# IMPROVING HEALTH AND THE BOTTOM LINE: THE CASE FOR HEALTH LITERACY

by Stan Hudson, MA, CDFT, R.V. Rikard, Ph.D., Ioana Staiculescu, MPH, CDFT, and Karen Edison, MD Commissioned by the Roundtable on Health Literacy, Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine 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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Stan Hudson, MA, CDFT Center for Health Policy School of Medicine University of Missouri DC375.10 MA105D Columbia, MO 65212

Phone: 573-884-7549

Email: hudsonst@health.missouri.edu

R.V. Rikard, PhD Michigan State University Department of Media and Information 409 Comm Arts, 404 Wilson Road East Lansing, MI 48824

Phone: 919-995-2721 Email: rvrikard@msu.edu

Ioana Staiculescu, MPH, CDFT Center for Health Policy School of Medicine University of Missouri DC375.10 MA105C

Columbia, MO 65212 Phone: 573-882-6486

Email: staiculescui@health.missouri.edu

Karen Edison, MD
University of Missouri Health System
DC19, MA111
Columbia, MO 65212
573-884-6415
EdisonK@health.missouri.edu

# **Corresponding Author:**

Stan Hudson, MA, CDFT

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#### **EXECUTIVE SUMMARY**

#### What is the case for health literacy?

Health care is a business and health literacy is a tool that can be used to reduce its costs and improve its value. Furthermore, 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 that means they will be able to make better decisions about managing 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. The business model we have now for providing health care is moving from one where we make money by using more health care to one in which 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.

The authors looked at many factors to make the case for health literacy. They include the impact 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 in which 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 using three distinct approaches. To start, we searched for research that showed health literacy's impact on one of the factors above. Next, we interviewed people who work in the field of health literacy. We asked them to send us research they had that showed the impact of health literacy. Then we sent out a survey to health literacy professionals asking for their own stories about health literacy programs that work well in communities, clinics, and adult classes.

#### Why is health literacy so vital?

Health literacy is often defined 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 a way that helps the patients easily use what they've been taught. That means that those who work in health care and public health need to address health literacy

problems that patients (or their loved ones and caregivers) may face. The use of good health literacy interventions is vital for this effort from the "top down and bottom up."

#### 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 to \$3.6 trillion each year. Good health literacy plans are designed 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:

- Lower emergency department (ED) use
- Fewer hospital readmissions
- More screenings to prevent illness and increase proper use of medicines
- Fewer dosing errors

Health literacy approaches can lead to better health outcomes, both for the patient and for health systems which, in turn, can lead to lower costs for people, systems, and society. Giving health literate written and spoken information has been found to help patients find their way through health systems. Plus, a plan developed using health literate principles can help patients get the follow-up care they need, for example coming in for follow-up visits or reporting their weight each day. And a good plan can help patients make better choices that lead to better control of chronic illnesses such as asthma, diabetes, and high blood pressure. Increasing what a patient understands can help that patient better manage his or her health and lead to fewer stays in the hospital. Public health literacy plans also have been found to reduce the total chance for disease.

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, health literacy interventions can help make the health of communities better.

Health literacy approaches also result in better patient satisfaction with their health care. Increased satisfaction helps build trust and rapport for both patients and providers. Trust helps align health care goals set by the patient and the doctor. Research has shown that hospitals with more satisfied patients make more money. What is more, value-based payment models are being designed. 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 following report provides evidence for many ways in which health literacy can change health outcomes through better care at less cost.

## 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 mediate the impact of race and gender for some health outcomes. And good plans tend to reduce racial and ethnic health disparities too.

Health literacy is also the right thing to do to meet current policy demands. For example, the Affordable Care Act (ACA) has many conditions that must be met to provide health care that meets the Culturally and Linguistically Appropriate Standards (CLAS). The ACA also stresses the fact that health literacy must be a part of all health care training. And the ACA streamlines the way patients sign up for health insurance. Those that sell health insurance must write summaries in such a way that patients can understand what their plans cover. And the summary must have clear and concise health information. In much the same way, the rules set up by the Centers for Medicare and Medicaid Services state that health care providers must teach patients in a way that gives a patient the understanding they need to know what to do to get to or stay in good health.

The U.S. does not have a central health agency that sets rules for how best to deliver health care. Therefore, payment models often serve as the main force shaping the way we provide health care. At this time, in the U.S., we often pay for the amount of health care we deliver. As payment methods shift, we will soon pay for the quality of health care we give.

The Medicare Access and CHIP Reauthorization Act set up new rules that pay health systems and clinics to use health literacy methods. These methods help patients get more engaged in managing their health care and improving the course of their care.

#### **Health Literacy and the Future**

There is more and more evidence that using health literacy strategies reduces costs, while boosting the equity, access to health care, and health care quality. As payment models change, clinics and health systems should use good health literacy practices to improve the health of their patients, communities, and profits.

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.

#### 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 at the University of Missouri, and a health literacy expert from Michigan State University to collect evidence that would 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 aims to go beyond the usual readership to gain traction in the C-suites 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.

Sorensen and colleagues (2012, p. 3) developed the following definition of health literacy:

"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 take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course."

We expand on this definition by adding that until we begin teaching health literacy as a life skill in elementary and secondary education as we do reading, writing, and math, we cannot blame the victim by placing the sole responsibility for health decisions 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 potential health literacy challenges that people face.

The importance of integrating and addressing health literacy falls into two primary categories:

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

The roundtable asked us to bring together evidence on the impact of health literacy in achieving the Quadruple Aim (Bodenheimer & Sinsky, 2014). The Quadruple Aim framework focuses on: 1) enhancing the quality of care, 2) improving the health of communities, 3) reducing costs, and 4) improving the care and experience of patients and providers. Health literacy is an essential component of achieving the Quadruple Aim. It 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 & 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 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 other 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 are 13,509 unique articles that include the phrase "health literacy" in either the title, abstract, or keywords. We also used Google Scholar to fill in missing citation information.

#### **Promising Practices (Non-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 impact of health literacy on cost, quality, access, satisfaction, equity, behavior change, organizational change, and other issues outlined in the Statement of Tasks. The team also requested that everyone send us any recently published articles 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 nonpeer 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 were collected using the online survey application Qualtrics (<a href="https://www.qualtrics.com/">https://www.qualtrics.com/</a>). 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 Statement of Tasks, we contacted the organization and conducted in-depth interviews via telephone with an identified organizational leader when allowed. Participants were given the option of providing their name and e-mail address at the end of the survey if they were willing to be contacted for follow-up questions; otherwise, their responses were anonymous.

Respondents (*n*=135) represented programs and institutions from the United States of America, Canada, Germany, Italy, Taiwan, Australia, Japan, Abu Dhabi, etc. The majority (77%) of respondents indicated that they or their organizations worked on a project exploring the impact of health literacy on one or more of the following areas: financial, behaviors, health outcomes, quality of care, patient satisfaction, provider satisfaction, equity, organizational culture, or another area related to the Quadruple Aim. Respondents indicated the primary area that the program explored was: behaviors (43%), financial (20%), patient satisfaction (16%), health outcomes (12%), quality of care (2%), and organizational culture (2%). Approximately, 66% of respondents presented their work at state or national conferences or published the research that resulted from their health literacy programs. The majority of respondents (90%) 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 the studies targeted education or health care. For the projects taking place in educational settings, the different populations studied included eighth grade, suburban middle school students, adults seeking GED or enrolled in literacy classes, English language learners, or 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 or 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, HIV, mental health diagnoses or 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, or 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 communitybased 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;
- Rating by patients of the health information provided by care team members;
- Providing various educational opportunities for healthcare providers;
- Integrating health literacy and teach back into clinical practice;
- Providing health literacy workshops for patients and family caregivers;
- 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 acknowledge 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 are a barrier to 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 (1960, p. 233) famously stated: "economics is all about how people make choices. Sociology is all about why they

don't have any choices to make." 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 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 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 a 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 impacts 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 that are crafted with health literacy in mind are often rejected by the health system legal team. This same dynamic is at play in state Medicaid departments across the U.S.
- 6. There are numerous initiatives and interventions that fall into the broad scope of health literacy but are not called "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% to 5% in total health costs due to limited health literacy for the health care system and a range of \$143 to \$7,798 of additional expenditures for individual patients with low/limited health literacy compared to those with adequate health literacy (Eichler, Wieser, & Brugger, 2009). In 2017, the U.S. is estimated to spend \$3.5 trillion on total health expenditures (CMS, 2016b). Translating Eichler and colleagues reported savings into 2017 U.S. healthcare dollars reflects a potential cost savings of \$105 to \$175 billion a year. Others have estimated

that low health literacy costs the U.S. economy between \$106 to \$238 billion annually in direct health costs and between \$1.6 to \$3.6 trillion annually when you include costs due to current public health activities (or lack of action) that would result from healthy eating, exercising, smoking cessation, etc. (Vernon & Finance, 2007). A three year retrospective service utilization study of nearly 93,000 veterans found that veterans with marginal and inadequate health literacy cost the system \$143 million more than veterans with adequate health literacy (Haun et al., 2015).

More specific research has demonstrated the financial impact 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 which 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, Sanders, Russell, Siegel, & Ganiats, 2016). For example, a computer-delivered intervention targeting HIV medication adherence found a net cost savings per user and per QALY for high health utilizers and wider deployment (Ownby, Waldrop-Valverde, Jacobs, Acevedo, & Caballero, 2013). Using the change in QALYs in the first year, the Life Enhancement Program, a program based on the principles of health literacy, estimated the cost of improved health status for participants was between \$376,400 to \$570,500 lower than other interventions that would produce similar health gains (Pleasant, 2017).

A Prescription to End Confusion documented numerous ways that health literacy can potentially reduce health care costs, including underuse of preventive and other services; inefficient access to health services, such as unnecessary emergency department (ED) visits and preventable hospitalizations; medication errors and mismanagement of chronic conditions; patient noncompliance due to not understanding care instructions; and inappropriate health services, to name a few (Institute of Medicine, 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, Xiang, Han, Yang, & Zhang, 2016), a multi-pronged 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 community health worker-led cancer screening intervention among Korean women (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 education video had significantly lower anxiety scores the day of the procedure and as a result required 18% less sedation medication and had a 14% decrease in procedure time (The Beryl Institute, 2015).

Patients were 11% 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% and, combined with a decline in unnecessary hospitalizations, they experienced a 7% annual net savings on enrolled patients and generated \$2.65 in savings for every dollar spent on the CRS (Vuletich & Farooqi, 2017).

Integrating health literacy can also increase incoming revenue. After implementing automated phone notifications to a group of 3,137 patients with recent orders for a colonoscopy or upper endoscopy, one health system found that 18% of patients contacted got the procedure resulting in \$684,930 of estimated revenue generated during the two-month campaign, based on national averages (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 over \$680,000 while providing savings to patients by ensuring the right level of care at the right price (Pfannenstiel & Brown, 2017).

Some long-standing health literacy programs have demonstrated behavior change that results in direct and indirect cost savings to systems, individuals, and society. For example, the "What to Do When Your Child Gets Sick" has been deployed in numerous places and ways and continues to provide new findings. In Wisconsin the book empowered parents to deal with health problems at home instead of either calling a hospital or clinic, or visiting an ED or urgent care center, demonstrating 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 one year of using the books, with additional support, there was a decrease in ED costs for children < 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% fewer unnecessary doctor visits, 55% fewer emergency room visits, 64% fewer school days missed by children because of illness or injury, and 56% fewer work days missed by parents because of children's illness (O'Neal, 2017). Lastly, a program based on use of the book in a partnership between UCLA 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% reduction in doctor's visits and a 58% reduction in ED visits after implementation (UCLA/Johnson & Johnson Health Care Institute).

#### **Recommended Areas for Future Study**

To date studies have only examined the short-term impact 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. This is especially the case for innovative

programs that propose a paradigm shift in how we share and teach health education such as integrating medical curriculum 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% in intervention vs. 29% 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 (Neighborhood Health Plan, 2008). Sometimes, these returns can be realized very quickly. Significant increases (between 28% to 36%) in those reporting their daily weights occurred within the first two 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, Paasche-Orlow, Bailey, & Wolf, 2011). 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, Bains, & Egede, 2010; Osborn, Cavanaugh, Wallston, & Rothman, 2010; Osborn & Egede, 2010). 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, Sheridan, Donahue, Halpern, & Crotty, 2011). 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, Curtis, Wardle, von Wagner, & Wolf, 2013) and patient activation has been shown to improve management of chronic conditions such as diabetes, high blood pressure, healthy behaviors, and preventive screenings. It has also been shown to reduce ED visits and hospitalizations (Smith et al., 2013). Both patient activation and health literacy have been found to be significantly associated with positive impacts on decision making and patient engagement in healthcare-related activities, healthy

behaviors, and chronic disease self-management (Greene, Hibbard, Tusler, & Institute, 2005; Hibbard, 2013). A more recent study found that patient activation mediates or transfers the relationship between education, health literacy, and hospital utilization, reporting that higher patient activation scores were significantly associated with reduced odds of utilization among Whites (Charlot et al., 2017). Those with higher patient activation scores are more likely to access and use online heath information (Smith, Pandit, Rush, Wolf, & Simon, 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 impact 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 BMI (Zoellner et al., 2016). Health literacy has also been associated with increased physical activity in Latinos (Dominick, Dunsiger, Pekmezi, & Marcus, 2013; Dominick et al., 2015a; Dominick et al., 2015b) 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, 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 as a result of the health literacy instruction (Chervin, Clift, Woods, Krause, & Lee, 2012). Other studies suggest that health literacy and self-efficacy are critical for preventive health screening (Davis et al., 2014; Tiraki & Yilmaz, 2017), intention to take an HIV test (Rikard, Head, & Thompson, 2016), smoking cessation (Parisod, Axelin, Smed, & Salanterä, 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, Maliski, Lewis, Macabasco-O'Connell, & Dimatteo, 2013, 2014).

## Recommended Areas for Future Study

With the growing focus on population health under value-based purchasing, more research is needed on the impact of public health literacy and behavior change in three important areas. First, 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, 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, Sheridan, Donahue, Halpern, & Crotty, 2011). 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 (M. Kim, Kim, Han, Huh, & Nguyen, 2013), regularly taking diabetic medication (Al Sayah, Majumdar, Williams, Robertson, & Johnson, 2013; Hofer et al., 2017; Y. Lee et al., 2016) and HIV medication (Colbert, Sereika, & Erlen, 2013). The same connection between health literacy, self-efficacy, and social support improves mental health outcomes, such as depression, among racial and ethnic minorities (Hernandez & Organista, 2013, 2015; S. Lee, Kang, Kim, & Son, 2013).

Videos and multimedia programs have been showing promise of impacting outcomes. Those who viewed a video education program were more likely to have controlled blood pressure regardless of blood control status (emmi Solutions, 2015b) and experienced shorter lengths of stay for total knee or hip replacement (emmi Solutions, 2015c). Moreover, coupling online interactive media with automated phone calls resulted in a 15-day delay in readmission for chronic obstructive pulmonary disease (COPD) with a 69% reduction in readmission length of stay. This approach also produced a 4-day delay in readmissions for congestive heart failure with a 51% 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 impact 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, Sadikova, Jack, & Paasche-Orlow, 2012). Medicare enrollees with above basic health literacy had a 12% lower risk of 30 day readmission after a heart attack and a 16% 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, Donnell-Jackson, Jhingan, Golden, & Paranjape, 2014), those receiving maintenance dialysis (Flythe, Hilbert, Kshirsagar, & Gilet, 2017), individuals with heart failure (Cox et al., 2017), those who experience post-discharge falls (Jaffee et al., 2016), and those transitioning to surgical care (Martin, Finlayson, & Brooke, 2017).

In addition, numerous evidenced-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 teach-back was found to significantly reduce readmission by 8% for 7-day readmissions and by 10% for 30-day readmissions (Shermont, Pignataro, Humphrey, & Bukoye, 2016). Implementing a patient navigator program for individuals with heart failure resulted in a 15.8% decrease in unplanned readmission (Di Palo, Patel, Assafin, & Pina, 2017). Similarly, individuals receiving post-discharge follow up from a care transition pharmacist were significantly less like to be readmitted within 30 days (Fera, Anderson, Kanel, & Ramusivich, 2014).

There is additional 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 teach-back and patient admission interviews reduced pneumonia readmission rates by 9.62% and heart failure readmission rates by 7.28% in phase one. Phase two 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% (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 impacts on outcomes (Watkins & Xie, 2014). A recent systematic review (H. Kim & Xie, 2017) revealed only nine intervention studies in examining the effect of websites or online apps use on health literacy. Of the nine studies, six educational based interventions among low-literacy adults and older adults report 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 own health care (King, Bickmore, Campero, Pruitt, & Yin, 2013; Mein, Fuentes, Soto Mas, & Muro, 2012; Robinson & Graham, 2010; Strong, Guillot, & Badeau, 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, many findings documented in the sections on the case for finance, behavior, outcomes, satisfaction, and equity also provide sufficient evidence of health literacy's impact

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 heath literacy is widely endorsed through initiatives by the Institute for Healthcare Improvement and the National Patient Safety Foundation (National Patient Safety Foundation, 2017), the Centers for Disease Control (CDC, 2017), the American Medical Association (Weiss, 2007), the Joint Commission (The Joint Commission, 2007), the U.S. Department of Health and Human Services (DHHS, 2010), and the Agency for Healthcare Research and Quality (AHRQ, 2017). Despite the widespread recognition, when one examines the literature for specific studies linked to medical errors, 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, Wolf, Bass, Middlebrooks, et al., 2006; Davis, Wolf, Bass, Thompson, et al., 2006; Institute of Medicine, 2008; Mira, Lorenzo, Guilabert, Navarro, & Perez-Jover, 2015; Persell, Bailey, Tang, Davis, & Wolf, 2010). Even employing simple health literacy universal precautions can make an impact, such as listing specific times to take doses (Davis et al., 2009), using milligram 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, Hassali, Lim, Saleeem, & Tan, 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 Veterans Administration developed and adopted a patient-centered medication label format in an attempt to improve the quality of care for its over 9 million veterans (Trettin, Ahram, Karwowski, & Schmorrow, 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 health literacy can play in reducing non-liquid 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 Healthcare 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, Rios, & Handa, 2017), eye health education (Rhodes et al., 2016), and maternal health education (Stikes, Arterberry, & Cynthia Logsdon, 2015). Shared-decision making models also continue to show much promise in improving patient satisfaction in the health care setting (Bozic KJ, 2013; Joosten et al., 2008; Olomu, Hart-Davidson, Luo, Kelly-Blake, & Holmes-Rovner, 2016; Slover, Shue, & Koenig, 2012).

Using video materials to improve patient knowledge and expectations has been found to enhance patient satisfaction for individuals receiving radiation therapy (Matsuyama, Lyckholm, Molisani, & Moghanaki, 2013), those prepping for a colonoscopy (Hayat, Lee, Lopez, Vargo, & Rizk, 2016), and recent stroke survivors (Denny, Vahidy, Vu, Sharrief, & Savitz, 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% of hospitals had a higher aggregate HCAHPS Top Box percentage. The HCAHPS contains 21 questions on the care that a patient received at a hospital. There are four response choices for each question: Never, Sometimes, Usually, and Always. The "Always" choice is the most positive survey response. In other words, Top-Box means that a higher percentage of patients choose the most positive survey response or literally the "top box" choice which is "Always." The comprehensive study also reported that 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 (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, Lustria, & Rankins, 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, Hageman, King, & Ring, 2013), standardizing emergency room instructions (Isaacman, Purvis, Gyuro, Anderson, & Smith, 1992), employing audio-recorded messages (Santo, Laizner, & Shohet, 2005), and encouraging patients to bring a family member or friend with them to the visit (Rosland, Piette, Choi, & Heisler, 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% higher hospital margins (Collier & Basham, 2015).

## **Provider Experience**

Perhaps due to the recent addition of provider experience to the Triple Aim to form the Quadruple Aim, there is very 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 KJ, 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.

# **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 appropriate choices about their health (Institute of Medicine, 2004; Mayer & Villaire, 2003; Parker, Ratzan, & Lurie, 2003), as well as the duty of public health agencies, professionals, and organizations to ensure that critical health messages to the public are actionable and understandable (Gazmararian, Curran, Parker, Bernhardt, & DeBuono, 2005; Nelson, Schwartzberg, & Vergara, 2005). Mission-based health care 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 care 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 our health care experiences. As such, health literacy is an integral part of the Culturally and Linguistically Appropriate Standards (CLAS) developed by the Department of Health and Human Services (Office of Minority Health, 2013). The Joint Commission adopted these standards and the Affordable Care Act (ACA) contains many conditions related to providing culturally and linguistically 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 clear, consistent and comparable health information in a standardized way (Somers & Mahadevan, 2010).

The Centers for Medicaid and Medicare Services (CMS) has integrated patient understanding in numerous regulations. Under Medicare and Medicaid Program: Conditions of Participation for Home Health Agencies (HHA), § 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 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 their Center for Patient Partnerships in Healthcare have been developing and implementing innovative health information tools to ensure patient understanding and empowerment (American College of Physicians, 2017). The American Board of Pediatrics developed online training modules including a Practice Improvement Module released in 2013 (The American Board of Pediatrics, 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 we 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 prohibits the federal government from providing payments to states for HACs and other provider-preventable conditions as of July 2012 (National Conference of State Legislatures, 2017).

In October of 2017, CMS increased penalties for 30-day readmissions by reducing Medicare payments to facilities whose readmission ratios exceed the national average. This reflects CMS 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 due to payment reforms, such as accountable care organizations, 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. Twenty-two states implemented Medicaid payments through health home models, 26 have Medicaid payments through medical homes, and 12 have implemented delivery system reform incentive payment programs (National Academy for State Health Policy, 2015). Bundled and global payment mechanisms

shift 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 towards value-based purchasing will strengthen in the next few years as the Medicare Access and CHIP Reauthorization Act (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, 2016). Under MACRA, providers will be paid only through two mechanisms: Meritbased 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. Health literacy improvement activities could support:

- 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] (TCPi, 2017).

Under APMs, beginning in 2019 some participating providers will receive lump sum payments through bundled payment, accountable care organizations, and patient-centered medical home models with higher annual payments being implemented in 2026.

## Because It's 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 (IOM, 2001). There has been a movement to

integrate social justice and health literacy, 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 & 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 that "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 healthcare." (Braveman, Arkin, Orleans, Proctor, & Plough, 2017). From a health literacy perspective, health equity also means that everyone has equal access to health information that they 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. One of the reasons people might not have equitable access to appropriate health information is lack of access to health care services. For those with some level of access to health care services, the information provided may meet the needs of some patients and caregivers, while the needs of others are not met.

The majority of health literacy research and interventions are focused on clinical outcomes and health care utilization (Berkman, Sheridan, Donahue, Halpern, Viera, et al., 2011). Most peer-reviewed and non-published 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 keep 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, Sheridan, Donahue, Halpern, & Crotty, 2011). Health literacy also mediated or transferred the effect of both race and sex in interpreting medication labels (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). 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 that examined 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, Monestel-Umaña, & Schulz, 2015).

In a 2015 discussion paper published by the National Academies 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 health literacy evidence-based tools, improved participant knowledge, attitudes, and behaviors and 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 is needed that focuses on the impact 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. In order to achieve health equity, there must exist a more equal power dynamic in health information exchange that values both 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 such as the Affordable Care Act, the National Plan to Improve Health Literacy from the Department of Health and Human Services, and the Plain Writing Act of 2010. They identified 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 that 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 (U. S. DHHS, 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;
- 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; increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy;
- 6. 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 ten attributes of health literate health care organization that highlights 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 that information as they navigate the health care system (IOM, 2012). The ten attributes of a health literate organization are:

- 1. Has leadership that makes health literacy integral to its mission, structure, and operations.
- 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 paper provides clear examples of how organizations and institutions can take immediate steps to improve the way in which 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 such as 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 and professionals working in these areas often operate in silos. Some interventions take place in clinical settings, others in community-based settings. Funding targeting these other areas often does not emphasize health literacy. Likewise, health literacy funding often doesn't include stipulations to examine and study health equity, so there is little incentive to collaborate with professionals and

conduct research across all 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 pre-school and K-12 curriculum, and community based approaches like home visiting programs, after school programs, etc. (Sanders, Shaw, Guez, Baur, & Rudd, 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 US, programs were funded by: state agencies; realigning resources within healt hcare institutions; operational funding; scholarships and fellowship programs; Agency for Healthcare Research and Quality, National Institutes for Health; Center for Disease Control and Prevention; Centers for Medicaid and Medicare Services; Adult Learning Centers; public health funding; private foundations; other grants; donations; and in-kind support.

## Agency for Healthcare Research and Quality (AHRQ)

AHQR is one of the pioneering federal agencies to fund health literacy focused research and initiatives. We searched the AHQR Grants On-line Database (GOLD) system (<a href="https://gold.ahrq.gov/projectsearch/">https://gold.ahrq.gov/projectsearch/</a>) for all funded projects that include "health literacy" in the project title, abstract, or scope of the project. AHQR supported a range of projects from large scale research through the R01 funding mechanism to conference grants using the R13 mechanism from 2003 to 2017. Table 1 presents the number of AHRQ funded health literacy projects classified by funding Portfolio/Program. The two main Portfolio/Program areas for health literacy funded projects are Health Information Technology (IT) and Prevention/Care Management. We point out that both Portfolio/Program areas emphasize evidence to improve quality of health care in terms of access to information and the delivery of services.

Table 1: Agency for Healthcare Research and Quality (AHRQ) - Number of Health			
Literacy Projects Funded by Portfolio/Program Area			
Portfolio/Program	Number		
Comparative Effectiveness	7		

Health Information Technology (IT)	16
Health Services Research, Data and Dissemination	2
Innovation/Emerging Issues	2
Patient Safety	3
Patient-Centered Health Research	1
Prevention/Care Management	16
Value	4

# 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 (<a href="https://report.nih.gov/">https://report.nih.gov/</a>) for currently funded projects that include "health literacy" in the project title, abstract, or scientific terms. The results of the search are presented in Table 2. 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 Libraries of Medicine (NLM) actively supports health literacy projects that address the Quadruple Aim framework. For example, 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 healthcare providers.

Table 2: National Institutes of Health (NIH) – Number of Currently Funde	d Health
Literacy Projects	
Administering Institute or Center	Number
National Center for Advancing Translational Sciences	3
National Center for Complementary and Integrative Health	1
National Cancer Institute	44
National Center for Injury Prevention and Control	1
National Human Genome Research Institute	4
National Heart, Lung, and Blood Institute	13
National Institute on Aging	21
National Institute on Alcohol Abuse and Alcoholism	1
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 on Drug Abuse	2

National Institute on Deafness and Other Communication Disorders	3
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 on Minority Health and Health Disparities	35
National Institute of Neurological Disorders and Stroke	6
National Institute of Nursing Research	18
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 Congress in 2010. PCORI supports comparative clinical effectiveness research, or CER, focusing on outcomes important to patients, caregivers, clinicians, employers, insurers, and policy makers in order to help 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 important questions and concerns. The team searched the PCORI Funding Portfolio for all projects with the phrase "health literacy." Table 3 provides a list of health literacy funded projects, specifically the name of the organizations, budget amount, type, and related funding announcement.

Table 3: 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- 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
The 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 Multi-Level 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 Pennington Biomedical Research Center	\$2,061,238 \$9,854,769	Research Project Research Project	Addressing Disparities Obesity Treatment Options Set in Primary Care for Underserved Populations
University of Illinois at Chicago	\$2,039,965	Research Project	Improving Healthcare 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 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

Source: Patient-Centered Outcomes Research Institute (PCORI) Funding Portfolio Search

(https://www.pcori.org/research-

results?keywords=%22health%20literacy%22&f%5B0%5D=field\_project\_type%3A320#search-results)

#### **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 previously discussed 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. We believe 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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