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How the U.S. Agency for Healthcare Research and Quality Promotes Health Literate Health Care

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Abstract

This report traces the U.S. Agency for Healthcare Research and Quality's (AHRQ) strategic approach to promote health literate health care delivery systems. For almost 15 years, the AHRQ Health Literacy Action Plan has served as the framework for the Agency's efforts to: 1) Develop Measures; 2) Improve the Evidence Base and Create Implementation Tools; 3) Create and Support Change; 4) Disseminate and Transfer Knowledge and Tools; and 5) Practice What We Preach. Drawing upon its core competencies in data and measurement, practice improvement, and health services research, AHRQ accelerated the uptake of evidence-based health literacy strategies by health care organizations.

Keywords

Health literacy; quality improvement; health systems; implementation; knowledge transfer

1. Introduction

This report describes the role of the Agency for Healthcare Research and Quality (AHRQ) as a leader in improving health literacy in health care delivery systems. AHRQ's niche in the U.S. Department of Health and Human Services (HHS) is to help improve how health care is delivered and to make sure the care people receive is high quality, safe, and high value. AHRQ has no regulatory authority, nor is it a payer for health care services. Rather, the agency strives to improve the lives of patients through health services research, practice improvement, and data analytics. AHRQ's work typically targets clinicians and health systems to help them have the best evidence and tools to improve the delivery of care.

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This report describes AHRQ's strategic approach to promoting health literacy from 2005 to 2018. Using the framework of the AHRQ Health Literacy Action Plan, the authors describe how AHRQ used its strengths in innovation and implementation to increase awareness about health literacy and provide the science, the data, and the tools for practice improvement.

2. The AHRQ Health Literacy Action Plan

AHRQ was part of the first national efforts to promote health literacy. In 2004, AHRQ and the Institute of Medicine (IOM) held a joint press conference to release AHRQ's ground-breaking review of evidence linking low literacy to poor health outcomes and the IOM's landmark report, 'Health Literacy: A Prescription to End Confusion' [1-2]. AHRQ's health literacy work intensified after the formation of the HHS Health Literacy Work Group. For the first time, an objective to improve health literacy had been included in the national health promotion program - *Healthy People* [3]. As part of this effort, Cynthia Baur (then-chair of the HHS Health Literacy Workgroup) asked all HHS agencies to form their own health literacy workgroups to foster health literacy improvement.

The AHRQ Health Literacy Workgroup quickly decided that in order to have an impact, it needed to educate AHRQ's senior leadership about health literacy. The Workgroup got on the agenda of AHRQ's Executive Management Meeting and made the case that addressing health literacy was fundamental to achieving the goals of each of AHRQ's portfolios of work. AHRQ's receptive leadership invited the Workgroup to return with a proposal for action.

In 2005, AHRQ leadership approved five points of the AHRQ Health Literacy Action Plan: 1) Develop Measures; 2) Improve the Evidence Base and Create Implementation Tools; 3) Create and Support Change; 4) Disseminate and Transfer Knowledge and Tools; and 5) Practice What We Preach. This report traces AHRQ's progress in implementing that Action Plan during the next decade and a half. Table 1 provides a summary of AHRQ's work within these five areas.

3. Developing Health Literacy Measures

Although AHRQ grantees have developed some measures of individuals' health literacy, AHRQ's main contribution to health literacy measurement has focused on organizational health literacy (OHL), i.e., measuring whether an organization makes it easy for people to navigate, understand, and use information and services to take care of their health [4-6]. AHRQ's work in health literacy measurement has accomplished three important goals. The first is to provide validated questions for health systems to get specific feedback on provider-patient communication. The second is to capture national progress on whether health care providers are using health literacy strategies and are making it easier for their patients to understand what they need to do to manage their conditions and take care of their health. The third is to impel the frontier of OHL measurement by publicizing how organizations can and are using metrics in their OHL improvement efforts.

AHRQ has developed a family of surveys that capture patient experiences in a variety of health care settings, with providers, and with health plans – the Consumer Assessment of

Healthcare Providers and Systems (CAHPS®). The communication composite items are a core part of the CAHPS surveys. They ask people whether their providers: 1) listened carefully to them; 2) explained things in a way that was easy to understand; 3) showed respect for what they had to say; and 4) spent enough time with them.

AHRQ wanted to develop additional items that would provide specific, actionable information to guide and track the impact of health literacy improvement activities undertaken by health care organizations. AHRQ used the rigorous CAHPS survey development process to develop health literacy supplemental items for the CAHPS Clinician and Group Survey, a survey to assess patient experiences with health care providers and staff in ambulatory care practices [7].

AHRQ conducted an environmental scan to identify domains of interest and relevant survey items, issued a Call for Measures in the U. S. Federal Register, interviewed health literacy experts and held stakeholder meetings, and drafted new survey items when existing items could not be adapted. The survey was translated into Spanish using the CAHPS protocol, and cognitive interviews were conducted in English and Spanish to determine whether the items were understood as intended. After adjustments were made and additional cognitive interviews conducted, the survey was field tested and psychometrically assessed. The result was a set of 30 supplemental items from which health systems can select to use with the CAHPS Clinician and Group Survey. Each item captures a distinct communication behavior (e.g., using unfamiliar medical words, talking too fast, failing to answer questions) that could be targeted for improvement. This process was repeated to generate supplemental health literacy item sets for the Health Plan and Hospital CAHPS surveys.

AHRQ measures are used to track national progress in improving health care providers' communication skills. AHRQ produced data for *Healthy People 2010* by inserting the four Health Plan CAHPS items from the communication composite into AHRQ's national household Medical Expenditure Panel Survey (MEPS). For *Healthy People 2020,* AHRQ added additional items from the Health Plan CAHPS Item Set of Addressing Health Literacy into MEPS. One of the metrics tracks the proportion of adults whose providers always initiated a teach-back method (i.e., how often providers asked them to describe how they would follow instructions), and another tracks the proportion of adults who always were offered help with forms at their physician's office. Table 2 shows data collection began with the 2011 fielding of MEPS, and, as of 2015, the metrics have increased significantly [8]. These data, which also suggest there is substantial room for improvement, also are analyzed and reported in the National Healthcare Quality and Disparities Report [9].

AHRQ also has explored methods to assess organizational health literacy improvement that does not rely on patient surveys. To avoid reinventing the wheel, AHRQ sought out OHL measures already in use by health care organizations. In addition to issuing a Call for Measures in the U.S. Federal Register and conducting a literature review, AHRQ interviewed 20 organizations that were working on OHL. A total of n=233 non-patient-reported organizational health literacy measures were identified. Using a modified Delphi process, consensus was reached that 22 OHL quality improvement (QI) measures were useful, meaningful, feasible, and had face validity [10].

4. Improving the Evidence Base and Creating Implementation Tools

Since AHRQ is key funder of health services research, improving the evidence base about health literacy was an inherent component of the AHRQ Health Literacy Action Plan. In 2004, AHRQ joined the National Institutes of Health in co-sponsoring program announcements, 'Understanding and Promoting Health Literacy.' Although it remained a co-sponsor of the health literacy program announcements until 2012, AHRQ ultimately funded relatively few health literacy grants through this mechanism. The Agency's more significant contribution to solidifying health literacy's evidence base during this time period was the commissioning and 2011 publication of an updated systematic review of the literature. 'Health Literacy Interventions and Outcomes: An Updated Systematic Review,' that identified strategies, such as multi-component self-management interventions, which mitigate the effect of low health literacy [11].

However, the availability of increased evidence rarely is sufficient (by itself) to change the behavior of health care providers. Indeed, health care providers need to know *how* to make changes. As a result, AHRQ has invested in the creation of a variety of tools and training to make it easier for health systems and clinicians to implement evidence-based health literacy strategies.

The first and best known is the AHRQ Health Literacy Universal Precautions Toolkit [12]. Prior to the toolkit's adoption, AHRQ observed an increased awareness and interest among some health care providers to offset limited health literacy, which was perceived as a barrier to achieve good health outcomes. AHRQ responded by commissioning a toolkit to explain how primary care practices could adopt health literacy 'universal precautions' - specific actions predicated on the assumption that all patients may have difficulty comprehending health information and accessing health services. AHRQ's toolkit, first published in 2010, became a touchstone for health literacy improvement in U.S. primary care and throughout the continuum of health care.

The release of the second edition in 2015 was accompanied by a guide for practice facilitators or quality improvement (QI) leaders [13-14]. The second edition presented concrete implementation advice based on the experiences of diverse primary care practices that participated in a demonstration of the toolkit. The AHRQ Health Literacy Universal Precautions Toolkit stimulated and informed health literacy improvement and was used by U.S. health systems of varying size and geographic location, such as such Intermountain Healthcare, Carolinas Healthcare Systems, Novant, Wellspan Health, and Johns Hopkins Healthcare [15].

Beyond using toolkits to promote health literate health care, AHRQ identified professional education as a practical lever to change organizational and clinician behavior. AHRQ seized on the requirement that physicians engage in continuing education (in order to maintain their medical board certifications) and developed two health literacy modules that cut across medical specialties.

Thousands of pediatricians and family physicians have received maintenance of certification credits for completing the AHRQ Health Literacy Knowledge Self-Assessment Module, and

hundreds completed the Health Literacy Practice Improvement Module, which entails implementing a tool from the AHRQ Health Literacy Universal Precautions Toolkit and tracking its impact. Optum Health Education also has awarded thousands of continuing education credit hours to health professionals who have completed AHRQ health literacy education modules.

A further opportunity to infuse health literacy into professional education arose when AHRQ discovered that pharmacy colleges, rather than pharmacies themselves, were the main users of the tools in AHRQ's Pharmacy Health Literacy Center. AHRQ decided to make it easier for pharmacy colleges to integrate health literacy into their education programs by developing the plug and play curricular modules, 'Advancing Pharmacy Health Literacy Practices Through Quality Improvement' [16].

Recognizing that health care professionals often lack the skills to communicate evidence while engaging patients in shared decision making, AHRQ included a training module and five tools dedicated to communication skills in its SHARE Approach curriculum and toolkit [17]. The latter training addressed limited health literacy and numeracy and used the teach-back method. AHRQ also sponsored train-the-trainer workshops across the country to help health systems, health payers, clinicians, and other professional use the SHARE Approach. The full curriculum and supporting materials, all designed in accordance with health literacy principles, are available online.

In addition, AHRQ developed tools to help the U.S. research community adopt more health literate approaches. AHRQ created the AHRQ 'Informed Consent and Authorization Toolkit for Minimal Risk Research' to help health services researchers obtain informed consent from prospective research participants (and authorization to use medical information in research) via more health literate strategies [18]. In its Funding Opportunity Announcement Guidance, AHRQ communicated its expectation that informed consent and authorization documents should be understandable to all potential research participants, including those with low levels of literacy and limited English proficiency. The guidance also urges grantees to make sure that AHRQ-funded consumer products are appropriate for the target audience, including individuals from diverse cultural, language, and literacy backgrounds, and recommends audience testing be part of the development process.

Finally, in addition to dedicated health literacy products, AHRQ has integrated health literacy into its other tools. For example, when AHRQ created patient safety guides for hospitals and primary care practices on patient and family engagement, it included training on clear communication and tools for staff and patients on teach-back [19-20].

5. Creating and Supporting Change

Creating and supporting change requires more than laying out the evidence and developing tools to help health care organizations become more health literate. It involves collaborating with others and providing inspirational and conceptual leadership. To accomplish this, AHRQ worked with other organizations that are similiarly interested in the diffusion of health literacy research, initiatives, and approaches. AHRQ's collaborators have included:

the American College of Physicians Foundation; the American Medical Association Foundation; America's Health Insurance Plans; U.S. Pharmacopeia; and The Joint Commission. Collaboration entailed co-sponsoring meetings, drafting white papers, conducting educational webinars and presentations, and serving on expert health literacy advisory groups.

One of the most fertile collaborations has been with the Roundtable on Health Literacy (the Roundtable) of the National Academies of Science, Engineering, and Medicine. The mission of the Roundtable, whose members come from the public and private sectors, is to inform, inspire, and activate a wide variety of stakeholders to support the development, implementation, and sharing of evidence-based health literacy practices and policies. With such alignment of interests, AHRQ actively participated in formulating the Roundtable's agenda and planning workshops and other activities that would help health care organizations seeking to become more health literate. Inspired by what the National Standards for Culturally and Linguistically Appropriate Services (CLAS) has accomplished in promoting CLAS, AHRQ led a collaborative paper with Roundtable members that defined, 'Ten attributes of health literate health care organizations' [6, 15, 21]. The paper was widely cited and became a focus of OHL measurement efforts, which influenced the health literacy activities of several nations outside the U.S.

Another conceptual contribution to how organizations can become health literate was advanced in a *Health Affairs* article that proposed the Health Literate Care Model [22]. The article describes how health literacy strategies can be integrated into the renowned Care Model. With its co-authors, AHRQ reasoned that addressing health literacy is a prerequisite for patient engagement and showed how each of the tools in the AHRQ Health Literacy Universal Precautions Toolkit could be used to implement the Health Literate Care Model.

6. Disseminate and Transfer Knowledge and Tools

Health care organizations must see health literacy improvement as critical to attaining their goals, rather than an additional task they have to heap upon an already crushing workload. In addition to using conventional means of spreading the word about AHRQ health literacy tools (e.g., webinars, listservs, publications, blogs, email blasts), AHRQ tried to portray health literacy as a way health care organizations could get their work done, rather than a new thing to do.

For example, AHRQ created a crosswalk between the standards for patient-centered care and the tools in the AHRQ Health Literacy Universal Precautions Toolkit that showed how using a particular tool could help engage patients and qualify for certification or recognition as a patient-centered medical home [23]. AHRQ worked with major accreditation organizations (i.e., The Joint Commission, National Committee for Quality Assurance, Utilization Review Accreditation Commission, and Accreditation Canada) to ensure accuracy in mapping tools to standards. In turn, these organizations let their members know about the crosswalks and, consequently, about the AHRQ Toolkit.

AHRQ's development of the Re-Engineered Discharge (RED) Toolkit provides another example of how health literacy can be mainstreamed by incorporating it within other key initiatives [24]. The RED was developed and tested by an AHRQ grantee to address the myriad of deficiencies in the hospital discharge process. The RED is both a patient safety and health literacy intervention. It tackles not only patient education and communication, but also contains strategies aimed at the challenging navigation of care transitions. The randomized controlled trial of the RED revealed that patients who received it were less likely to return to the hospital (the emergency department or readmission) than patients who received standard discharge practices, and partially confirmed the importance of addressing health literacy to achieve improved health outcomes [25].

Interestingly, when AHRQ contracted with the Joint Commission Resources (JCR) to support hospitals interested in replicating the RED, enthusiasm for the intervention was tempered by financial realities. Approximately 270 hospitals availed themselves of JCR's instructional webinars and technical assistance. However, some hospitals were concerned about implementing an intervention that might reduce their revenues. This situation changed dramatically when the U.S. Centers for Medicare and Medicaid Services' (CMS) introduced penalties for 'excessive' 30-day readmissions. By the time the penalties kicked in, the RED Toolkit was published (that AHRQ commissioned to provide step-by-step implementation guidance to hospitals serving diverse populations). Within one month of its publication, more than 1,700 visits were paid to the RED Toolkit site. Many partners, including CMS' Hospital Engagement Networks, the Department of Defense, the American Hospital Association, and America's Health Insurance Plans, became interested in disseminating RED tools. By becoming a means to an end (i.e., reducing readmissions), attending to health literacy was embraced as part of a needed overhaul of discharge practices.

7. Practice What We Preach

Although much of AHRQ's health literacy work is externally focused, that is, concentrated on helping health care systems become more health literate, AHRQ also strives to observe health literacy principles. As a U.S. Federal agency, AHRQ is bound by the Plain Writing Act of 2010. The Act requires all new public facing documents use plain writing, defined by the legislation as writing that is clear, concise, well-organized, and follows other best practices appropriate to the subject or field and intended audience [26].

AHRQ's primary audiences are clinicians and health systems that deliver health care services. There is a fear that making products health literate will 'dumb them down.' However, it is important to recognize that AHRQ's audience members are busy individuals who require materials that are clear and actionable. Materials that are excessively wordy, visually dense, or overwhelm readers with too much information, may not be read - much less understood.

AHRQ has used a number of strategies to promote plain writing in its products. These have included staff training, using focus groups to obtain audience feedback, and pilot testing products. For example, when AHRQ tested both the first and second editions of the AHRQ Health Literacy Universal Precautions Toolkit, it discovered the tools had to be short and to

the point, while layered with details and tips [27-28]. AHRQ has used a tool it developed – the Patient Education Materials Assessment Tool (PEMAT) – to assess the understandability and actionability of popular publications to identify areas for improvement [29]. AHRQ also created a checklist from the PEMAT and included it in the AHRQ Publishing and Communications Guidelines, which all contractors that produce materials for AHRQ are instructed to follow.

More recently, as part of an HHS-wide health literacy quality improvement effort, AHRQ worked with the U.S. Preventive Services Task Force (USPSTF) to improve communication about its evidence-based recommendations. AHRQ provides the USPSTF - an independent, volunteer panel of national experts in prevention and evidence-based medicine - with scientific, administrative, and dissemination support. As part of the USPSTF's commitment to ensure its recommendations about clinical preventive services are clear and useful to primary care clinicians, the Task Force updated the format of its recommendation statement, as well as its brief summary of each recommendation for clinicians (the clinician summary) [30].

The USPSTF, with support from AHRQ, used a health literacy improvement process that included conducting a literature review, interviews with primary care clinicians and dissemination and implementation experts, and feedback obtained from primary care clinicians on the recommendation statements [30]. AHRQ also solicited and incorporated feedback from USPSTF partner organizations, including clinical professional organizations that help disseminate and implement the recommendations.

To assess whether the new clinician summary format was an improvement from the prior version, two AHRQ staff completed the PEMAT and found the new format was more understandable and actionable. The USPSTF adopted the new health literate template for clinician summaries, which includes only the most important and actionable information and uses informative section headings.

While AHRQ has made progress towards becoming a health literate organization, limited time and funds have constrained achievements. For example, only limited testing of the new clinician summary format could be undertaken, in part due to the U.S. Paperwork Reduction Act clearance process required for any data collection from ten or more individuals. Similarly, tight deadlines prevent AHRQ's funding opportunity announcements from routinely going through a plain language editing process. Nevertheless, AHRQ strives to publish information that audience members understand the first time they read it.

8. Conclusion

AHRQ has pursued a strategic path to promoting health literacy quality improvement in health care delivery systems. Its multi-pronged Health Literacy Action Plan - to develop measures, improve the evidence base and create implementation tools, create and support change, disseminate and transfer knowledge and tools, and practice what we preach - drew upon AHRQ's core competencies in data and measurement, practice improvement, and health services research. AHRQ's work has accelerated the uptake of evidence-based health

literacy strategies by health care organizations in the U.S. and influenced similar activities in other nations.

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Table 1.

Summary of AHRQ's Work to Promote Health Literate Health Care, 2005-2019

Activity	Outcome
Develop Measures	
Developed health literacy patient survey items	Validated CAHPS® survey items that capture distinct communication behaviors that can be targeted for improvement
Identified and assessed organizational health literacy quality improvement measures	Organizational health literacy quality improvement measures that do not rely on patient-reported data which were determined to be useful, meaningful, feasible, and have face validity
Added health literacy items to national household survey (MEPS)	National tracking and reporting of health care providers' communication practices by Healthy People and the National Healthcare Quality and Disparities Report
Improve the Evidence Base and Create Implementation Tools	
Co-sponsored health literacy research program announcement with NIH	Funded grants focused on understanding and promoting health literacy
Commissioned health literacy systematic evidence reviews	*Literacy and Health Outcomes and Health Literacy Interventions and Outcomes* summarized and synthesized evidence on the impact of limited literacy and identified effective strategies to mitigate its effects
Created and updated tools to help primary care practices adopt health literacy "universal precautions"	*AHRQ Health Literacy Universal Precautions Toolkit* (1st and 2nd editions)
Developed health literacy educational modules for clinicians as part of ongoing continuing medical education requirements	*AHRQ Health Literacy Knowledge Self-Assessment Module*, offered by American Board of Pediatrics (ABP), American Board of Family Physicians (ABFP), and Optum Health Education; and *Health Literacy Practice Improvement Module* offered by ABP and ABFP
Developed pharmacy health literacy plug-and-play modules for pharmacy colleges	*Advancing Pharmacy Health Literacy Practices Through Quality Improvement* (Four PowerPoint presentations and 17 guides for student projects
Developed health literate approach to obtaining informed consent from prospective research participants and authorization to use medical information	AHRQ Informed Consent and Authorization Toolkit for Minimal Risk Research
Integrated health literacy into other tools	Examples: *Guide to Patient and Family Engagement in Hospital Quality and Safety* (Strategy 2: Communicating to Improve Quality); Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families (Be Prepared To Be Engaged, Teach-Back); SHARE Approach (Tool 4: Health Literacy and Shared Decision Making)
Create and Support Change	
Supported other organizations efforts to promote health literacy	Collaborated (e.g., co-sponsoring meetings, drafting white papers, educating, and serving on expert health literacy advisory groups) with a variety of U.S. organizations, including the American College of Physicians Foundation, the American Medical Association Foundation, America's Health Insurance Plans, U.S. Pharmacopeia, The Joint Commission, and Roundtable on Health Literacy of the National Academies of Science, Engineering, and Medicine
Provided inspirational and conceptual leadership	Articles and presentations: Ten Attributes of Health Literate Health Care Organizations, A Proposed 'Health Literate Care Model' Would Constitute a Systems Approach to Improving Patients' Engagement in Care.
Disseminate and Transfer Knowledge and Tools	
Portrayed how health literacy strategies could help organizations achieve their goals	Crosswalk between the standards for patient-centered care and the tools in the AHRQ Health Literacy Universal Precautions Toolkit
Helped hospitals replicate the Re-Engineered Discharge (RED), a patient safety and health literacy intervention	Program of education and technical assistance, and the Re-Engineered Discharge (RED) Toolkit
Practice What We Preach	

Activity	Outcome
Developed tool to assess the understandability and actionability of print and audiovisual materials and used it to identify areas for AHRQ improvement	Patient Education Materials Assessment Tool (PEMAT), PEMAT checklist, opportunities for AHRQ improvement identified
Applied health literacy principles to U.S. Preventive Services Task Force (USPSTF) Clinician Summary, addressing user feedback and measuring improvement with the PEMAT	Improved Clinician Summary, the summary version of USPSTF recommendations for clinicians, so that only the most important and actionable information is included, easy to find, and easy to understand

Table 2:

Proportion of adults 25 and older who reported receiving health literate care

Health Literacy Metrics	2011	2015	Increase
Instructions always easy to understand	64%	70%	9.6% (p<.001)
Teach-back always initiated	24%	29%	22% (p<.001)
Help with forms always offered	14%	17%	16% (p<.1)