Health Literacy Research Funded by the NIH for Disease Prevention

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ABSTRACT

Background: Advancing health literacy is a fundamental step toward achieving population health. To that end, the National Institutes of Health (NIH) funded research to increase scientific understanding of how health literacy can reduce disparities and enhance the health of the United States. Objective: This study identified and evaluated NIH-funded health literacy research focusing on disease prevention. Methods: New R01, R03, and R21 research project grants awarded from fiscal year (FY) 2004 to FY 2017 studying health literacy and disease prevention were identified. Study characteristics, including the role of health literacy, how health literacy was measured, populations studied, and study design, were coded for each grant. Administrative grant data were obtained from the NIH's internal database. Research impact was assessed using the relative citation ratio (RCR). Key Results: There were 192 grants studying health literacy and disease prevention awarded by 18 NIH institutes and centers from FY 2004 to FY 2017, covering a wide variety of health conditions including cancer (26.0%), infectious diseases (13.5%), nutrition (8.3%), drug/alcohol use (7.8%), and cardiovascular disease (6.3%). Most grants studied the health literacy skills of patients (88%), with a few studies assessing the health literacy practices of health care providers (2.1%) or systems (1%). There was good representation of populations with traditionally low levels of health literacy, including Black/ African American participants (30.2%), Hispanic/Latinx participants (28.6%), older adults (37%), and people with low income (20.8%). The scientific articles generated by these grants were more than twice (RCR = 2.18) as influential on the field as similar articles. **Conclusions:** The NIH provided support for a wide array of prevention-focused health literacy research. The value of this research is highlighted by the number of funding institutes and centers, the diversity of populations and health conditions studied, and the effect these grants had on the field. Future research should move beyond patient-level health literacy to health literacy practices of health care systems and providers. [HLRP: Health Literacy Research and Practice. 2020, 4(4):e212-e223.]

Plain Language Summary: This study describes health literacy research funded by the National Institutes of Health that focused on disease prevention. These grants sought to prevent a variety of health conditions, but health literacy research over the past 14 years continued to concentrate on the capacity of patients despite increased attention on the health literacy practices of health care providers and systems.

A person's health literacy skills can substantially affect their health. For example, people need the capacity to understand medical advice and public health messages to take preventive actions to improve or maintain their health status. In fact, many studies have linked limited health literacy to less use of preventive services (Bennett et al., 2009; Fortenberry et al., 2001; Scott et al., 2002; White et al., 2008). Accordingly, those with limited health literacy are

more likely to experience emergency department visits and hospitalizations (Cho et al., 2008), and suffer from higher mortality rates (Baker et al., 2007; Sudore et al., 2006).

The burden of limited health literacy at the population level is significant and continues to be unequal. There are 90 million adults in the United States who have limited health literacy, with the prevalence disproportionately higher among racial/ethnic minorities, older adults, people with

low income, and those with less than a high school diploma (Kindig et al., 2004). Furthermore, it is projected that low health literacy is responsible for an additional \$215 billion in health care spending (Rasu et al., 2015). Rasu et al. (2015) estimated that people with public health insurance have significantly lower health literacy scores and significantly higher health care expenditures, thus making limited health literacy an expensive societal problem.

Over the past two decades, the federal government has given substantial attention to advancing our understanding of health literacy. In 2000, improving health literacy became a developmental objective of Healthy People 2010, an evidence-based set of national health promotion goals for the next decade (US Department of Health and Human Services, 2000). Four years later, the Institute of Medicine (IOM) issued the report, "Health Literacy: A Prescription to End Confusion." In the report, the IOM recommended the National Institutes of Health (NIH), as the largest public funder of medical research, increase funding support for health literacy research as a way to improve population health (Kindig et al., 2004). That same year, the NIH issued the first in a series of 12 funding opportunity announcements to encourage research on health literacy and its relation to health outcomes (PAR-04-116: Understanding and Promoting Health Literacy (R01) [National Institutes of Health, 2004a]; PAR-04-117: Understanding and Promoting Health Literacy (R03) [National Institutes of Health, 2004bl).

Advancing knowledge about health literacy can be a tool for disease prevention. In fact, Healthy People 2030 announced one of its overarching goals for the public's health is the attainment of health literacy among all Americans (Office of Disease Prevention and Health Promotion, 2018). The NIH has provided millions of dollars in

grant funding for both investigator-initiated and solicited health literacy research projects for years, yet no systematic assessment of NIH-funded research in health literacy and prevention has occurred to date. Therefore, in this study, we systematically quantify and characterize health literacy research funded by the NIH that addresses disease prevention. In addition, we measure the impact of these studies on their respective fields.

METHODS

Research Grants

To identify NIH-funded health literacy research grants, we performed a search using the agency's internal extramural awards database for new (i.e., type 1, 2, or 9) R01, R03, and R21 research project grants awarded in fiscal year (FY) 2004 to FY 2017 that used the terms "literacy," "literate," "numeracy," or "health communication" in its title, abstract, public health relevance statement, or specific aims. The latter term was included to increase the sensitivity of our search. The search was limited to R01, R03, and R21 grants during this timeframe because NIH efforts to solicit health literacy research projects started in 2004 and involved these three types of grants exclusively. However, the search was not limited to only research grants submitted in response to these solicitations. For this analysis, health literacy was defined broadly as the ability of people to obtain, understand, and use health information (both text and numeric) received verbally, in writing, or by electronic means.

Data Curation

The resulting set of grants was divided evenly between the authors to independently review each grant's full application to determine whether it studied health literacy (i.e., the investigators were measuring health literacy among

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participants, developing methods or tools for measuring health literacy, or studying populations known to be at-risk for low health literacy skills). Grants that failed this validity check were excluded (e.g., those studying literacy development, financial literacy, media literacy). The authors evaluated the validated set of grants to identify specific study characteristics. Characteristics included the role and type of health literacy in the study, what instrument was used to measure health literacy, which populations were studied, at which level the intervention operated, and which health conditions were targeted. The coding within those categories was not mutually exclusive. Results were reviewed jointly for consistency and all grants were validated by both authors.

Coding for the role of health literacy included independent variable, dependent variable, mediator, moderator, methods, or the role was unclear (e.g., studies of populations most likely to experience low health literacy that do not specifically measure health literacy). The type of health literacy studied was either general health literacy, a diseasespecific health literacy, or health numeracy. If health literacy was measured by the investigators, it was categorized as using one of the following tools: the Brief Health Literacy Screener (Chew et al., 2004); eHealth Literacy Scale (Norman & Skinner, 2006); Newest Vital Sign (NVS) (Weiss et al., 2005); Numeracy Scale (Lipkus et al., 2001); Rapid Estimate of Adult Literacy in Medicine (REALM; includes its shortened version and versions for specific fields [Davis et al., 1991]); Short Assessment of Health Literacy (includes for both Spanish-speaking adults and Spanish & English version [Lee et al., 2006; Lee et al., 2010]); Subjective Numeracy Scale (Fagerlin et al., 2007); Test of Functional Health Literacy in Adults (TOFHLA; includes its shortened version [Baker et al, 1999; Parker et al. 1995]); or Other Tool, to cover a variety of less frequently used measures. Coding for populations included race, Hispanic ethnicity, youth (ages 0 to 17 years), adults (age 18 to 64 years), older adults (age 65 years and older), urban, rural, low income, women, and men. If the sample included people with any of these characteristics, then we selected it. The level of intervention was coded as patient, parent/caregiver, health care provider, or health care system depending on the targeted population(s) of the research. For example, "patient" was selected for grants that studied people at risk for low health literacy or if the study measured the health literacy of people receiving health care. "Parent/caregiver" was selected for grants where health literacy skills were measured for parents or caregivers of someone receiving health care. If a grant measured the health literacy skills of clinicians when delivering care, then it would be coded as "health care provider." A study that assessed the ability of a health care system to implement health literate best practices would be coded as "health care system."

To identify grants focusing on prevention, a team of two research analysts individually reviewed the title, abstract, and public health relevance statement and determined whether each grant was conducting prevention research as defined by the NIH Office of Disease Prevention. Specifically, studies must have identified risk or protective factors for disease onset or recurrence, screened for a risk factor or early disease, tested interventions to prevent or slow progression of a disease, or developed methods for prevention research (Murray et al., 2015). The analysts discussed each grant and developed a consensus between them.

All grants identified by the health literacy keyword search that met the prevention research definition were then examined to ascertain the study designs used using the same coding process above. The analysts selected all applicable study designs for each grant: methods research, nonrandomized intervention study, observational study, pilot/feasibility study, randomized intervention study, secondary data analysis, or other/unclear study design. Grants may employ multiple study designs, so selections were not mutually exclusive.

Other Grant Data

Administrative data for each grant were obtained from the NIH's internal database of information on extramural awards. Data collected included the primary institute or center managing the grant, whether it was investigator-initiated or solicited by the NIH, the grant activity code used (i.e., R01, R03, or R21), and the total amount awarded by the NIH during the study period.

The scientific impact of the grants was also measured using the relative citation ratio (RCR) (Hutchins et al., 2016) assigned to each published scientific article that listed one of the grants as a source of funding according to the NIH's internal database on extramural research funding. The RCR was developed as an article-level metric that field-normalizes the number of citations it has received to allow for comparing the impact of articles from disparate fields. The scientific field is determined based on the co-citation network of the article (i.e., the articles listed with the article of interest in reference lists). The RCR is calculated as the number of citations the article received per year, normalized to the number of citations other NIH R01-funded articles received in the same field and same year. Therefore, an

article with an RCR of 1.0 has been cited equally as much per year as the median article funded by an R01 grant from the NIH in the same field and year.

RESULTS

Prevention-Focused Health Literacy Grants

The keyword search yielded 722 new R01, R03, and R21 grants awarded from FY 2004 to FY 2017. Of these, 192 grants (26.6%) sought to measure health literacy or addressed populations with low health literacy and were classified as prevention research. There were 103 R01, 55 R03, and 34 R21 grants. Figure 1 shows the proportional contribution of the 18 NIH institutes and centers that awarded these grants. The National Cancer Institute (NCI) supported the most health literacy research in prevention (34.9%), followed by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) (10.9%), the National Institute of Nursing Research (NINR) (7.3%), the National Heart, Lung, and Blood Institute (NHLBI) (6.8%), and the National Institute of Mental Health (NIMH) (6.8%). Cancer (26%), infectious diseases (13.5%; mostly focused on HIV), nutrition (8.3%), drug/alcohol use (7.8%; mostly focused on tobacco), and cardiovascular disease (6.3%) were the top five health conditions studied (Figure 2).

Beginning in 2004, there was a marked increase in the number of prevention-focused health literacy research grants awarded each year, followed by a leveling off from 2013 to 2017 (Figure 3). Despite the number of awards remaining steady over the last 5 years, the total costs awarded continued to increase, growing from \$17 million in FY 2013 to more than \$26 million in FY 2017. From FY 2009 to FY 2017, the award amounts for health literacy grants in prevention represented a stable 0.19% of the NIH's total funding for all R01, R03, and R21 awards on average each year (National Institutes of Health, 2019). Most of the grants were in response to an NIH funding opportunity announcement, with just 24.9% submitted in response to the health literacy program announcements and 48.2% submitted in response to other topic-specific announcements (Villani, 2018). No data were available for three grants (1.6%). The remaining grants (24.9%) were investigatorinitiated.

During this 14-year period, health literacy was most often studied in randomized intervention studies (49.5%) followed by observational studies (34.4%) and pilot/feasibility studies (26%) (**Table 1**). When measured, health literacy was frequently the independent variable (23.4%), moderator (21.9%), dependent variable (13%), or media-

tor (6.3%). Twenty-three studies (12%) developed and/or tested new instruments for measuring health literacy and were considered method development.

Table 1 shows 71.9% of prevention grants measured general health literacy, 29.2% measured a health condition-specific type of health literacy, and 20.8% measured health numeracy. In total, there were 137 grants (73.3%) that explicitly measured health literacy levels among study participants, with most researchers using the TOFHLA or its short version (25%) followed by the REALM (14.6%), and the NVS (9.9%).

A majority of the grants focused on the health literacy of patients (88%) or parents/caregivers (15.1%), whereas only 2.1% evaluated the health literacy skills of providers, and just 1.0% of grants addressed the health care system (Table 2). The populations studied by health literacy grants in prevention were diverse, with both Black/African American and White people well represented in the studies (79.2% and 75%, respectively). Hispanic/Latinx people were also represented in the studies (61.5%). Most of the grants focused on the general adult population (86.5%), with 37% evaluating health literacy levels of older adults and 19.8% assessing children and adolescents. Studies of only women were more common than studies of only men (21.4% and 4.7%, respectively). About one-fifth of the grants studied people with low incomes. Few grants studied rural populations (8.3%) or low-income populations (20.8%).

As of June 23, 2019, the average RCR for the prevention-focused health literacy grants in our study was 2.16, meaning the articles that were generated from these grants were more than twice as influential than the median NIH-funded article in the same field and year. The 192 grants evaluated in this study generated 998 total publications, with about 40 publications per year.

All Health Literacy Grants

Although the focus of this analysis was prevention-related health literacy research, results are shown for all 368 grants that studied health literacy, including 199 R01, 91 R03, and 78 R21 grants. **Figure A** shows the proportional contribution of the 21 NIH institutes and centers that administered these grants. The NCI supported the most health literacy research overall (25.5%), followed by NINR (10.1%), NICHD (9.8%), NIMH (8.4%), NHLBI (7.9%), the National Institutes on Aging (7.6%), and the National Institutes of Diabetes and Digestive and Kidney Diseases (6.8%). Cancer was the most frequently studied health condition (20.1%), followed by general health (14.7%), infectious diseases (11.1%; mostly focused on HIV), diabetes (8.2%), and cardiovascular disease (6.8%) (**Figure B**).

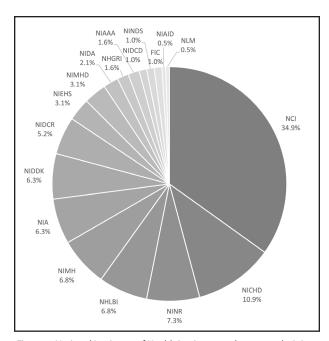


Figure 1. National Institutes of Health institutes and centers administering health literacy research grants in prevention for fiscal years 2004 to 2017 (N = 192). FIC = Fogarty International Center; NCI = National Cancer Institute; NHLBI = National Heart, Lung, and Blood Institute; NHGRI = National Human Genome Research Institute: NIA = National Institute on Aging; NIAAA = National Institute on Alcohol Abuse and Alcoholism; NIAID = National Institute of Allergy and Infectious Diseases; NICHD = Eunice Kennedy Shriver National Institute of Child Health and Human Development: NIDCD = National Institute on Deafness and Other Communication Disorders; NIDCR = National Institute of Dental and Craniofacial Research; NIDDK = National Institute of Diabetes and Digestive and Kidney Diseases; NIDA = National Institute on Drug Abuse; NIEHS = National Institute of Environmental Health Sciences; NIMH = National Institute of Mental Health; NIMHD = National Institute on Minority Health and Health Disparities; NINDS = National Institute of Neurological Disorders and Stroke; NINR = National Institute of Nursing Research; NLM = National Library of Medicine.

Table A shows that the broader group of NIH-funded health literacy research grants followed a similar pattern as the subset of grants focused on prevention research. Overall, 44% conducted randomized intervention studies and 34.2% were observational studies. Almost 80% of the grants measured general health literacy, and 31.5% used TOFHLA. Health literacy was often the independent variable (30.2%), moderator (19.8%), or dependent variable (15.8%) under study.

The NIH-funded health literacy research grants showed good representation from Black/African American (83.2%), White (79.6%), and Hispanic/Latinx communities (71.7%) (**Table B**). Most of the grants studied women and men (82.3%), but 13.6% studied only women and 4.1% studied only men. The focus of these grants was usually the general adult population (87.8%), followed by older adults (45.7%). Urban populations were enrolled in 34% of the grants, whereas rural populations participated in 8.2% of the grants.

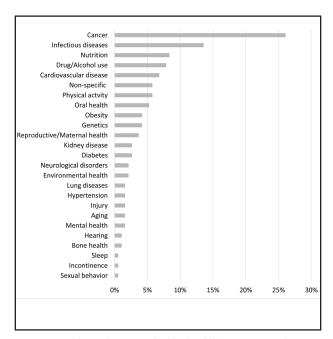


Figure 2. Health conditions studied by health literacy research grants in prevention for fiscal year 2004 to fiscal year 2017 (N = 192). Note that the percentages do not sum to 100% because some grants study more than one health condition.

DISCUSSION

The results reveal an increasing trend in new health literacy grants awarded by the NIH with a focus on disease prevention. This research portfolio grew steadily from 2004 through 2012 in accordance with NIH's issuance of 12 funding opportunity announcements on health literacy from 2004 to 2013. Despite this parallel timing, most of the grants in this study responded to other NIH solicitations. This finding indicates that health literacy research is being integrated into many different fields of study, as was recommended by Parker and Ratzan (2010). The number of institutes and centers administering these grants and the variety of health conditions studied provides additional evidence that health literacy is increasingly seen as an important factor across several medical disciplines.

Overall, the grants evaluated in this study enrolled a diverse set of participants. Low health literacy is prevalent among ethnic/racial minorities, older adults, people with less education, and people with public health insurance or no health insurance (Kutner et al., 2006). Using low income as a proxy for less education and either Medicaid coverage or no insurance coverage, these grants had good representation of populations at risk for facing health literacy challenges. This finding is important because previous research has demonstrated health literacy contributes to disparities in health (Bennett et al., 2009; Sentell & Halpin, 2006).

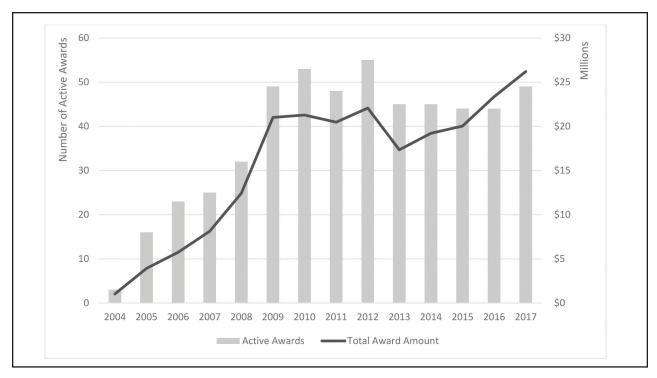


Figure 3. National Institutes of Health total award amounts and number of active awards for health literacy research grants in prevention from fiscal year 2004 to fiscal year 2017 (N = 192). The bars on the graph represent active grants in each year of the grant award period, and the line shows the award amounts for each year a grant is active.

Furthermore, some have advocated for more integration of health literacy measurement into disparities research (Paasche-Orlow & Wolf, 2010; Parker et al., 2003). A future study could investigate to what extent this integration is being done.

Despite increasing attention on improving the health literacy practices of health care providers (Lambert et al., 2014; Rajah et al., 2018), most of the studies in this analysis focused on patient-level health literacy. Parker and Ratzan (2010) described health literacy as the alignment of patients' skills and abilities to obtain health information and services with the ease of use and accessibility of information provided by health care systems. Given its dual nature, more health literacy studies should focus on how providers and systems deliver health information. In fact, health literacy experts developed a list of 10 attributes of health care organizations that exemplify health literacy best practices (Brach et al., 2012). One of these systems-level health literacy practices has been linked to greater patient knowledge and better health behaviors (Kaphingst et al., 2014). In addition, quality improvement measures for organizational health literacy were recently developed (Brega et al., 2019) and may serve as a valuable resource for systems-level change to improve population health. Additional research is

needed to examine the impact of these provider- and systems-level health literacy practices on patient outcomes.

The value of this research is underscored by the impact these grants have had on scientific understanding about health literacy. An RCR of 2.16 means, on average, scientific articles from this set of health literacy research grants were cited more than twice as much compared to similar scientific articles published in the same field and year. The high proportion of randomized study designs used by these grants may have contributed to a relatively high measure of influence.

A comparison between the prevention-focused health literacy grants and the health literacy grants overall yielded few differences in the proportions of observed characteristics. Prevention-focused health literacy grants had a higher percentage of randomized intervention studies, whereas all health literacy grants had a higher percentage of nonrandomized intervention studies. The health literacy grants in prevention measured a health condition-specific type of health literacy and health numeracy more often than health literacy grants overall. Additionally, more health literacy grants overall studied diabetes and mental health compared to the health literacy grants in prevention.

TABLE 1

Study Characteristics of NIH-Funded Health Literacy Research Grants in Prevention,
Fiscal Year 2004 to Fiscal Year 2017 (N = 192)

Characteristic	%	n
Study design		•
Randomized intervention study	49.5	95
Observational study	34.4	66
Pilot/feasibility study	26	50
Methods research	15.1	29
Secondary data analysis	10.9	21
Nonrandomized intervention study	8.9	17
Unclear/other design	3.1	6
Role of health literacy		
Unclear role	37.5	72
Independent variable	23.4	45
Moderator	21.9	42
Dependent variable	13	25
Methods development	12	23
Mediator	6.3	12
Health literacy tool		
Test of Functional Health Literacy for Adults ^a	25	48
Rapid Estimate of Adult Literacy ^b	14.6	28
Newest Vital Sign ^c	9.9	19
Brief Health Literacy Screener ^d	6.3	12
Numeracy Scale ^e	5.7	11
Subjective Numeracy Scale ^f	5.2	10
eHealth Literacy Scale ⁹	3.6	7
SAHL-S&E ^h or SAHLSA ⁱ	3.6	7
Other tools	29.7	57
Type of health literacy		
General health literacy	71.9	138
Condition-specific health literacy	29.2	56
Health numeracy	20.8	40

Note. Study characteristics are not mutually exclusive. Sum is not always 368 and percentages do not always equal 100%. SAHL-S&E = Short Assessment of Health Literacy for both Spanish & English; SAHLSA = Short Assessment of Health Literacy-Spanish. *Parker et al. (1995), Baker et al. (1999). *Davis et al. (1991). *Weiss et al. (2005). *Chew et al. (2004). *Lipkus et al. (2001). *Fagerlin et al. (2007). *Norman & Skinner (2006). *Lee et al. (2006). *Lee et al. (2010).

STUDY LIMITATIONS

The findings of this study are limited by the parameters set during the query of the NIH's internal database and the data curation process. The search included only three grant activity codes (i.e., R01, R03, and R21). Although it is possible that the NIH funded health literacy research in prevention using other grant activity codes, it is unlikely that the grants missed would have significantly affected the results of this study. Furthermore, the keywords used to identify the grants evaluated

in this study may have missed some health literacy research, especially if the investigators used a different term in their grant applications. However, studies specifically measuring the health literacy levels of their participants are unlikely to omit the term "literacy" or "numeracy" and, therefore, would have been captured by the search strategy. In fact, all grants that were submitted to NIH in response to 1 of the 12 health literacy funding opportunity announcements were captured by the search strategy. Another limitation relates to how the

TABLE 2
Population Characteristics of NIH-Funded Health Literacy Research Grants in Prevention, Fiscal Year 2004 to Fiscal Year 2017 (N = 192)

Characteristic	%	n
Population level		
Patients	88	169
Parent/caregiver	15.1	29
Provider	2.1	4
Health care system	1	2
Race/ethnicity		
Black/African American	79.2	152
White	75	144
Hispanic/Latinx	61.5	118
Asian	53.6	103
American Indian/Alaskan Native	41.7	80
Native Hawaiian/Pacific Islander	31.8	61
Sex		
Female	21.4	41
Male	4.7	9
Female and male	74	142
Age		
Adults	86.5	166
Older adults	37	71
Youth	19.8	38
Other demographics		
Urban	32.8	63
Low income	20.8	40
Rural	8.3	16

Note. Population characteristics are not mutually exclusive. Sum is not always 192 and percentages do not always equal 100%.

grants were manually coded for specific study characteristics; however, each grant was reviewed and coded independently by at least two investigators to ensure consistency. Types of prevention research and study designs were identified by research analysts who were trained to recognize these areas as part of another study (Murray et al., 2018). Study characteristics related to health literacy and population demographics were identified by the authors using the full grant proposal to establish the appropriate classifications.

CONCLUSION

In recent years, the NIH has supported a steady number of health literacy research grants focused on disease prevention. These studies have contributed to scientific

understanding of health literacy in large part because of the range of health topics addressed, the representation of populations with risk factors studied, and the influence these grants have had on the field. With additional research on systems-level health literacy and its impact on patient health outcomes, it may be possible to achieve Healthy People 2030's goal of attaining health literacy among all Americans. These focused efforts are necessary to move the needle toward a health literate society.

REFERENCES

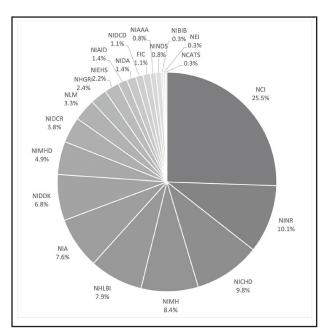
Baker, D. W., Williams, M. V., Parker, R. M., Gazmararian, J. A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling*, 38(1):33-42. https://doi.org/10.1016/s0738-3991(98)00116-5 PMID:14528569

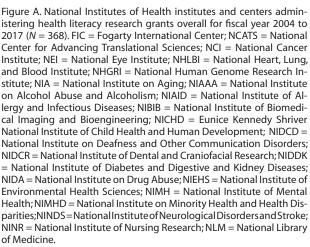
- Baker, D. W., Wolf, M. S., Feinglass, J., Thompson, J. A., Gazmararian, J. A., & Huang, J. (2007). Health literacy and mortality among elderly persons. *Archives of Internal Medicine*, 167(14), 1503-1509. https://doi.org/10.1001/archinte.167.14.1503 PMID:17646604
- Bennett, I. M., Chen, J., Soroui, J. S., & White, S. (2009). The contribution of health literacy to disparities in self-rated health status and preventive health behaviors in older adults. *Annals of Family Medicine*, 7(3), 204-211. https://doi.org/10.1370/afm.940 PMID:19433837
- Brach, C., Keller, D., Hernandez, L. M., Baur, C., Dreyer, B., Schyve, P., & Schillinger, D. (2012). Ten attributes of health literate health care organizations. Retrieved from National Academy of Medicine website: https://nam.edu/perspectives-2012-ten-attributes-of-health-literate-health-care-organizations/
- Brega, A. G., Hamer, M. K., Albright, K., Brach, C., Saliba, D., Abbey, D., & Gritz, R. M. (2019). Organizational health literacy: Quality improvement measures with expert consensus. *Health Literacy Research and Practice*, 3(2), e127-e146. https://doi.org/10.3928/24748307-20190503-01 PMID:31294314
- Chew, L. D., Bradley, K. A., & Boyko, E. J. (2004). Brief questions to identify patients with inadequate health literacy. *Family Medicine*, 36(8), 588-594. PMID:15343421
- Cho, Y. I., Lee, S.-Y. D., Arozullah, A. M., & Crittenden, K. S. (2008). Effects of health literacy on health status and health service utilization amongst the elderly. *Social Science & Medicine*, 66(8), 1809-1816. https://doi.org/10.1016/j.socscimed.2008.01.003 PMID:18295949
- Davis, T. C., Crouch, M. A., Long, S. W., Jackson, R. H., Bates, P., George, R. B., & Bairnsfather, L. E. (1991). Rapid assessment of literacy levels of adult primary care patients. *Family Medicine*, 23(6), 433-435. PMID:1936717
- Fagerlin, A., Zikmund-Fisher, B. J., Ubel, P. A., Jankovic, A., Derry, H. A., & Smith, D. M. (2007). Measuring numeracy without a math test: Development of the Subjective Numeracy Scale. *Medical Decision Making*, 27(5), 672-680. https://doi.org/10.1177/0272989X07304449 PMID:17641137
- Fortenberry, J. D., McFarlane, M. M., Hennessy, M., Bull, S. S., Grimley, D. M., St Lawrence, J., Stoner, B. P., & VanDevanter, N. (2001). Relation of health literacy to gonorrhoea related care. Sexually Transmitted Infections, 77(3), 206-211. https://doi.org/10.1136/sti.77.3.206 PMID:11402232
- Hutchins, B. I., Yuan, X., Anderson, J. M., & Santangelo, G. M. (2016). Relative citation ratio (RCR): A new metric that uses citation rates to measure influence at the article level. *PLoS Biology*, 14(9), e1002541. https://doi.org/10.1371/journal.pbio.1002541 PMID:27599104
- Kaphingst, K. A., Weaver, N. L., Wray, R. J., Brown, M. L., Buskirk, T., & Kreuter, M. W. (2014). Effects of patient health literacy, patient engagement and a system-level health literacy attribute on patientreported outcomes: A representative statewide survey. BMC Health Services Research, 14(1), 475. https://doi.org/10.1186/1472-6963-14-475 PMID:25288179
- Kindig, D. A., Panzer, A. M., & Nielsen-Bohlman, L. (Eds). (2004). Health literacy: A prescription to end confusion. Retrieved from National Academies Press website: https://www.nap.edu/catalog/10883/ health-literacy-a-prescription-to-end-confusion.
- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy. Retrieved from National Center for Education Statistics website: https://nces.ed.gov/pubs2006/2006483.pdf
- Lambert, M., Luke, J., Downey, B., Crengle, S., Kelaher, M., Reid, S., & Smylie, J. (2014). Health literacy: Health professionals' understandings and their perceptions of barriers that Indigenous patients encounter. *BMC Health Services Research*, 14(1), 614. https://doi.org/10.1186/s12913-014-0614-1 PMID:25471387

- Lee, S. Y. D., Bender, D. E., Ruiz, R. E., & Cho, Y. I. (2006). Development of an easy-to-use Spanish Health Literacy test. *Health Services Research*, 41(4 Pt 1), 1392-1412. https://doi.org/10.1111/j.1475-6773.2006.00532.x PMID:16899014
- Lee, S. Y. D., Stucky, B. D., Lee, J. Y., Rozier, R. G., & Bender, D. E. (2010). Short Assessment of Health Literacy–Spanish and English: A comparable test of health literacy for Spanish and English speakers. Health Services Research, 45(4), 1105-1120. https://doi.org/10.1111/j.1475-6773.2010.01119.x PMID:20500222
- Lipkus, I. M., Samsa, G., & Rimer, B. K. (2001). General performance on a numeracy scale among highly educated samples. *Medical Decision Making*, 21(1), 37-44. https://doi.org/10.1177/0272989X0102100105 PMID:11206945
- Murray, D. M., Cross, W. P., Simons-Morton, D., Engel, J., Portnoy, B., Wu, J., Watson, P. A., & Olkkola, S. (2015). Enhancing the quality of prevention research supported by the National Institutes of Health. *American Journal of Public Health*, 105(1), 9-12. https://doi. org/10.2105/AJPH.2014.302057 PMID:25393184
- Murray, D. M., Villani, J., Vargas, A. J., Lee, J. A., Myles, R. L., Wu, J. Y., Mabry, P. L., & Schully, S. D. (2018). NIH primary and secondary prevention research in humans during 2012-2017. *American Journal of Preventive Medicine*, 55(6), 915-925. https://doi.org/10.1016/j. amepre.2018.08.006 PMID:30458950
- National Institutes of Health. (2004a). PAR-04-116: *Understanding and promoting health literacy (R01)*. Retrieved from https://grants.nih.gov/grants/guide/pa-files/par-04-116.html
- National Institutes of Health. (2004b). PAR-04-117: *Understanding and Promoting Health Literacy (R03)*. Retrieved from https://grants.nih.gov/grants/guide/pa-files/par-04-117.html
- National Institutes of Health. (2019). *Budget and spending*. Retrieved from https://report.nih.gov/budget_and_spending/index.aspx
- Norman, C. D., & Skinner, H. A. (2006). eHEALS: The eHealth Literacy Scale. *Journal of Medical Internet Research*, 8(4), e27. https://doi.org/10.2196/jmir.8.4.e27 PMID:17213046
- Office of Disease Prevention and Health Promotion. *Healthy People 2030 Framework*. (2018). Retrieved from https://www.healthypeople.gov/2020/About-Healthy-People/Development-Healthy-People-2030/Proposed-Framework
- Paasche-Orlow, M. K., & Wolf, M. S. (2010). Promoting health literacy research to reduce health disparities. *Journal of Health Communica*tion, 15(Suppl. 2), 34-41. https://doi.org/10.1080/10810730.2010.49 9994 PMID:20845191
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, 10(10), 537-541. https://doi.org/10.1007/bf02640361 PMID:8576769
- Parker, R., & Ratzan, S. C. (2010). Health literacy: A second decade of distinction for Americans. *Journal of Health Communication*, 15(Suppl. 2), 20-33. https://doi.org/10.1080/10810730.2010.50109 4 PMID:20845190
- Parker, R. M., Ratzan, S. C., & Lurie, N. (2003). Health literacy: a policy challenge for advancing high-quality health care. *Health Affairs*, 22(4), 147-153. https://doi.org/10.1377/hlthaff.22.4.147 PMID:12889762
- Rajah, R., Ahmad Hassali, M. A., Jou, L. C., & Murugiah, M. K. (2018). The perspective of healthcare providers and patients on health literacy: A systematic review of the quantitative and qualitative studies. *Perspectives in Public Health*, 138(2), 122-132. https://doi. org/10.1177/1757913917733775 PMID:28980881
- Rasu, R. S., Bawa, W. A., Suminski, R., Snella, K., & Warady, B. (2015).
 Health literacy impact on national healthcare utilization and expen-

- diture. International Journal of Health Policy and Management, 4(11), 747-755. https://doi.org/10.15171/ijhpm.2015.151 PMID:26673335
- Scott, T. L., Gazmararian, J. A., Williams, M. V., & Baker, D. W. (2002). Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Medical Care*, 40(5), 395-404. https://doi.org/10.1097/00005650-200205000-00005 PMID:11961474
- Sentell, T. L., & Halpin, H. A. (2006). Importance of adult literacy in understanding health disparities. *Journal of General Internal Medicine*, 21(8), 862-866. https://doi.org/10.1111/j.1525-1497.2006.00538.x PMID:16881948
- Sudore, R. L., Yaffe, K., Satterfield, S., Harris, T. B., Mehta, K. M., Simonsick, E. M., Newman, A. B., Rosano, C., Rooks, R., Rubin, S. M., Ayonayon, H. N., & Schillinger, D. (2006). Limited literacy and mortality in the elderly: The health, aging, and body composition study. *Journal of General Internal Medicine*, 21(8), 806-812. https://

- doi.org/10.1111/j.1525-1497.2006.00539.x PMID:16881938
- US Department of Health and Human Services (2000). Healthy people 2010; with understanding and improving health and objectives for improving health (2nd ed., Vol. 1). Washington, DC: United States Government Printing Office.
- Villani, J. (2018). [Grants awarded by National Institutes for Health for health litracy: Fiscal years 2004-2017.] Unpublished raw data.
- Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. A., Pignone, M. P., Mockbee, J., & Hale, F. A. (2005). Quick assessment of literacy in primary care: The newest vital sign. *Annals of Family Medicine*, 3(6), 514-522. https://doi.org/10.1370/afm.405 PMID:16338915
- White, S., Chen, J., & Atchison, R. (2008). Relationship of preventive health practices and health literacy: A national study. American Journal of Health Behavior, 32(3), 227-242. https://doi.org/10.5993/ AJHB.32.3.1 PMID:18067463





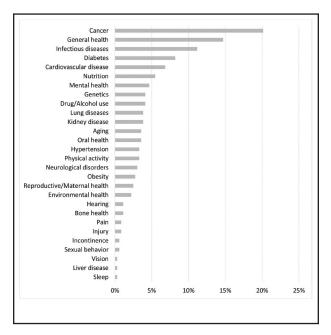


Figure B. Health conditions studied by health literacy research grants overall from fiscal year 2004 to fiscal year 2017 (N = 368). Note that the percentages do not sum to 100% because some grants study more than one health condition.

TABLE A

Study Characteristics of National Institutes of Health-Funded Health Literacy Research Grants Overall from Fiscal Year 2004 to Fiscal Year 2017 (N = 368)

Characteristic	%	n
Study design		
Randomized intervention study	44	162
Observational study	34.2	126
Pilot/feasibility study	23.6	87
Nonrandomized intervention study	14.4	53
Methods research	14.1	52
Secondary data analysis	9.5	35
Unclear/other design	1.6	6
Role of health literacy		
Unclear role	31.5	116
Independent variable	30.2	111
Moderator	19.8	73
Dependent variable	15.8	58
Methods development	10.6	39
Mediator	5.7	21
Health literacy tool		
Test of Functional Health Literacy for Adults ^a	31.5	116
Rapid Estimate of Adult Literacy ^b	16.8	62
Newest Vital Sign ^c	9.2	34
Brief Health Literacy Screener ^d	6.8	25
Numeracy Scale ^e	4.1	15
Subjective Numeracy Scale ^f	4.1	15
eHealth Literacy Scale ^g	4.1	15
SAHL-S&E ^h or SAHLSA ⁱ	3.8	14
Other tools	24.7	91
Type of health literacy		
General health literacy	78.8	290
Condition-specific health literacy	25.3	93
Health numeracy	16.8	62

Note. Study characteristics are not mutually exclusive. Sum is not always 368 and percentages do not always equal 100%. SAHL-S&E = Short Assessment of Health Literacy for both Spanish & English; SAHLSA = Short Assessment of Health Literacy-Spanish. *Parker et al. (1995), Baker et al. (1999). *Davis et al. (1991). *Weiss et al. (2005). *Chew et al. (2004). *Lipkus et al. (2001). *Fagerlin et al. (2007). *Norman & Skinner (2006). *Lee et al. (2006). *Lee et al. (2010).

TABLE B

Population Characteristics of National Institutes of Health-Funded Health Literacy
Research Grants Overall from Fiscal Year 2004 to Fiscal Year 2017 (N = 368)

Characteristic	%	n
Population level		
Patients	89.9	331
Parent/caregiver	12.5	46
Provider	3	11
Health care system	1.1	4
Race/ethnicity		
Black/African American	83.2	306
White	79.6	293
Hispanic/Latinx	71.7	264
Asian	57.3	211
American Indian/Alaskan Native	41.3	152
Native Hawaiian/Pacific Islander	31	114
Sex		
Female	13.6	50
Male	4.1	15
Female and male	82.3	303
Age		
Adults	87.8	323
Older adults	45.7	168
Youth	16	59
Other demographics		
Urban	34	125
Low income	22.6	83
Rural	8.2	30

 $Note.\ Population\ characteristics\ are\ not\ mutually\ exclusive.\ Sum\ is\ not\ always\ 368\ and\ percentages\ do\ not\ always\ equal\ 100\%.$