? Is it becoming a patient-centered medical home? Health literacy fits into all of those," said Brach. "Let the health literacy case be a chameleon." At the same time, buy-in from leadership does not always result in change because change ultimately results from the bottom up, from getting clinicians and other staff who have contact with patients to act. "We need to grab teachable moments as they occur, and we need to make health literacy work for the people who have to do the transformation work and make the case at that level, too," she added.

She noted that she heard two strategies for getting people to the "Aha!" moment. The first was to get staff to try some health literacy strategies and realize their patients have not been understanding them. "Just try that teach-back method with your last patient of the day or do a brown-bag medication review and see whether there are any medication errors going on," Brach suggested. The second strategy is to use patient narratives to win hearts and minds.

For Jay Duhig from AbbVie Inc., the message that stood out was on the opportunities to apply health literacy principles when communicating with caregivers. He also thanked the roundtable members for their willingness to expand the definition of health literacy and the many dimensions in which health literacy applies. He reiterated Brach's comment about the importance of using patient narratives when making the case for health literacy, and noted that he has brought in patients and caregivers to speak to audiences in his organization and has seen the effect their stories have on winning hearts and minds.

Earnestine Willis from the Medical College of Wisconsin also appreciated starting the day with the patient perspective and said those stories drove home the point that health literacy is a tool or tactic to bring the humanity back to the practice of medicine and to get providers to listen to and engage their patients. She commented on the use of paid community investigators and wondered if there should be paid community institutional review boards to ensure that research reflects the community voice. Her final comment was on the need for health care systems to be more nimble and organic in how they serve their customers and to remember that compliance does not equal success when it comes to consumers.

Wilma Alvarado-Little from the New York State Department of Health thanked the speakers on the first panel for their powerful stories and hoped they were not retraumatized by relaying their stories to the workshop. The important points she heard from those presentations were that communication breakdown was the most common cause of medical errors, that Martin Ratermann told his story not looking for sympathy but to be a partner in the roundtable's efforts, and Jennifer Pearce's comment that health literacy is about experience, not words. Regarding the commissioned paper, she thanked the authors for identifying gaps that she now sees as opportunities to continue to move the field forward and look at the case for health literacy from a strength-based perspective. She then commented on Hall's mention of motivational interviewing and trauma-informed care, noting that those are about meeting patients where they are and that they can apply equally to meeting the provider where she or he is when trying to make them effective partners. Alvarado-Little also spoke about the need to define leadership and remember that leaders are not always the people who have a particular title, and she wondered how to help those doing this work who see themselves as leaders or potential leaders in this field and in their organizations.

Jennifer Dillaha from the Arkansas Department of Health said the message that stood out the most for her in almost every presentation was the supreme importance of listening and treating people with respect. "If we do not find the time and a way to do that in whatever system we work in, then we cannot succeed," said Dillaha. She added that there must be ways for those working in this field to live that message, promote it, and implement it in their organizations.

One important point for Suzanne Bakken from Columbia University was that while technology can be a problem, it must be part of the solution, and it can be when using the principles of co-producing and co-designing with patients. She noted that the National Library of Medicine will be releasing a strategic plan that completely changes the definition of what a librarian is and has many initiatives related to the personal health library, which she predicted will have major health literacy implications. She also predicted that the OpenNotes movement will have great implications for health literacy and present new opportunities for the field to make health information more meaningful to patients.

Bakken then announced that the National Academies had opened a new website centered around the 2017 *Pathways to Health Equity* report,¹ which includes a discussion of the link between health equity and health literacy (NASEM, 2017). She also noted that the home for work on the science of

¹ For more information, see <https://www.resources.nationalacademies.org/infographics/healthequity/healthequity.html> (accessed February 1, 2018).

caregiving is at the National Institute of Nursing Research, which has a grant program focused explicitly on creating health literate resources for caregivers of individuals with Alzheimer's disease and other forms of dementia.

Francis said that she started seeing health literacy differently as the day progressed. She also wondered if someone could develop a smartphone app that would combine 23andMe and the Adverse Childhood Events score to look at how culture and epigenetics work together to create resilience from a health literacy standpoint. She also thought about health literacy as part of the health equity issue and suggested combining the health literacy and health equity efforts to work together on important drivers of health and well-being.

Stacey Rosen from the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell commented that the needle will never move as long as health literacy is bolted on rather than baked in. She noted how the novel curriculum that Smith developed for medical students at his institution has managed to bake health literacy into how students learn and has produced physicians who care about how they listen to and speak with patients. For her, that reinforces the idea that the definition of health literacy must evolve to include how medical personnel communicate both as consumers and providers of health. She reiterated Alvarado-Little's comment on the importance of meeting the health care workforce where it is and remembering that nobody likes to communicate badly with patients. Just as consumers need training to be more health literate, so too do members of the health care profession. "If we are educating patients to come in with a family member, to come in with a list of questions or a brown bag [with their medications], then we need to educate the health care workforce on how to deal with that educated consumer," she said.

Andrew Pleasant from Health Literacy Media noted the importance of including rigorous qualitative and quantitative evaluation with research. Both are needed, he said. "Numbers will get you in the door, but stories will win hearts and minds, and that is what we need to do for health literacy," said Pleasant. He also commented on the term "health literacy" as jargon and said that it will become dogma. "Health literacy is a social construct, which means it is a living idea that will and should evolve," he said. He reminded the workshop attendees that health literacy started in the clinical context and that it took a deficit approach and often blamed consumers. Most of health, however, exists outside of the clinic, and if the field remembers that, it broadens the case for health literacy into prevention instead of sick care. Sick care, he said, is not where most people live, and if health literacy becomes part of prevention, it can then be seen as a resource for life and not an end in and of itself.

Terry Davis from the Louisiana State University Health Sciences Center said she loved starting the workshop with presentations by patients, who

she said communicated earnestly on so many levels. She also said she did not care what the field calls health literacy and that what is important is to recognize that health care is changing, so much so that the roundtable has discussions today about things that did not exist when she joined 3 years ago.

Alicia Fernandez from the University of California, San Francisco, said that she calls health literacy “effective patient care,” and that is how she teaches medical students about communication issues. In that regard, she resents having to build a case for health literacy or health equity because why would anyone be in favor of ineffective patient care. What she found useful in the discussion, and that she will use going forward, was the idea of identifying pain points or other ways to communicate that did not completely adopt the assumptions of the people who run an effective health care system. One of her worries as a physician who works in a low-income setting at San Francisco General Hospital is thinking that good care sometimes requires more money and more resources, and she dislikes the premise that to discuss effective care, she has to say it will save money. “Sometimes it will, but often it will not and that is okay, too,” said Fernandez.

Bernard Rosof from the Quality Health Care Advisory Group and the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, offering the final comments, said that while health care has changed and will continue to change, the need for effective communication has not, and in fact, it has only increased. “We can call health literacy what we will, but the need for communication remains and skilled communication is important,” he said. He then told a story about when he and Smith started practicing medicine together during the first 20 years of their careers. At that time, primary care doctors went to the hospital, and hospitalists and emergency department physicians did not exist. Instead, physicians gathered in the hospital coffee shop where they could talk to one another about patient care, their concerns about health care delivery and how they were practicing medicine, and about how to communicate with patients. “The absence of the coffee shop obviously does not mean we still do not learn communication skills, but it was a place you could practice it,” said Rosof.

Referring to his presentation, Rosof said the National Quality Strategy and the Quadruple Aim are about improving care and improving the health of the population and the community, which means taking the underserved into consideration. In his opinion, it is not possible in the absence of effective communication to address the health disparities that affect underserved populations. He also believes that the goal of improving health care for the entire population is something that the young people who are going into health care today are taking on, and that is something of which he is proud. On that note, Rosof adjourned the workshop.

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Appendix A

Workshop Agenda

Building the Case for Health Literacy: A Workshop

November 15, 2017

Lecture Room, National Academy of Sciences Building
2101 Constitution Avenue, NW
Washington, DC 20418

- 8:15–8:30 Welcome and Introductions
Bernard Rosof, Roundtable Chair
- 8:30–9:30 Patient Perspective on the Need for Health Literacy
 8:30–8:50 *Marty Ratermann*
 8:50–9:10 *Jennifer Pearce, M.P.A.*
 9:10–9:30 *Julie Steffen*
- 9:30–10:00 Discussion
- 10:00–10:05 Introduction of Speakers
- 10:05–10:25 Presentation of Commissioned Paper
*Stanton Hudson, M.A., Center for Health Policy,
University of Missouri*
*R. V. Rikard, Ph.D., Senior Research Associate,
Department of Media and Information, Michigan
State University*

- 10:25–10:45 Discussion
- 10:45–11:00 BREAK
- 11:00–12:15 Panel: Why Health Literacy?
- 11:00–11:05 Introduction of Speakers
- 11:05–11:25 Why Health Literacy Is Important
Cathryn Gunther, Vice President, Global Population Health, Merck Sharp & Dohme Corp.
- 11:25–11:45 Achieving the Quadruple Aim: Health Literacy as an Essential Component
Bernard Rosof, M.D., MACP, CEO, Quality HealthCare Advisory Group
- 11:45–12:15 Discussion with Panel Speakers
- 12:15–1:00 LUNCH
- 1:00–2:45 Adopting Health Literacy in an Organization
- 1:00–1:05 Introduction of Speakers
- 1:05–1:25 Adoption and Early Implementation of Health Literacy in a Health System: What Research Shows
Audrey Riffenburgh, Ph.D., President, Health Literacy Connections
- 1:25–1:45 A Case Study: Adopting Health Literacy in a Health Plan
Chris Carlson, Senior Vice President Consumer & Customer Experience, UnitedHealthcare
- 1:45–2:05 A Case Study: Adopting Health Literacy in a Public Health System
Jennifer Dillaha, M.D., Medical Director for Immunizations, Medical Advisory for Health Literacy and Communication, Arkansas Department of Health
- 2:05–2:45 Discussion with Panel Speakers
- 2:45–3:00 BREAK

- 3:00–3:05 Introduction of Speakers
- 3:05–4:00 Moderated Discussion: Where Do We Go from Here?
 Moderator:
Laura Noonan, M.D., Director of the Center for Advancing Pediatric Excellence (CAPE) at Levine Children’s Hospital
- Panelists:
- Legal
Christopher Trudeau, J.D., University of Arkansas for Medical Sciences and University of Arkansas William H. Bowen School of Law
- Pharmaceutical
Lori Hall, Director of Health Literacy, Eli Lilly and Company
- Health Care System
Thomas K. Bauer, M.B.A., RT, Senior Director of Patient and Family Education, Johns Hopkins Health Centers
- Federally Qualified Health Center
Laurie H. Francis, M.P.H., RN, Executive Director, Partnership Health Center
- Education/Training
Lawrence G. Smith, M.D., MACP, Dean, Donald and Barbara Zucker School of Medicine at Hofstra/Northwell
- 4:00–4:30 Discussion
- 4:30–5:00 Reflections on the Day
- 5:00 ADJOURN

Appendix B

Biographical Sketches of Workshop Moderators, Speakers, and Panelists

Thomas K. Bauer is the Senior Director of Patient and Family Education at the Johns Hopkins Health System. Mr. Bauer has led the research development and implementation of health literacy initiatives in two health systems encompassing more than 40,000 health professionals in both the academic and community health setting. Throughout his career, his primary focus has been equipping patients with the knowledge necessary to become active partners in their own care.

Mr. Bauer's work has been recognized by the National Academies of Sciences, Engineering, and Medicine for the successful deployment of health literacy tactics addressing the 10 attributes of a health literate organization. He has also been featured in two published case studies by the Agency for Healthcare Research and Quality. Mr. Bauer is the Moderator Emeritus of the World Health Organization course Population Health Community on Global Health Delivery–Online.

Chris Carlson is the Senior Vice President, Consumer & Customer Experience at UnitedHealthcare Shared Service Operations. Mr. Carlson's primary responsibilities include developing and deploying strategic initiatives that enable the consumer strategy and an improved experience for members. These initiatives include consumer services and consumer communications improvements, measurement and reporting tools that support consumer vision, and collaboration across UnitedHealth Group.

Jennifer Dillaha, M.D., is the Medical Advisor for Health Literacy at the Arkansas Department of Health (ADH). Under her leadership, low health

literacy has been recognized as an important public health problem in Arkansas, and the ADH has integrated health literacy into its strategic plan. Until recently, Dr. Dillaha served as the Chair of the Partnership for Health Literacy in Arkansas, which is the Health Literacy Section of the Arkansas Public Health Association.

Dr. Dillaha has been with the ADH since 2001, where she has played a variety of additional leadership roles. In November 2013, Dr. Dillaha became the Medical Director for Immunizations. Her charge in that role is to improve Arkansas's immunization rates, particularly among adults. She is uniquely prepared for that role as a physician with specialty training in internal medicine and subspecialty training in infectious diseases and in geriatric medicine. She has faculty appointments as an assistant professor in the University of Arkansas for Medical Sciences. She is currently serving as the Chair of the Arkansas Cervical Cancer Task Force and Chair of the Arkansas Immunization Action Coalition's Board of Directors.

Laurie Francis, M.P.H., RN, has been working in health care for the past 20 years, constantly learning ways to reach deeper (or broader) to improve health and well-being in individuals and communities. After working in critical care and beginning a number of prevention-type programs, she founded a community health center (medical, dental, behavioral health, education) more than 17 years ago. Related to this work and more recent exposures, she has given numerous talks concerning patient-centeredness, staff engagement, organizational alignment, health literacy, and measurement systems that drive improvement. Her publications are in the areas of health literacy, outcomes, and self-efficacy.

During the summer of 2017, Ms. Francis returned to health center leadership after 6 years at Oregon's Primary Care Association as Senior Director of Innovations. There she led an incredible team of talented individuals while advancing the understanding and implementation of advanced and emergent models of care, services, and partnerships to move upstream in order to dramatically improve population health and well-being. Now, Ms. Francis resides in Missoula, Montana, and serves as Executive Director of Partnership Health Center and continues to experiment with programs that attend to drivers of health while focusing significantly on staff engagement and joy at work. She serves on a number of boards as well as the National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy. Her educational background includes a bachelor's in human biology from Stanford, a bachelor's in nursing, and an M.P.H. from the University of Washington.

Cathryn Gunther started her career with Merck in sales, health sciences, and management in support of the commercial business. She was recruited

into the AstraMerck joint venture to design and launch the marketing and sales organization. She co-led the steering committee and project teams that reengineered traditional methods of marketing prescription drugs resulting in rapid revenue growth from \$600 million to more than \$5 billion in 6 years.

In 1999, she founded and served as Managing Director of Graham Group Consulting, providing executive consulting services to a diverse set of health care clients, including Fortune 50 payers, life sciences, and consumer products companies, as well as provider systems and policy organizations in the United States and globally. She served as Senior Vice President of Market Development for a start-up mobile health care technology firm developing end-to-end solutions designed to improve patient adherence to chronic care management plans.

Ms. Gunther rejoined Merck in 2012 after working as an executive health care strategist, innovator, and collaborator. She developed a new U.S. market commercial strategy for Merck's pharmaceutical business, helped shape the corporate strategy, and led the execution of a transformational business-to-business strategic engagement model with Merck's top costumers. Ms. Gunther is recognized for respectfully challenging the status quo, championing an externally informed perspective, and advancing the organization's competencies to increase sustainable shared value and business performance. As a health care consumer advocate, she led a cross-functional team to design, develop, and pilot technology solutions to improve medication adherence—a problem that costs the United States \$290 billion annually. She developed a U.S. Center of Excellence and a global Community of Excellence in adherence.

Most recently, Ms. Gunther was appointed to launch Merck's Global Population Health platform to establish the corporate framework and leadership for innovative population health approaches that create sustained social and business value. Areas of focus include antimicrobial stewardship, prevention through immunization, women's health, noncommunicable diseases, and Merck's own employee health and well-being.

She serves on the Board of the National Business Group on Health and its Institute on Health, Productivity, and Human Capital. She also serves on the Board of Directors at Grand View Health Foundation and is a member of the Global Chief Medical Officer's Network. Ms. Gunther earned a B.S. in biology, minor in chemistry, from the University of Connecticut.

Lori K. Hall, B.S.N., is the Director of Health Literacy at Eli Lilly and Company. Ms. Hall brings to this role more than 30 years of health care experience in the clinical setting as well as in the diagnostics and pharmaceutical industries. Throughout her career, her focus has been in the areas of patient education, adult learning, effective communication, project management, training, and leadership development.

Ms. Hall serves as the source of health literacy expertise at Lilly to support the creation of industry-leading patient experiences throughout the drug development and commercialization continuum. Her scope of work and responsibility are centered on providing visibility and guidance as well as helping to set organizational expectations and accountability for all aspects of communications with patients as it plays a direct role in supporting Lilly's corporate priorities around medication adherence, patient safety, clinical innovation, launch preparedness, real-world evidence, corporate responsibility, value-based contracting, and informed patient engagement.

Stanton Hudson, M.A., is the Associate Director of the Center for Health Policy at the University of Missouri. Mr. Hudson is a health literacy expert and health policy analyst with 20 years of experience in health services research and 13 years of experience in health literacy with a focus on curriculum development. He earned an M.A. in sociology from the University of Missouri and a B.A. in history, political science, and sociology from Columbia College. Over the past decade he has led the development and implementation of health literacy education programs and curricula for consumers, health professionals, public health agents, consumer advocates, and health educators. In 2014, he became a National Conference for Community and Justice of Metropolitan St. Louis-Certified Diversity Facilitator and has been developing and implementing innovative inclusion and diversity workshops for education, health, public health professionals, and students that bridge cultural competency and health literacy.

Laura K. Noonan, M.D., joined the Department of Pediatrics at Carolinas Medical Center (CMC) in 1994. She is a founding organizer and current Director of the Center for Advancing Pediatric Excellence (CAPE) at Levine Children's Hospital at CMC. CAPE was established in 2007 to implement a Quality Improvement (QI) curriculum for pediatric residents and provide QI project and data management for the department. CAPE's innovative curriculum has been recognized at the national level with peer-reviewed publications, national presentations, and it won the 2015 Children's Hospital Association Pediatric Quality Award in the Delivery System Transformation category. For more than 20 years her focus has been on health care QI, teaching courses at the local, regional, and national levels. She is currently involved in QI teaching or coaching roles for a variety of state and national collaboratives. In addition to being a QI consultant for PARTNERS Patient Powered Research Network, she is a QI consultant and Parent Advisor for Pediatric Rheumatology Care and Outcomes Improvement Network.

Dr. Noonan also has extensive experience teaching and advising about health literacy. She was the Collaborative Director for Carolinas Health-Care System's QI-based health literacy initiative for 24 facilities across

the second largest nonprofit health care system in the United States. She is currently co-chair of the system's Health Literacy Governance Council, and has been an advisor for subsequent phases of the original initiative. She frequently lectures on this topic locally and nationally, including at the National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy; the Institute for Healthcare Improvement's National Forum; the American Academy of Pediatrics' National Convention; and Boston University's Health Literacy Annual Research Conference. From 2015 to 2016, she was included in an Agency for Healthcare Research and Quality grant as part of a Technical Expert Panel for Organizational Health Literacy. She continually works on a national level to integrate health literacy into broader health care discussions; for example, through her recent participation in a roundtable hosted by the Secretary of Health and Human Services and a think tank sponsored by RTI International.

Jennifer Pearce, M.P.A., is the founder of Plain Language Health, a consultancy specializing in coproducing content and care experiences that patients can easily understand and act on.

A passionate advocate for patient engagement through understanding, she brings 18 years of experience collaborating with researchers, providers, and patients to advance health literacy. Ms. Pearce pioneered and led Sutter Health's award-winning health literacy initiatives, in addition to directing patient experience research within the 24-hospital system's digital health department. Prior to joining Sutter, she led national patient engagement efforts for five National Institutes of Health-funded genetic studies of autoimmune disease at the University of California, San Francisco. Ms. Pearce's work earned ClearMark Awards of Distinction in 2012 and 2013 from the Center for Plain Language in Washington, DC. Today she serves on the center's board of directors and consults on health literacy initiatives for clients in the public, private, nonprofit, and academic and government sectors.

Martin Ratermann is a craftsman from central Missouri with roots in St. Louis. He started in the carpentry trade in 1973 and started Ratermann Woodworking in 1981. Mr. Ratermann has done residential cabinetry, high-end architectural woodwork, and numerous liturgical commissions. He has also built fine handcrafted furniture.

He represented Missouri in Phyllis George's 1994 book: *Celebrating the Creative Work of the Hand*. In 2009, his furniture was selected as one of the top 100 sustainable products in the United States by Ogden Press and *Natural Home* magazine. His work is in private homes and public spaces in 22 states throughout the country. Mr. Ratermann is a survivor of cancer that was the result of medical errors. He speaks publicly to medical schools, health care providers, and advocates for patient safety.

Audrey Riffenburgh, Ph.D., has more than 20 years of experience in health literacy work. She holds a Ph.D. in health communication. Her dissertation topic was the implementation of health literacy initiatives in health care organizations. Dr. Riffenburgh is the President of Health Literacy Connections (formerly Plain Language Works). The firm specializes in helping health care systems and providers, public health departments, academic researchers, tribal communities, and others effectively communicate health information to patients, families, and the public. Its services also include helping organizations align health literacy strategies to support their major organizational goals. For several years, Dr. Riffenburgh was the Senior Health Literacy Specialist for an academic health system, where she led efforts to improve communication and access for patients and families and to become a more “health literate organization.” She managed organizational change efforts and consulted with leaders at all levels on using health literacy strategies to strengthen outcomes and meet organizational goals. She was on the faculty of the Health Literacy Summer Institute (nationally recognized as the premier learning opportunity in health literacy and plain language) for more than a decade. Dr. Riffenburgh is a founding member of the Clear Language Group, a national consortium of health literacy, plain language, and intercultural communications specialists established in 2000. She is co-author of *Building Health Literate Organizations: A Guidebook to Achieving Organizational Change* (2014). Dr. Riffenburgh’s recent contributions to the field include serving on the Technical Expert Panel for the Patient-Centered Outcomes Research Translation Center, 2016–2018; the Health Literacy Job Task Analysis Task Force, 2016; and the Technical Expert Panel for the research project “Making Patient Navigation and Understanding Easier: Developing Quality Improvement Measures,” 2015–2016.

R. V. Rikard, Ph.D., is a Senior Research Associate in the Department of Media and Information at Michigan State University. Dr. Rikard’s research focuses on how the social determinates of health affect health literacy, the intersection of health literacy and health disparities, and the social effect of information and technology on health.

Dr. Rikard is a founding member of the International Health Literacy Association, a member of the International Union for Health Promotion and Education Global Working Group on Health Literacy, and the Health Equity Initiative. Dr. Rikard is also an Honorary Fellow in the School of Health and Social Development at Deakin University in Victoria, Australia.

Bernard M. Rosof, M.D., MACP (*Roundtable Chair*), is at the forefront of national initiatives in the areas of quality and performance improvement. Following completion of a fellowship in gastroenterology at the Yale

University School of Medicine, Dr. Rosof practiced internal medicine and gastroenterology for 29 years. He is a Past Chair of the Board of Directors of Huntington Hospital (Northwell Health) and is a current member of the Board of Overseers of the Health System. He is a past member of the Board of Directors of the National Quality Forum (NQF), and the Co-Chair of the National Quality Partnership (NQP) convened by the NQF to set national priorities and goals to transform America's health care. The NQP was advisory to U.S. Department of Health and Human Services former-Secretary Sebelius in the development of the National Quality Strategy.

Dr. Rosof is a Past Chair of the Physician Consortium for Performance Improvement convened by the American Medical Association that continues to lead efforts in developing, testing, and implementing evidence-based performance measures for use at the point of care. He was a member of the Clinical Performance Measurement Committee of the National Committee for Quality Assurance and the Chair of the Physician Advisory Committee for UnitedHealth Group. He has chaired committees for the New York State Department of Health and the Institute of Medicine, and is currently the chair of the Roundtable on Health Literacy of the National Academies of Sciences, Engineering, and Medicine, and Chair of the New York State Department of Health Committee on Quality in Office-Based Surgery. Dr. Rosof is CEO of the Quality in HealthCare Advisory Group, which provides strategic consultative services to the community of health care providers interested in improving the quality and safety of health care delivery in the United States. Dr. Rosof is a professor of medicine at the Zucker School of Medicine at Hofstra/Northwell in New York. He is a Master of the American College of Physicians (ACP) and Chair Emeritus of the Board of Regents of the ACP. Dr. Rosof is the recipient of the Laureate Award from the ACP and the Theodore Roosevelt Award for Distinguished Community Service. He has also received the 2011 Founders Award presented by the American College of Medical Quality in recognition of his long-standing national leadership and exceptional ability to foster and support health care quality improvement. Dr. Rosof is also the recipient of the 2012 Stengel Award from the ACP for outstanding service as well as his influence in maintaining and advancing the best standards of medical education, medical practice, and clinical research, and received the New York University Alumni Leadership Award in 2016.

Lawrence G. Smith, M.D., MACP, is the Executive Vice President and Physician-in-Chief of Northwell Health. As Physician-in-Chief, Dr. Smith is Northwell Health's senior physician on all clinical issues. He previously served as Northwell's Chief Medical Officer. Dr. Smith is the founding Dean of the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell,

which received full accreditation by the Liaison Committee on Medical Education and whose first class graduated in May 2015.

Dr. Smith earned a bachelor of science degree in physics from Fordham University and a medical degree from the New York University School of Medicine. His residency in internal medicine at Strong Memorial Hospital was followed by military service as a captain in the Army Medical Corps at Fitzsimmons Army Medical Center in Denver.

Dr. Smith has held senior leadership positions in national societies for medical education and residency training, authored numerous peer-reviewed publications in the area of medical education, and he has received many awards and honors from national and international organizations. He is a member-at-large of the National Board of Medical Examiners and a member of the Board of Visitors of Fordham College. He is also a former Regent of the American College of Physicians and a former member of the board of directors of the American Board of Internal Medicine. In April 2011, he was elected to Mastership of the American College of Physicians. The Arnold P. Gold Foundation invited Dr. Smith to join its board in early 2017.

Christopher R. Trudeau, J.D., is an associate professor in the University of Arkansas for Medical Sciences' Center for Health Literacy, and he holds a dual appointment with the Faculty of Law at the University of Arkansas Little Rock William H. Bowen School of Law. He is an internationally recognized expert on health literacy, plain language, and informed consent. He has spoken for the Food and Drug Administration, the Centers for Disease Control and Prevention, and many health systems. He specializes in developing clear, health literate communication that both engages patients and complies with health care regulations.

Appendix C

Improving Health and the Bottom Line: The Case for Health Literacy

By

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Commissioned by the Roundtable on Health Literacy
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¹ The authors are responsible for the content of this article, which does not necessarily represent the views of the National Academies of Sciences, Engineering, and Medicine.

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EXECUTIVE SUMMARY

What Is the Case for Health Literacy?

Health care is a business. At the same time, health literacy is a way to bring down costs and improve value. When health systems and those who work in health care use health literate methods, there is a better chance that patients will know what they need to do and they should be able to act and manage their health.

Health literacy is not just the right thing to do for the patient. It is also the right thing to do to make sure we control costs and improve quality. We need this as we switch our payment model to value-based purchasing. The business model we have now for providing health care is moving from one where we make money by using more health care. Soon, providers will make the most money when they keep people in better health and out of the hospital. Health literacy is a vital tool to aid in this movement.

We looked at many factors to make the case. They include the effect that health literacy has on:

- The quality of care
- The cost of care
- Providing equitable care
- The health of communities
- The care experience of patients and providers

Plus, we tried to find out if changing the way we pay for health care (as well as other rules) would lead to improved health literate methods for health systems and those who work in health care.

Where Did We Find the Information?

We found the information through three distinct ways. To start, we searched for research that showed health literacy's effect on one of the factors above. Next, we reached out and interviewed those who work in the field of health literacy. We asked them to send us all research they might have that showed the effect of health literacy. Then, we sent out a survey to those who work the field of health literacy. We asked them for their own stories about health literacy programs that work well in communities, clinics, and adult classes.

Why Is Health Literacy So Vital?

Most of the time, health literacy is known as one's ability to find, know, and use health information to make choices each day. Plus, to be health literate means health systems and health providers must teach patients in such a way that helps the patient use what they have been taught with ease. That means that all who work in health care need to do all they can to help get rid of any health literacy problems patients (or their loved ones and caregivers) may face. The use of good health literacy is vital for all who work in health care from the "top down and bottom up." Those who work in public health need to do this, too.

The Business Case

In the United States, low health literacy is estimated to cost \$105 billion to \$238 billion each year in direct health care costs. Indirect costs are between \$1.6 trillion and \$3.6 trillion each year. Good health literacy plans can take more than one form. All forms are set up to help patients (as well as their loved ones and caregivers) make their way through detailed health information and systems to get the care they need and stay in good health. Health literacy cuts health care costs through:

- Fewer emergency department (ED) visits
- Fewer hospital readmissions
- More screenings to prevent illness and increase medicine adherence
- Fewer dosing errors

Good health literacy plans work to change how patients act, which, in turn, can lead to fewer costs for people, systems, and society. Giving help through written guides and speech helps patients find their way through health systems. Plus, a good plan can help patients get the follow-up care they need. This would be for things like coming in for follow-up visits or to report their weight each day. A good plan can lead to more control of chronic illness such as asthma, diabetes, and high blood pressure. A change in what a patient understands can lead them to do as their doctor or nurse asks and lead to fewer stays in the hospital. Public health literacy plans have been found to reduce the chance for disease.

If done right, a change in the way a patient acts can lead to better health outcomes, both for the patient and for health systems. With more knowledge and better care for chronic illness, health literacy helps to cut down on:

- Days in a hospital
- Needless ED use

- Preventable hospitalizations
- Readmission rates

At the same time, it helps to make the health of communities better. These are just a few of the improved health outcomes. The full report gives this and more evidence for how health literacy can change health outcomes through better care at less cost.

A good health literacy plan also helps the patient make good health choices. They will be more satisfied with their health care, too. This builds trust and rapport for both patients and providers. This trust helps a patient to learn more. Plus, the trust helps to align health care goals set by the patient and doctor. Research has shown that hospitals with more satisfied patients make more money. Furthermore, there are some value-based payment models being designed now. These models have bonus payments linked to how many satisfied patients a health system has. The use of these new models will help make the financial case for health literacy.

The Ethical Case

Health literacy is the right thing to do to reduce health disparities and provide equal care for all. Good health literacy plans have been found to reduce the effect of race and sex for some health outcomes. And good plans tend to reduce racial and ethnic health disparities as well.

Health literacy is also the right thing to do to meet the policy demands we have now. For example, the Patient Protection and Affordable Care Act (ACA) has many terms that must be met that deal with health care that is based on Culturally and Linguistically Appropriate Standards (CLAS). CLAS were designed by the U.S. Department of Health and Human Services. Plus, the ACA makes a point to emphasize that health literacy must be a part of all health care training. The ACA also streamlines the way patients sign up for health insurance. Those who sell health insurance must write summaries in such a way that patients can know what their plan covers and how. And the summary must have clear and concise health information. In much the same way, the rules set up by the Centers for Medicare & Medicaid Services (CMS) state the same thing. The rules state that health care providers must teach patients in a way that gives the patient the chance to know what to do to get to or stay in good health.

The United States does not have a central health agency to set up rules for how best to deliver health care. Because of this, from time to time payment models serve as the main force to shape the way we provide health care. At this time, in the United States we often pay for the amount of health care we give. As payment methods shift, we will soon pay for the quality of health care we give.

As such, we would like to note that the Medicare Access and Children's Health Insurance Program (CHIP) Reauthorization Act (MACRA) set up new rules that pay health systems and clinics to use health literacy methods. These methods help the patient get more engaged to manage their health care, as well as improve the course of their care.

Health Literacy and the Future

There is more and more proof that using health literacy strategies reduces costs while boosting the quality, equity, and access to health care—all while making the health care of the patient better. As payment models change, clinics and health systems need to put good health literacy practices in place that help the health of their patients, communities, and profits. Once we have done that, then we can better meet future health reforms and challenges.

In the appendices of this report you will find fact sheets that show the benefits of health literacy on cost, quality, equity, outcomes, behavior change, and satisfaction. Please use these with local, state, and federal policy makers to allow them to make more informed decisions to prepare patients and health systems for the future.

INTRODUCTION

The Roundtable on Health Literacy, Health and Medicine Division, National Academies of Sciences, Engineering, and Medicine, commissioned the Center for Health Policy, School of Medicine, University of Missouri, as well as a health literacy expert from Michigan State University, to build the case that health literacy is important for everyone. A key principle of health literacy is to know and understand your audience. Previous roundtable commissioned papers focus on disseminating the latest academic research. Our paper goes beyond the usual readership to gain traction in the corporate offices of hospitals and health systems. This report is accompanied by a health literate, plain language executive summary and fact sheets designed specifically for policy makers.

We expand on a broad definition of health literacy that Sorensen and colleagues (2012, p. 3) developed as our guide:

Health literacy is linked to literacy and entails people's knowledge, motivation, and competencies to access, understand, appraise, and apply health information in order to make judgments and make decisions in everyday life concerning health care, disease prevention, and health promotion to maintain or improve quality of life during the life course.

Add to this that until we begin teaching health literacy as a life skill in elementary and secondary education like reading, writing, and math, we cannot blame the victim by placing the sole responsibility on patients, family members, and caregivers. The health system and health professionals must take responsibility to simplify systems and information, as well as provide support to minimize all potential health literacy challenges that people face.

Many cases could be made for the importance of integrating and addressing health literacy. We make numerous cases, which fall under two primary categories:

- The business case, which includes health literacy's effect on cost, quality, behavior, access, and patient experience, and
- The ethical case, which includes health literacy's effect on health equity, as well as the legal/regulatory case.

The roundtable asked us to bring together evidence on the effect of health literacy in achieving the Quadruple Aim (Bodenheimer and Sinsky, 2014). The Quadruple Aim framework focuses on health literacy as a primary way to: (1) enhance the quality of care, (2) improve the health of communities, (3) reduce costs, and (4) improve the care and experience of patients and providers. Health literacy is especially important for those people who experience medication errors, higher rates of hospitalization and emergency room use, poorer health outcomes, and increased illness and early death (Williams and Parker, 1995). Through numerous scoping reviews, a survey of the field, and informal interviews with key health literacy informants, we have attempted to gather as much evidence as possible about health literacy's best and promising practices and their implications for health care delivery and public health in America. We hope that advocates use this evidence to put into action best practices in places where people live, learn, work, play, and heal together.

METHODS

Best Practices (Peer-Reviewed)

One of the authors maintains an extensive database of peer-reviewed health literacy research. He identified peer-reviewed evidence through a comprehensive review of pertinent literature from his and existing databases for peer-reviewed articles that address at least one or more of the four foundational issues of health literacy within the Quadruple Aim framework. In addition, through scoping literature searches, we incorporated recently published and submitted articles and manuscripts.

We began the citation collection process by searching for the phrase “health literacy” in either the title, abstract, or keywords of peer-reviewed articles published from 1950 to August 2017 and indexed all articles in research databases. The databases included PubMed, ISI Web of Science, Academic Search Premier, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycARTICLES, Ingenta, ProQuest, and Science Direct. Conducting multiple searches within and across the databases yielded duplicate citation data. Duplicate citations were removed and/or collapsed into a single citation. From 1950 to August 2017 there were 13,509 unique articles that included the phrase “health literacy” in the title, abstract, or keywords. We also used Google Scholar to fill in missing citation information.

Promising Practices (Not Peer-Reviewed)

The team searched the grey literature using MedNar, EthOS, OpenDOAR, and Worldwidescience. The team also reached out to their respective colleagues and networks and posted repeated messages to the Health Literacy Discussion List (HLDL) requesting people to identify any non-peer-reviewed evidence and promising practices of the effect of health literacy on cost, quality, access, satisfaction, equity, behavior change, organizational change, and other issues outlined in the workshop’s Statement of Task. The team also requested that everyone send us any recently published articles and/or manuscripts submitted for peer review that are relevant to the overall project but not in publication yet. We posted the same request to several health literacy discussion groups on LinkedIn as well as Twitter, Facebook, Google+, and Google Newsstand.

We designed and implemented a survey of health literacy professionals to further collect non-peer-reviewed literature and anecdotal evidence (stories) that highlight and humanize best and promising practices from community-based initiatives, clinical quality improvement programs, adult learning settings, and public health campaigns.

Survey Results

The survey was conducted between June 23, 2017, and July 15, 2017. The responses ($n = 138$) were collected using the online survey application Qualtrics.² The survey was distributed via the HLDL, LinkedIn, and Twitter. If we found existing policies, programs, or initiatives that met the framework criteria outlined in the Roundtable on Health Literacy’s Statement of Task, we contacted the organization and conducted in-depth

² See <https://www.qualtrics.com> (accessed February 15, 2018).

interviews via telephone with an identified organizational leader when allowed. Participants were given the option of providing their name and email address at the end of the survey if they were willing to be contacted for follow-up questions; otherwise, their responses were anonymous.

Respondents represented programs and institutions from the United States of America, Canada, Germany, Italy, Taiwan, Australia, Japan, Abu Dhabi, and more. Seventy-seven percent of respondents said that they or their organization had worked on a project exploring the effect of health literacy on any of the following areas: finance, behaviors, health outcomes, quality of care, patient satisfaction, provider satisfaction, equity, organizational culture, or another area related to the Quadruple Aim. The areas explored by the projects were behaviors (16 percent of programs), patient satisfaction (15 percent of programs), health outcomes, quality of care, equity, etc. Sixty-five percent of respondents presented their work at state or national conferences or published the research that resulted from their health literacy programs. Forty-four respondents provided contact information for further follow-up.

The survey also asked about the target population for many of the health literacy projects represented. Most of these studies targeted education or health care. For the projects taking place in educational settings, the populations included were eighth grade, suburban middle school students, adults seeking GED or enrolled in literacy classes, English language learners, and teachers in primary and secondary schools.

For projects that focused on organizational infrastructure and creating health literate institutions, projects targeted leadership, senior leaders and department chairs, and other key decision makers in hospitals, pharmacies, and primary care practices. Other projects focused on frequent emergency room patients; medically underserved patients; hospitalized patients; pediatric patients and their caregivers; patients receiving services for various acute and chronic conditions like asthma, breast cancer, colonoscopy, diabetes, cancer, or HIV; mental health diagnoses; and substance abuse. Some studies have looked at low-income patients, immigrants, refugees, Australian Aboriginal communities, older adults, people with disabilities, and inmates in a county jail setting.

Health care professionals were the focus of programs and interventions for more than half of the survey respondents. They represented doctors, nurses, registered nurses, dentists, dental hygienists, nurse practitioners, dietitians and dietetic interns, and other clinic and hospital providers and staff members.

Thirteen respondents included information about health literacy programs that have not been presented at conferences nor published in peer-reviewed literature. The focus of these projects included

- Building health literacy collaborations between health professionals and community-based organizations serving new immigrants and refugees;
- Determining an overall, basic understanding about health and health care in middle school students;
- Providing medication review to ensure patients understand why they are taking the medicines and answering any questions patients may have;
- Revealing to patients the true risks of proposed procedures;
- Patients rating the health information provided by care team members;
- Providing various educational opportunities for health care providers;
- Integrating health literacy and the teach-back method into clinical practice;
- Providing health literacy workshops for patients and family caregivers; and
- Assessing the organization's health literacy competencies based on the 10 attributes of a health literate organization (Brach et al., 2012).

Challenges to the Case for Health Literacy

In building the case for health literacy, we identified several potential challenges from a diverse variety of perspectives that need to be acknowledged and contemplated as we continue to strengthen the case.

1. Current volume-based reimbursement and traditional fee-for-service payments for health services do not incentivize good health literacy practices. Value-based reimbursement (for example, the Medicare Access and CHIP Reauthorization Act of 2015) does incentivize health literacy practices. Until we fully move to value-based purchasing, existing reimbursement incentives will be structured against the integration of health literacy principles into practice and may undermine the case for health literacy.
2. Consumer information in health care is not as transparent as in other consumer-based industries. One attribute of a health literate organization directs that an organization “communicates clearly what health plans cover and what individuals will have to pay for service” (Brach et al., 2012). Rarely, if ever, are the out-of-pocket costs for health care services communicated before they are delivered. Duesenberry famously stated: “Economics is all about how people make choices. Sociology is all about why they don't have any choices to make” (1960, p. 233). Health literacy is a

similar paradox in that we expect people to be empowered to use health literacy skills once learned, yet they are confined by complex health systems, structures, policies, and procedures that limit choice and restrict the equitable information exchange necessary to navigate the health care market and insurance marketplaces. Until there is a movement toward cost and quality transparency, implementing comprehensive health literacy practices will be difficult.

3. Research is needed to support the efficacy of health literacy interventions. Many professionals in the field fear that a lack of supporting evidence hampers future funding, initiatives, and interventions. During personal interviews conducted as part of this paper, numerous health literacy experts hypothesize that the lack of research will contribute to the lack of sufficient evidence.
4. There is sufficient evidence of short-term outcomes that support the effectiveness of specific health literacy interventions. To date, however, there are no large-scale longitudinal studies that examine long-term outcomes related to cost, quality, satisfaction, and effects of broad-based health literacy initiatives and interventions. Funding is needed to support such an endeavor.
5. The legal profession has not embraced the literacy movement and can be a barrier in health care. For example, patient consent forms for procedures in health care crafted with health literacy in mind are commonly rejected by the health system legal team. This same dynamic is at play in state Medicaid departments across the United States.
6. There are numerous initiatives and interventions that fall into the broadening scope of health literacy but do not fall under the label of health literacy. As a result, there is available evidence that may not be uncovered by traditional methods (for example, literature reviews, surveys, and informant interviews) when searching more broadly for data in the domain of health literacy.

The Business Case for Health Literacy

The Financial Case

The health literacy field has a long history of forecasting the potential cost savings of addressing health literacy from a societal standpoint. An early systematic review reported a range of an additional 3–5 percent in total health costs attributable to limited health literacy for the health care system and a range of \$143–\$7,798 of additional expenditures for individual patients with low/limited health literacy compared to those with adequate health literacy (Eichler et al., 2009). In 2017, the United States

was estimated to spend \$3.5 trillion on total health expenditures (CMS, 2016b). Translating the reported range into 2017 U.S. health care dollars reflects a potential cost savings of \$105–\$175 billion per year. Others have estimated that low health literacy costs the U.S. economy between \$106 and \$238 billion annually in direct health costs and between \$1.6 and \$3.6 trillion annually when you include the costs of current public health activities (or lack of action) that would result from healthy eating, exercising, smoking cessation, and so on (Vernon et al., 2007). A 3-year retrospective service utilization study of nearly 93,000 veterans found that veterans with marginal and inadequate health literacy cost \$143 million more than veterans with adequate health literacy (Haun et al., 2015).

More specific research has demonstrated the financial effect of integrating health literacy in two primary arenas: public health and health care delivery. In public health, savings have been documented using the quality-adjusted life year (QALY) measures that use preference-based measurements of health-related quality of life to provide an assessment of the overall burden of diseases associated with both mortality and morbidity (Neumann et al., 2016). For example, a computer-delivered intervention targeting HIV medication adherence found a net cost savings per user and per QALY for high health users and wider deployment (Ownby et al., 2013). Using the change in QALYs in the first year, the Life Enhancement Program estimated the cost of improved health status for participants was between \$376,400 and \$570,500 lower than other interventions that would produce similar health gains (Pleasant, 2017).

The Institute of Medicine report *A Prescription to End Confusion* documented numerous ways that health literacy can potentially reduce health care costs, ranging from underuse of preventive and other services; inefficient access to health services, such as unnecessary ED visits and preventable hospitalizations; medication errors and mismanagement of chronic conditions; patient noncompliance caused by not understanding care instructions; and inappropriate health services (IOM, 2004). In addition, many specific health literacy health care delivery interventions have been found to be cost-effective, including using cell phones to deliver health education via text messaging (Zhuang et al., 2016), a multipronged intervention targeting colorectal cancer screenings involving health literacy training for physicians and establishing a feedback loop to monitor patient compliance (Khankari et al., 2007), a pharmacist intervention for those with heart failure to increase cardiovascular medication compliance (Murray et al., 2007), and a cancer screening intervention among Korean women led by community health workers (Schuster et al., 2015).

Health literacy can be implemented in a variety of ways and can save money in many different ways. For example, first-time colonoscopy patients who watched an educational video had significantly lower anxiety scores

the day of the procedure and as a result required 18 percent less sedation medication and had a 14 percent decrease in procedure time (The Beryl Institute, 2015). Patients were 11 percent more knowledgeable about the procedure, and that increased knowledge saved the system both time and money. Massachusetts General Hospital reported significant savings from employing a community resource specialist (CRS). After hiring a CRS, Mass General reduced ED visits by 13 percent; and combined with a decline in unnecessary hospitalizations, it experienced a 7 percent annual net savings on enrolled patients and generated \$2.65 in savings for every dollar spent on the CRS (Vuletic and Farooqi, 2017). Integrating health literacy can also increase incoming revenue. After implementing an automated phone notification to a group of 3,137 patients with recent orders for a colonoscopy or upper endoscopy, one health system found that 18 percent of patients contacted went ahead and got the procedure, resulting in \$684,930 of estimated revenue generated during the 2-month campaign, based on national averages (West Healthcare, 2015). A dental diversion program in Missouri led to an additional 3,107 tooth extractions over an 18-month period, increasing clinic revenue by more than \$680,000 while providing savings to patients by ensuring the right level of care at the right price (Pfannenstiel and Brown, 2017).

Some long-standing health literacy programs have demonstrated time and again behavior change that results in direct and indirect cost savings to systems, individuals, and society. For example, the guidebook *What to Do When Your Child Gets Sick* has been deployed in numerous places and ways and continues to provide new findings. In Wisconsin, this book empowered parents to deal with health problems at home instead of calling a hospital or clinic, or visiting an ED or urgent care center, demonstrating that approximately \$1.50 was saved in health care usage for every dollar spent on the project (Cook, 2013). In a pilot study in Michigan, parents stating they would seek care in the ED decreased by 14.6 percentage points and a review of claims found that after 1 year of using the books with additional support there was a decrease in ED costs for children younger than 2 years (Molina, 2005). Implementing a *What to Do When Your Child Gets Sick* program in Kansas led to numerous cost savings to the health system and society, with 46 percent fewer unnecessary doctor visits, 55 percent fewer emergency room visits, 64 percent fewer school days missed by children because of illness or injury, and 56 percent fewer work days missed by parents because of their children's illness (O'Neal, 2012). Last, a *What to Do...* partnership between the University of California, Los Angeles, and Head Start in California found that Medicaid can potentially save at least \$554 per family annually in direct costs related to clinic/ED visits. Costs were extrapolated from a 42 percent reduction in doctor's visits and a 58 percent reduction in ED visits after implementation (UCLA, n.d.).

Recommended Areas for Future Study

To date, studies have only examined the short-term effect of specific health literacy practices. Longitudinal studies of broad-based health literacy activities are needed to truly assess the savings from long-term outcomes and behavior change, especially innovative ones that propose a paradigm shift in how we share and teach health education, such as integrating medical curricula normally targeted for medical students into elementary and secondary education (Weinstein et al., 2017). These and similar upstream approaches have the potential for a much greater return on investment once implemented and fully evaluated.

The Behavioral Case

The relationship between health literacy and behavior change has been explored in many studies, from targeted interventions to broader ones that integrate health literacy strategies with social support. For example, a randomized controlled trial found that people with heart failure were more likely to report daily weights when provided picture-based instructions, a digital scale, and follow-up phone support (79 percent in intervention versus 29 percent in control) (DeWalt et al., 2006). The Neighborhood Health Plan began distributing the *What to Do When Your Child Gets Sick* books to expecting mothers in 2006 and reported statistically significant reductions in total ED visits, especially for common diagnoses such as fever and viral, ear, and urinary tract infections (NHP, 2008). Sometimes, these returns can be realized very quickly. Significant increases (between 28 and 36 percent) in those reporting their daily weights occurred within the first 2 weeks of implementing interactive phone calls for recently discharged heart failure patients (Emmi Solutions, 2016a).

Other studies looked specifically at the links between health literacy and behavior change. Health literacy has been linked to behavior change for people with hypertension through knowledge and self-efficacy pathways (Osborn et al., 2011c). Similarly, health literacy and numeracy were directly and indirectly associated with greater self-efficacy or social support, which was linked to better glycemic control (Osborn and Egede, 2010; Osborn et al., 2010a,b). A 2011 systematic review found that low/limited health literacy was associated with numerous behavior-influenced health outcomes including more use of the ED, increased hospitalizations, and lower use of some types of preventive care such as mammography screenings and flu vaccines (Berkman et al., 2011a). In fact, the evolving definition of health literacy has even included models such as the Calgary Charter definition (Coleman et al., 2009) that posit health literacy as a theory of behavior change, with behavior change as the true outcome of improved health literacy.

Health literacy has also been linked to patient activation (Smith et al., 2013), and patient activation has been shown to improve management of chronic conditions such as diabetes and high blood pressure, healthy behaviors, and preventive screenings, while reducing ED visits and hospitalizations (Smith et al., 2013). Both patient activation and health literacy have been found to be significantly associated with positive effects on decision making and patient engagement in health care–related activities, healthy behaviors, and chronic disease self-management (Greene et al., 2005; Hibbard, 2013). A more recent study found that patient activation mediates or transfers the relationship among education, health literacy, and hospital use, reporting that higher patient activation scores were significantly associated with reduced odds of use among whites (Charlot et al., 2017). Those with higher patient activation scores are more likely to access and use online health information (Smith et al., 2015). Integrating patient activation into health literacy interventions could not only improve the public’s health information–seeking ability but also further enhance population-based health.

Studies are starting to examine the effect of public health literacy interventions on behavior change. For example, an initiative using education classes, a teach-back call, and interactive voice response calls led to reductions in drinking sugar-sweetened beverages, resulting in small but significant decreases in body mass index (Zoellner et al., 2016). Health literacy has also been associated with increased physical activity in Latinos (Dominick et al., 2013, 2015a,b) and with parents’ preferences for rotavirus vaccination (Veldwijk et al., 2015), suggesting that health literacy plays a role in addressing these and many other public health challenges.

There is also evidence that community-based interventions focusing on the combination of health literacy, self-efficacy, sense of empowerment, self-esteem, and/or social support influence beneficial health behaviors. For instance, adult learners who receive health literacy-based education had increased knowledge about health issues and self-efficacy because of the health literacy instruction (Chervin et al., 2012). Other studies suggest that health literacy and self-efficacy are critical for preventive health screening (Davis et al., 2014; Tiraki and Yilmaz, 2017), intention to take an HIV test (Rikard et al., 2016), smoking cessation (Parisod et al., 2016; Stewart et al., 2013), and diabetes management (Rak, 2014; White et al., 2015). In addition, interventions to increase health literacy that use existing social support resources improve patient–provider communication (Fry-Bowers et al., 2013, 2014).

Recommended Areas for Future Study

With the growing focus on population health under value-based purchasing, more research is needed on the effect of public health literacy and behavior change in three important areas. First, there must be an understanding that people do not live, learn, work, and play in clinics and hospitals. The social determinants of health are significant factors that shape the resources, or lack of resources, for behavior change. It is unclear whether health literacy is a social determinant of health or a result of those social determinants. Second, interventions must focus on increasing public and individual health literacy, as well as self-efficacy, sense of empowerment, self-esteem, social support, mastery, and/or sense of mattering. Third, public health literacy provides an upstream “pay off” in terms of the opportunity to change health behaviors and health outcomes.

The Case for Health Outcomes

Lower health literacy has been found to be clearly associated with poorer health status and a higher risk of mortality for seniors, as well as decreased ability to take medications appropriately and interpret labels and health messages (Berkman et al., 2011b). Health literacy has also been associated with preventable ED visits. Patients with limited literacy had 2.3 times the number of preventable ED visits resulting in hospital admission compared to individuals with adequate health literacy, 1.4 times the number of treat-and-release visits, and 1.9 times the number of total preventable ED visits (Balakrishnan et al., 2017). Interventions to increase health literacy and self-efficacy provide greater improvements in hemoglobin A1c, glucose, and total cholesterol (Kim et al., 2013), regularly taking diabetic medication (Al Sayah et al., 2013; Hofer et al., 2017; Lee et al., 2016), and HIV medication (Colbert et al., 2013). The same connection among health literacy, self-efficacy, and social support improves mental health outcomes, such as depression, among racial/ethnic minorities (Hernandez and Organista, 2013, 2015; Lee et al., 2013).

Videos and multimedia programs have been showing promise on affecting outcomes. Those who viewed a video education program were more likely to have controlled blood pressure regardless of blood control status and experienced shorter length of stay for total knee or hip replacement (Emmi Solutions, 2015b,c). Moreover, coupling online interactive media with automated phone calls resulted in a 15-day delay in readmission for chronic obstructive pulmonary disease with a 69 percent reduction in readmission length of stay and a 4-day delay in readmissions for congestive heart failure with a 51 percent reduction in readmission length of stay (Emmi Solutions, 2016b).

Because CMS started implementing readmission penalties in 2012, there is a plethora of studies that have examined health literacy's effect on readmission rates. Health literacy has been found to be a significant and independent predictor of 30-day all-cause readmission (Bailey et al., 2015; Mitchell et al., 2012). Medicare enrollees with above basic health literacy had a 12 percent lower risk of 30-day readmission after a heart attack and a 16 percent lower incidence rate compared to those with basic or below basic health literacy (Bailey et al., 2015). Other studies have found health literacy to be a contributing factor to readmissions among individuals with diabetes (Rubin et al., 2014), those receiving maintenance dialysis (Flythe et al., 2017), individuals with heart failure (Cox et al., 2017), those who experience postdischarge falls (Jaffee et al., 2016), and those transitioning to surgical care (Martin et al., 2017).

In addition, numerous evidence-based health literacy practices have been found to reduce readmission rates for many conditions. In a pilot study in an urban pediatric hospital, coupling a discharge bundle with the use of the teach-back method was found to significantly reduce readmission by 8 percent for 7-day readmissions and by 10 percent for 30-day readmissions (Shermont et al., 2016). Implementing a patient navigator program for individuals with heart failure resulted in a 15.8 percent decrease in unplanned readmission (Di Palo et al., 2017). Similarly, individuals receiving postdischarge follow-up from a care transition pharmacist were significantly less likely to be readmitted within 30 days (Fera et al., 2014).

There is quite a bit more evidence for integrating health literacy to improve readmission rates being undertaken by hospital quality improvement programs. However, much of the evidence is not published in the peer-reviewed literature and could not be discovered using traditional literature methods. Also, many hospitals do not call this work "health literacy" even though the work fits within the health literacy umbrella. For example, a two-phase readmission reduction initiative employing the teach-back method and patient admission interviews reduced pneumonia readmission rates by 9.62 percent and heart failure readmission rates by 7.28 percent in phase 1. Phase 2 added the patient readmission interview to their electronic medical record, increased patient support through follow-up phone calls and appointments, and collaborated with local and regional skilled nursing facilities to reduce all-cause readmission by 4.67 percent (SoutheastHEALTH, 2017).

Recommended Areas for Future Study

With the emergence and adoption of information and communication technologies to access eHealth resources, there is a significant gap in studies examining eHealth literacy interventions and their effects on outcomes

(Watkins and Xie, 2014). A recent systematic review (Kim and Xie, 2017) revealed only nine intervention studies examining the effect of websites or online app use on health literacy. Of the nine studies, six education-based interventions among low-literacy adults and older adults reported positive effects on knowledge about health conditions, use of computers and the Web, search skills, confidence finding and using eHealth resources, and use of health information for one's own health care (King et al., 2013; Mein et al., 2012; Robinson and Graham, 2010; Strong et al., 2012; Xie, 2012). As we continue in the digital age, more research is needed to ensure that these electronic tools translate into better health outcomes.

The Case for Quality of Care

It must be noted that many findings documented in the sections on the case for finance, behavior, outcomes, satisfaction, and equity also provide sufficient evidence of health literacy's effect on quality of care. To avoid redundancy, the findings documented in those sections are not repeated here. Health literacy has a long-recognized role in patient safety. This is why health literacy is widely endorsed through initiatives by the Institute for Healthcare Improvement and the National Patient Safety Foundation (NPSF, 2017), the Centers for Disease Control and Prevention (CDC, 2017), the American Medical Association (Weiss, 2007), the Joint Commission (2007), the U.S. Department of Health and Human Services (HHS, 2010), and the Agency for Healthcare Research Quality (AHRQ, 2017). Despite the widespread recognition, when the literature for specific studies linked to medical errors is examined, there is extensive research in only one area and broad gaps in all others.

Numerous studies have examined the role health literacy plays in medication adherence and dosing errors (Davis et al., 2006a,b; IOM, 2008; Mira et al., 2015; Persell et al., 2010). Even employing simple health literacy universal precautions can have an effect, such as listing specific times to take doses (Davis et al., 2009), using milligrams as the standard unit for liquid medication (Yin et al., 2014), and using oral syringes over cups for small doses (Yin et al., 2016). A systematic review of the use of pictograms to assist caregivers in dosing liquid medication found limited but clear evidence that integrating pictograms into verbal or text-based instructions reduced dosing errors and enhanced comprehension and recall of instructions, while improving adherence (Chan et al., 2015).

Likewise, the use of patient-centered medication labels has been found to improve adherence for those with limited health literacy (Wolf et al., 2016). The U.S. Department of Veterans Affairs developed and adopted a patient-centered medication label format in an attempt to improve the quality of care for its more than 9 million veterans (Trettin et al., 2015).

Recommended Areas for Future Study

We point out that most of the direct studies on health literacy and quality only examined liquid medication, and more research is needed to examine the role that health literacy can play in reducing nonliquid dosing errors and adherence. It also must be noted that no study directly links health literacy to medical errors. One study did identify health literacy-related adverse events and found that they led to outcomes such as delaying or cancelling a procedure, surgery, treatment, or test; falls; premature removal of catheters; and wrong procedure or site (Gardner, 2016). The study provided recommendations on health literacy universal precautions to employ to avoid adverse events but did not explore the relationship or causal link between health literacy and adverse events. More research is needed to understand the direct relationship between health literacy and medical errors.

The Case for Health Care Experience

Patient Experience

Inadequate health literacy has been associated with reduced patient satisfaction (MacLeod et al., 2017; Shea et al., 2007). Likewise, interventions addressing health literacy have been found to improve patient satisfaction in medication adherence and management (Graumlich et al., 2016; Murray et al., 2007; Ruiz et al., 2014), hypertension management (Piette et al., 2012), obtaining informed consent (Hallock et al., 2017), eye health education (Rhodes et al., 2016), and maternal health education (Stikes et al., 2015). Shared decision-making models also continue to show much promise in improving patient satisfaction in the health care setting (Bozic, 2013; Joosten et al., 2008; Olomu et al., 2016; Slover et al., 2012).

Using video materials to improve patient knowledge and expectations has been found to enhance patient satisfaction for individuals receiving radiation therapy (Matsuyama et al., 2013), those prepping for a colonoscopy (Hayat et al., 2016), and recent stroke survivors (Denny et al., 2017). In a comprehensive study of nearly 100,000 Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) surveys from hospitals employing commercially developed and implemented video programs, 100 percent of hospitals had a higher aggregate HCAHPS Top Box percentage, 69 percent of aggregate Top Box answers were 4 percent higher or more, 86 percent of hospitals had higher “doctor communication” dimension scores, 62 percent of hospitals had higher “discharge information” dimension scores, and 59 percent of hospitals had higher “nurse communication” dimension scores (Emmi Solutions, 2015d).

In addition to video, use of Web-based applications has been linked

to enhanced patient satisfaction, such as employing automated illustrations for cardiovascular education (Hill et al., 2016) and using Web-based interventions allowing diabetes patients to better track glucose levels, communicate directly with health providers, and interact with other individuals with diabetes (Brown et al., 2007). Satisfaction can be further enhanced by coupling these with telephone-based education and support services (Emmi Solutions, 2015a; Wolf et al., 2014).

Solutions do not have to be extensive or expensive to develop and implement. Even following simple health literacy universal precautions like rewording MRI reports (Bossen et al., 2013), standardizing emergency room instructions (Isaacman et al., 1992), employing audio-recorded messages (Santo et al., 2005), and encouraging patients to bring a family member or friend with them to the visit (Rosland et al., 2011) have been found to enhance patient satisfaction. Increased satisfaction translates into increased revenue. An analysis conducted by Accenture found that those hospitals that offer a superior patient experience have 50 percent higher hospital margins (Collier and Basham, 2015).

Provider Experience

Perhaps because of the recent addition of provider experience to the Triple Aim to form the Quadruple Aim, there is little evidence published on the direct relationship between health literacy and provider satisfaction. One study reported that orthopedic surgeons were more satisfied with patient visits when patients received a video and written information describing treatment alternatives for hip and knee osteoarthritis and developed a structured list of questions for their surgeon in consultation with a health coach (Bozic, 2013). Another study found higher satisfaction rates for bowel preparation prior to a colonoscopy when patients received a patient-centered educational video versus traditional print materials, with those not receiving the video having higher rates for needing a repeat colonoscopy within 3 years (Hayat et al., 2016). More research is clearly needed to examine the link between becoming a health literate organization and provider satisfaction in communicating with patients, ensuring patient understanding, and overall job satisfaction.

The Ethical Case for Health Literacy

Because It Is the Right Thing to Do (The Regulatory Case)

Numerous articles draw attention to the ethical case for health literacy. Early calls focused on the duty of health care organizations and professionals to ensure that their patients are equipped and provided with

supports to make truly informed and appropriate choices about their health (IOM, 2004; Mayer and Villaire, 2003; Parker et al., 2003), and it is the duty of public health agencies, professionals, and organizations to ensure that critical health messages to the public are actionable and understandable (Gazmararian et al., 2005; Nelson et al., 2005). Mission-based health and public health organizations have a responsibility to meet their patients where they are and provide health information and care with appropriate and adequate supports to empower health and public health consumers. Indeed, addressing health literacy lies at the heart of providing truly patient-centered care.

In addition to the integral role of health literacy in providing patient-centered information and care, health literacy is the right thing to do to comply with current regulatory requirements. Communication is at the core of health care experiences. As such, health literacy is an integral part of the CLAS developed by the U.S. Department of Health and Human Services (OMH, 2013). The Joint Commission adopted these standards and the ACA contains many conditions related to providing culturally and appropriate services. The ACA incorporates health literacy into professional training and streamlines the procedures for enrollment into federal and state insurance programs. Health plans and insurers are now required to provide patient-oriented summaries that give them clear, consistent, and comparable health information in a standardized way (Somers and Mahadevan, 2010).

CMS has integrated patient understanding in numerous regulations. Under Medicare and Medicaid Program: Conditions of Participation for home health agencies (HHAs), § 484.50(a)(1):

We proposed that the HHA provide the patient and patient's representative with verbal notice of the patient's rights in the primary or preferred language of the patient or representative, and in a manner that the individual can understand, during the initial evaluation visit, and in advance of care being furnished by the HHA.

According to the CMS State Operations Manual Appendix PP—Guidance to Surveyors for Long-Term Care Facilities § 483.10(b)(3):

The resident has the right to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition.

Several national medical associations and boards have deemed health literacy as the right thing to do. The American Medical Association has long recognized the importance of health literacy in meeting patients' needs,

improving quality of care, and enhancing patient safety (Weiss, 2007). The American College of Physicians has also valued the importance of health literacy and through its Center for Patient Partnerships in Healthcare has been developing and implementing innovative health information tools to ensure patient understanding and empowerment (ACP, 2017). The American Board of Pediatrics developed online training modules, including a Practice Improvement Module released in 2013 (ABP, 2013). The American College of Obstetricians and Gynecologists (2016) makes the following recommendations for addressing health literacy to promote quality of care:

Because of the potential effect of health literacy on patient outcomes, obstetrician–gynecologists should take the appropriate steps to ensure that they communicate in an understandable manner so patients can make informed decisions about their health care.

Personnel at all tiers of the medical system must learn to communicate with patients in a way that takes into account each individual’s unique circumstances and abilities for comprehending health-related information.

As mentioned earlier, under current fee-for-service reimbursement mechanisms there is an actual disincentive to address health literacy. Reimbursement penalties have begun to restructure these incentives. In October 2014, CMS began reducing Medicare payments for hospitals that rank in the lowest quartile regarding hospital-acquired conditions (HACs) (CMS, 2017). In 2011, 21 states already had nonpayment penalties for HACs, and section 2702 of the ACA has prohibited the federal government from providing payments to states for HACs and other provider-preventable conditions since July 2012 (NCSL, 2017).

In October 2017, CMS increased penalties for 30-day readmissions by reducing Medicare payments to facilities whose readmission ratios exceed the national average. This reflects CMS’s continuing commitment “to increasingly shift Medicare payments from volume to value” with a goal of linking half of all Medicare payments to value-based reimbursement by 2018 (Whiteman, 2016). These new reimbursement structures place more risk on hospitals and providers and truly incentivize the integration of health literacy in providing enhanced patient supports to ensure people have the understanding and access to home and community resources to successfully negotiate the road to recovery. As more insurers follow suit, there will be increasing financial pressure to integrate health literacy practices to enhance profit margins. Hospitals are also being compelled to reduce Medicaid readmissions because of payment reforms, such as accountable care organizations and other alternative payment models, and through regulatory actions from state governments that require hospitals to demonstrate reductions in avoidable admissions and readmissions (Boutwell, 2014).

In addition, many state Medicaid programs are starting to implement payment mechanisms that incentivize more continuity and efficiency in care delivery. So far, 22 states have implemented Medicaid payments through health home models, 26 have Medicaid payments through medical homes, and 12 have implemented delivery system reform incentive payment programs (NASHP, 2015). Using bundled and global payment mechanisms shifts financial responsibility and risk to the provider. Integrating health literacy universal precautions into practice can assist providers in reducing risk and strengthening the health of their patients and their bottom line.

The shift toward value-based purchasing will strengthen in the next few years as MACRA replaces the sustainable growth rate formula and establishes “a new payment framework for rewarding health care providers for giving better care and not more care” (CMS, 2015). MACRA began implementation in 2015, and by 2021 physician Medicare payments will be truly aligned to quality and performance measures. Some have suggested that combined with more private-sector attention to inefficiencies in physician payment, MACRA may trigger a “disruptive innovation” in health care delivery (Findlay, 2015). Under MACRA, providers will only be paid through two ways: Merit-based Incentive Payment System (MIPS) and Alternative Payment Models (APMs).

Under MIPS, providers will be measured on quality, resource use, clinical practice improvement, and meaningful use of electronic health/medical records. Several 2017 MIPS improvement activities are focused on elements of care that are enhanced by health literacy:

- Engagement of patients, family, and caregivers in developing a plan of care (MIPS activity IA_BE_15),
- Engagement of patients through implementation of improvements in patient portal (MIPS activity IA_BE_4),
- Enhancements/regular updates to practice websites/tools that also include considerations for patients with cognitive disabilities (MIPS activity IA_BE_5),
- Use of toolsets or other resources to close health care disparities across communities (MIPS activity IA_PM_6),
- Evidenced-based techniques to promote self-management into usual care (MIPS activity IA_BE_16), and
- Implementation of medication management practice improvements (MIPS activity IA_PM_16).

These are a few of the MIPS activities that could be supported by health literacy improvement (TCPI, 2017). Under APMs, beginning in 2019 some participating providers will receive lump sum payments through bundled

payment, and accountable care organizations and patient-centered medical home models with higher annual payments being implemented in 2026.

Because It Is the Right Thing to Do (The Case for Health Equity)

Equity or providing equitable health services is one of the six dimensions of quality care defined in a seminal report by the Institute of Medicine (2001). As such, there has been a movement to integrate social justice and health literacy by making the moral or ethical case for the equitable distribution of health information across diverse cultures and communities with a focus on underserved populations, which tend to have higher rates of low/limited health literacy (Marks, 2009; Volandes and Paasche-Orlow, 2007).

Two goals of the 2016 CMS Quality Strategy to eliminate disparities included health literacy:

- Goal 1: Improve safety and reduce unnecessary and inappropriate care by teaching health care professionals how to better communicate with people of low health literacy and more effectively link health care decisions to person-centered goals.
- Goal 3: Enable effective health care system navigation by empowering persons and families through educational and outreach strategies that are culturally, linguistically, and health literacy appropriate.

In fact, one of the desired outcome measures focused on reducing admission and readmission for Goal 3 is increased health literacy (CMS, 2016a).

According to the Robert Wood Johnson Foundation (RWJF), health equity means:

Everyone has a fair and just opportunity to be healthier. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care. (Braveman et al., 2017)

From a health literacy perspective, health equity also means that everyone has equal access to health information that people can act upon. Health information should be targeted, tailored, easy to read, understandable, culturally appropriate, and available where people live, learn, play, work, and worship. Many of the reasons people might not have equitable access to appropriate health information is a lack of access to health care services. For those with some level of access to health care services, the information provided meets the needs of some patients and caregivers, while the needs of others are not met.

The majority of the health literacy research and interventions are focused on clinical outcomes and health care use (Berkman et al., 2011a). Most peer-reviewed and nonpublished work in health literacy is not addressing social determinants of health at the community and individual levels (Logan, 2015).

Perhaps because of its strong relationship with the social determinants of health, health literacy has been found to mediate the effect of race on health outcomes, including conditions that kept people from working, chronic illness, self-reported health status, flu vaccination rates, quality of life, prostate-specific antigen levels, medication adherence, and enrollment in health insurance (Berkman et al., 2011a,b). Health literacy also mediated or transferred the effect of both race and sex in interpreting medication labels (Berkman et al., 2011b). Rothman and colleagues showed that a diabetes disease management program addressing literacy may be particularly beneficial for patients with low literacy, and that increasing access to such a program could help reduce health disparities (Rothman et al., 2004).

A systematic review published in 2015 examining the relationship between health literacy and health disparities found that many studies and interventions do not describe the nature of the disparity that is explored. Most studies looked at racial and ethnic health disparities. Some have found evidence of the mediating function of health literacy on self-rated health status across racial and ethnic disparities, as well as on the potential effect of health literacy and numeracy on reducing racial/ethnic disparities in medication adherence and understanding of medication intake (Mantwill et al., 2015).

In a 2015 discussion paper published by the National Academy of Medicine, health literacy experts provided arguments that health literacy is a necessary element for achieving health equity because of the strong relationship with the social determinants of health and because health literacy interventions and best practices are a contributing factor to achieving health equity and social justice (Logan, 2015). The authors found that tailored and culturally competent programs, delivered where people live and learn using evidence-based health literacy tools, improved participant knowledge, attitudes, and behaviors were also successful in reducing health disparities in the target populations (Aiken, 2010; Herman, 2012; Neuhauser et al., 2007).

Recommended Areas for Future Study

The power dynamic in health care is one subject that needs more research. Specifically, research must focus on the effect of the power dynamic on health equity and on the opportunities that people have to achieve a healthy life. Traditionally, health care providers and institutions have had

more power in health care encounters. To achieve health equity, there must exist a more equal power dynamic in health information exchange that values the knowledge that the provider brings equally with the knowledge that patients, family members, and caregivers bring to the encounter.

IMPLICATIONS FOR HEALTH POLICY AND PRACTICE

In 2012, health policy and health literacy experts analyzed health policy initiatives like the Patient Protection and Affordable Care Act, the National Plan to Improve Health Literacy from the U.S. Department of Health and Human Services, and the Plain Writing Act of 2010 and identified the incredible opportunities that are available to further health literacy research and practice (Koh et al., 2012). The current health policy arena is changing and poses challenges to health care organizations, systems, communities, and patients. These challenges might interfere with many of the health literacy approaches to patient-centered care, provider training, and community-based interventions.

The *National Plan to Improve Health Literacy* highlights clearly what health care organizations and professionals can do (HHS, 2010). It will take everyone working together in a linked and coordinated manner to improve access to accurate and actionable health information and usable health services.

The plan's seven goals are:

1. Develop and disseminate health and safety information that is accurate, accessible, and actionable.
2. Promote changes in the health care system that improve health information, communication, informed decision making, and access to health services.
3. Incorporate accurate, standards-based, and developmentally appropriate health and science information and curricula in child care and education through the university level.
4. Support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community.
5. Build partnerships, develop guidance, and change policies.
6. Increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy.
7. Increase the dissemination and use of evidence-based health literacy practices and interventions.

In 2012, the Institute of Medicine published a discussion paper on the 10 attributes of health literate health care organizations. The paper

highlighted many opportunities and strategies that organizations have to create more opportunities for patients to access health care, access health care information, and be able to use as they navigate the health care system (Brach et al., 2012). The 10 attributes of a health literate organization are:

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

The white paper provides clear examples of how organizations and institutions can take immediate steps to improve how they communicate with patients, caregivers, providers, and staff. Yet, it is unclear how many organizations throughout the country or around the world are implementing these strategies.

As mentioned in the report, health literacy research and practice is mainly focused on clinical interventions, whereas other areas like quality of care, patient safety, cost, outcomes, medication adherence or medication errors, health equity, and health disparities research and practice often do not include health literacy as a major component, with professionals working in these areas often operating in silos. Some interventions take place in clinical settings, others in community-based settings. Many times funding targeting these other areas does not emphasize health literacy and vice versa, so there is little incentive to collaborate with professionals and conduct research across all of these domains. A 2009 review of health literacy and child health promotion research and practice recommended and discussed cross-domain interventions that included targeting all areas of care, from patient care, health system characteristics, educational systems like

preschool and the K–12 curricula, and community-based approaches such as home visiting programs and after-school programs (Sanders et al., 2009).

Along with incentivizing cross-domain collaborations in our organizations and systems, policies should encourage improvement in health care professional competencies that include knowledge about community resources, everyday lived experience, and community partners. A comprehensive approach to integrate appropriate professional and community resources in order to meet the needs of the populations is critical.

Funding Support

When asked about the funding source for health literacy programs on our survey, respondents identified the national ministries of health and the World Health Organization for countries other than the United States. Within the United States, programs were funded by state agencies, realigning resources within health care institutions, operational funding, scholarships and fellowship programs, the National Institutes of Health, the Centers for Disease Control and Prevention, CMS, Adult Learning Centers, public health funding, private foundations, other grants, donations, and in-kind support.

National Institutes of Health (NIH)

One of the primary sources for health literacy research related funding was the “Understanding and Promoting Health Literacy” (PAR-13-130-132) funding mechanisms. However, the funding series was not reissued as of May 2016. We searched the NIH RePORT Expenditures and Results Tool (RePORTER) system for currently funded projects that include “health literacy” in the project title, abstract, or scientific terms.³ The results of the search are presented in Table C-1. The NIH is made up of 27 institutes and centers. Each institute or center focuses on a specific disease or body system and a specific funding strategy for research projects.

We point out that the National Library of Medicine (NLM) actively supports health literacy projects that address the Quadruple Aim framework. For example, the NLM’s Information Resource Grants to Reduce Health Disparities (RFA-LM-17-002) funding opportunity focuses on projects that develop or upgrade usable tailored health information for populations who experience health disparities and increase the information capacity of health care providers.

³ See <https://report.nih.gov> (accessed February 15, 2018).

TABLE C-1 National Institutes of Health (NIH)—Number of Currently Funded Health Literacy Projects

Administering Institute or Center	Number
Agency for Healthcare Research and Quality	7
National Cancer Institute	44
National Center for Complementary and Integrative Health	1
National Center for Injury Prevention and Control	1
National Heart, Lung, and Blood Institute	13
National Human Genome Research Institute	4
National Institute of Allergy and Infectious Diseases	3
National Institute of Arthritis and Musculoskeletal and Skin Diseases	2
National Institute of Biomedical Imaging and Bioengineering	1
National Institute of Child Health and Human Development	17
National Institute of Dental and Craniofacial Research	3
National Institute of Diabetes and Digestive and Kidney Diseases	35
National Institute of Environmental Health Sciences	31
National Institute of General Medical Sciences	7
National Institute of Mental Health	12
National Institute of Neurological Disorders and Stroke	6
National Institute of Nursing Research	18
National Institute on Aging	21
National Institute on Alcohol Abuse and Alcoholism	1
National Institute on Deafness and Other Communication Disorders	3
National Institute on Drug Abuse	2
National Institute on Minority Health and Health Disparities	35
National Library of Medicine	17
Office of the Director	13

Patient-Centered Outcomes Research Institute (PCORI)

The Patient-Centered Outcomes Research Institute (PCORI) is an independent nonprofit, nongovernmental organization authorized by the U.S. Congress in 2010. PCORI supports comparative clinical effectiveness research focusing on outcomes important to helping patients, caregivers, clinicians, employers, insurers, and policy makers make better-informed health decisions. PCORI is not allowed to fund research projects that examine cost-effectiveness outcomes for any interventions. PCORI involves

patients and other health care stakeholders during the research process with the goal that the resulting evidence addresses the most important questions and concerns. The team searched the PCORI Funding Portfolio for all projects with the phrase “health literacy.” Table C-2 provides a list of health literacy-funded projects, specifically the names of the organizations, budget amount, type, and related funding announcement.

TABLE C-2 Patient-Centered Outcomes Research Institute (PCORI) Funded Health Literacy Projects

Organization	Project Budget	Project Type	Funding Announcement
Boston Medical Center	\$249,821	Engagement in Research Project	Meeting and Conference Support, Engagement Award
Colorado Center for Primary Care Innovation	\$13,930	Engagement in Research Project	Tier I, Pipeline to Proposal
University of Maryland	\$249,999	Engagement in Research Project	Engagement Award
University of Alabama at Tuscaloosa	\$1,339,684	Research Project	Addressing Disparities
American Institutes for Research		Research Dissemination and Implementation Project	
El Poder de Decidir	\$14,996	Engagement in Research Project	Tier I, Pipeline to Proposal
Matrix Institute on Addictions	\$14,966	Engagement in Research Project	Tier I, Pipeline to Proposal
Spina Bifida San Diego	\$50,000	Engagement in Research Project	Tier III, Pipeline to Proposal
Multicultural AIDS Coalition	\$15,000	Engagement in Research Project	Tier I, Pipeline to Proposal
The Cholangiocarcinoma Foundation	\$46,500	Engagement in Research Project	Meeting and Conference Support, Engagement Award
Trustees of Dartmouth College	\$2,089,937	Research Project	Communication and Dissemination Research
University of New Mexico Health Sciences Center	\$2,053,631	Research Project	Addressing Disparities

continued

TABLE C-2 Continued

Organization	Project Budget	Project Type	Funding Announcement
University of North Carolina at Chapel Hill	\$2,092,443	Research Project	Communication and Dissemination Research
University of Alabama at Birmingham	\$9,494,562	Research Project	Testing Multilevel Interventions to Improve Blood Pressure Control in Minority Racial/Ethnic, Low Socioeconomic Status, and/or Rural Populations (UH2/UH3)
Mayo Clinic	\$8,780,420	Research Infrastructure Project	PCORnet: Clinical Data Research Networks (CDRN) Phase II
Vanderbilt University	\$2,061,238	Research Project	Addressing Disparities
Pennington Biomedical Research Center	\$9,854,769	Research Project	Obesity Treatment Options Set in Primary Care for Underserved Populations
University of Illinois at Chicago	\$2,039,965	Research Project	Improving Health Care Systems
University of Pennsylvania	\$2,020,806	Research Project	Asthma Treatment Options for African Americans and Hispanics/Latinos
Emory University	\$2,143,727	Research Project	Assessment of Prevention, Diagnosis, and Treatment Options
University of North Carolina at Chapel Hill	\$2,112,206	Research Project	Assessment of Prevention, Diagnosis, and Treatment Options
University of Kentucky	\$15,496,215	Research Project	The Effectiveness of Transitional Care
Icahn School of Medicine at Mount Sinai	\$3,153,311	Research Project	Asthma Treatment Options for African Americans and Hispanics/Latinos
Georgetown University	\$2,019,316	Research Project	Addressing Disparities

SOURCES: Patient-Centered Outcomes Research Institute (PCORI) Funding Portfolio Search. See https://www.pcori.org/research-results?keywords=%22health%20literacy%22&cf%5B0%5D=field_project_type%3A320#search-results (accessed February 15, 2018).

Summary of Funding Support

With some exceptions, funding support for health literacy research and practice is primarily focused on clinical interventions to reduce health care disparities and facilitate preventive screening and treatment. Both areas are critical to inform the shift in reimbursement and regulatory policy. However, as stated above, there remains little incentive for professionals across a range of disciplines to collaborate and examine health literacy across a range of domains. Funding agencies and organizations should invest in interdisciplinary research and practice that is inclusive of new and experienced investigators. In addition, funding portfolios need to emphasize involving participants in the initial phase of the research project, sharing the research findings with participants and listening for participant feedback, and translating findings to policy makers.

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THE FISCAL CASE FOR HEALTH LITERACY

In the United States, low health literacy is estimated to cost \$105 to \$238 billion each year in direct health care costs. Indirect costs are between \$1.6 to \$3.6 trillion each year [1]. A 3-year study of close to 93,000 veterans found that those with low or limited health literacy cost \$143 million more than those with ample health literacy [2].

There are lots of diverse ways that health literacy can be used to cut costs or boost profits. Some ways to do this are:

- Increase the use of preventive health care
- Lower unneeded emergency room (ER) visits
- Lower preventable stays in the hospital and readmissions
- Lower dosing errors and poor management of chronic conditions [3].

More in depth examples are:

- Massachusetts General Hospital hired a Community Resource Specialist (CRS). This move cut ER visits by 13%. At the same time, they increased annual net savings by 7%. For each \$1 spent on the CRS, Mass General saved \$2.65 [3].
- About 18% of those who received an automated phone call to remind them to have a cancer screening, were screened. This led to an increase of close to \$684,930 in income in just 2 months [4].
- A program to divert those who showed up at the ER for dental problems to a nearby clinic led to a more than \$680,000 in revenue for the clinic. And it gave those patients the right kind of care at the right price [5].
- Patients who got their first colonoscopy and watched an education video had much less anxiety scores the day of the procedure. This led to 18% drop in sedation medicine, as well as, a 14% drop in procedure time [6].
- The *What to Do When Your Child Gets Sick* book gave parents the knowledge to know what to do to deal with their child's health care at home. This is instead of taking their child to urgent care. An average of close to \$1.50 in health care costs for each \$1 spent was saved [7].
- A *What to Do When Your Child Gets Sick* partnership by UCLA and Head Start in California found that Medicaid can save at least \$554 per family each year in direct costs. The savings were attributable to less clinic and ER visits [8].

Health literacy gives a broad range of schemes and tools to support patients, their loved ones, and caregivers. This helps the health of patients while strengthening the bottom line of clinics and health systems.

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THE BEHAVIORAL CASE FOR HEALTH LITERACY

There is proof that health literacy programs help patients get healthy. Some programs try to change one behavior at a time. Other programs try to change more than one behavior at the same time.

Low or limited health literacy can lead to patients acting in ways that negatively affect their health. Patients such as this might use emergency rooms (ER) for care when they don't need to. Or they may spend more days in the hospital. Or they may avoid some types of preventive care such as screenings for cancer and flu shots [1]. Health literacy is a way to help the patient act in ways that can lead to better health.

Here are some ways health literacy has helped:

- The *What to Do When Your Child Gets Sick* books were given to new moms who would soon give birth to a child. This led to less ER use [2].
- An interactive phone call was made to patients who had heart failure. In the first 2 weeks, the percentage of patients who called in to tell their daily weight increased from 28% to 36% [3].
- An adult education class added health literacy into the course. This gave a boost in knowledge of health to the learners [4].
- Health literacy is linked to patient activation. Patient activation helps the patient to know how to treat their chronic conditions such as asthma and high blood pressure. Plus, patients from a study were more likely to act in healthy ways like getting screened for breast cancer and not having to stay in the hospital [5].
- Health literacy plays a role in addressing public health burdens. These would be things like more exercise for people who need to lose weight [6-8], or parents might make the choice to have their child get a flu shot [9].
- Good health literacy plans and having faith in one's ability to care for one's health are key to better health outcomes. As a result, patients tend to get more health screenings when they need them [10, 11]. Plus, patients tend to be more willing to take an HIV test [12], stop smoking [13, 14], care for their asthma [15, 16], and be more honest with their doctor [17, 18].

As we move more towards payment models that are based on value, health literacy gives an upstream payoff in terms of the chance to change patient and population health outcomes.

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THE HEALTH LITERACY CASE FOR HEALTH OUTCOMES

Low health literacy has been found to have a strong link with worse health. It increases the risk of death for seniors. Plus, it can make a person less likely to know how to take their medicine like they should. And there is less of a chance they will know what a health label or message means [1]. A good health literacy plan will yield improved health outcomes and better 30-day readmission rates [2].

Plus, those with low health literacy have been known to use the Emergency Room (ER) more than they should [3]. Those with low health literacy had:

- More than twice the number of ER visits that led to a stay in the hospital,
- 1.4 times the number of hospital visits where they were seen and released, and
- Almost twice the number of total ER visits that were not needed.

A patient who has a good health literacy plan and who feels like he or she knows how to control their health care can do better with:

- Hemoglobin A1c, glucose, and total cholesterol [4]
- Regularly taking diabetic medication [5–7], and
- HIV medication [8].

The same connection between health literacy, self-efficacy, and social support improves mental health outcomes, such as depression, among racial/ethnic minorities [7, 9, 10]. What is the impact on readmission rates?

- Health literacy has been found to be a great source for predicting readmissions that occur in the first 30 days [11, 12].
- Medicare patients with more than basic health literacy had a 12% less risk of coming back to the hospital after a heart attack in the first 30 days. The same group was 16% less likely to actually come back [11].

More studies have found health literacy to be a factor to readmissions. They found it to affect the rates for those who:

- Have diabetes [13],
- Get maintenance dialysis [14],
- Have had heart failure [15],
- Have had a post-discharge fall [16], and
- Are moving to surgical care [17].

There is strong support that addressing health literacy can improve health outcomes.



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THE HEALTH LITERACY CASE FOR QUALITY CARE

The role health literacy plays in patient safety is well known. This is why health literacy is widely endorsed by:

- Institute for Healthcare Improvement and the National Patient Safety Foundation [1],
- Centers for Disease Control and Prevention [2],
- American Medical Association [3],
- Joint Commission [4],
- U.S. Department of Health and Human Services [5], and
- Agency for Healthcare Quality [6].

Health literacy can enhance all six aims of quality improvement [7] and can make health care more:

1. Safe,
2. Effective,
3. Patient centered,
4. Timely,
5. Efficient, and
6. Equitable.

Many studies have looked at the role health literacy plays to help patients take their medicine like they should [8–12]. Some things that help patients are:

- Use universal precautions such as giving exact times to take medicine [13].
- Use only milligrams as the set unit for liquid medicine [14].
- Use oral syringes, not cups, when the dose is small [15].
- Add pictures to voice or text instructions. This will cut down on dosing errors. This helps the patient know and recall what they've been told to do. Both lead to better adherence [16].
- Use medicine labels that are clear and easy to read [17, 18].

Most studies on health literacy and quality focus only on medicine in liquid form. We need more research to understand the role health literacy can play in reducing dosing errors and improving adherence for medicine in other forms.

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IMPROVING PATIENT EXPERIENCE: THE CASE FOR HEALTH LITERACY

Low health literacy has been linked to low patient satisfaction with their health care [1, 2]. Tackling health literacy has been found to boost patient satisfaction in:

- Medicine adherence and management [3-5],
- High blood pressure management [6],
- Getting informed consent [7],
- Eye health education [8], and
- Maternal health education [9].

Plus, when a patient can give their say on their own health care (which is a big part of health literate care), patient satisfaction grows [10–13].

In a recent study of close to 100,000 Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) surveys from hospitals that used videos made by experts:

- 100% of hospitals had a higher aggregate HCAHPS Top Box percentage scores,
- 69% of aggregate Top Box answers were 4% higher or more,
- 86% of hospitals had a higher “doctor communication” dimension scores,
- 62% of hospitals had higher “discharge information” dimension scores, and
- 59% of hospitals had higher “nurse communication” dimension scores [14].

Plus, the use of web-based tools has been known to boost patient satisfaction too. These tools are things like:

- The use of pictures to teach about heart disease [15], and
- The use of web-based tools to help patients with diabetes better track glucose level, talk directly to health care providers, and talk to other patients with diabetes [16].

Satisfaction can be helped by pairing these tools with education and support through the phone [17, 18].

Solutions do not have to be large scale, nor do they need to cost a lot to start. Just the use of simple health literacy universal precautions has been known to help with patient satisfaction. These would be things such as:

- Putting MRI reports into plain language [19],
- Using standard emergency room instructions [20],
- Using audio-recorded messages [21], and
- Urging patients to bring a friend or loved one with them to the visit [22].

Increased satisfaction improves patient experience and leads to more profits. A study done by Accenture found that hospitals whose patients felt their health care was great, made 50% more money [23].



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THE HEALTH EQUITY CASE FOR HEALTH LITERACY

The term equity (or to give health care that is the same for all patients) is one of the six aims of quality care [1]. To reach health equity, we must take out all barriers to good health care. These barriers include things such as being poor or facing discrimination, the result of which might include feeling helpless to change one's life. Or it might be a lack of access to good jobs with fair pay, good education, a safe place to live, and having good health care [2].

Plus, health equity means that we all have the same access to health care knowledge. Health information should be:

- Targeted, tailored, easy to read, understandable, and culturally appropriate, and
- Available where people live, learn, play, work, and worship.

There has been a movement in health justice to make the moral or ethical case for equal access to health information for all patients. This includes the underserved. They tend to lack the means that others have to get and stay healthy [3, 4].

Findings:

- Most of the health literacy research looks at clinical outcomes and the way we use health care [5].
- Most peer-reviewed work (as well as work not published) in health literacy does not look at the social determinants of health at the community nor the patient level [6]
- Health literacy has been found to mediate the effect of race on such health outcomes as:
 - Illness that keeps people from working,
 - Chronic disease,
 - Self-reported health status,
 - Flu vaccination rates,
 - Quality of life,
 - Prostate-specific antigen levels,
 - Medicine adherence, and
 - Enrollment in health insurance [5].

Health care should fit each patient's own life. And they should get the health information where they live and learn. The use of health literacy can improve patient knowledge, attitudes, and skills. And it can be a path to health equity for all [9–11].

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