

INNOVATIONS IN HEALTH LITERACY RESEARCH
WORKSHOP SUMMARY

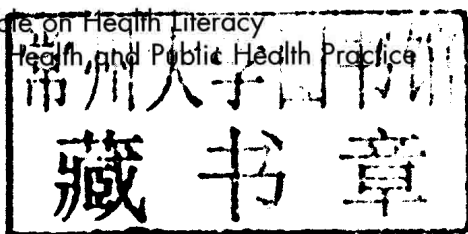
INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

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WORKSHOP SUMMARY

Cori Vancheri, *Rapporteur*

Roundtable on Health Literacy
Board on Population Health and Public Health Practice



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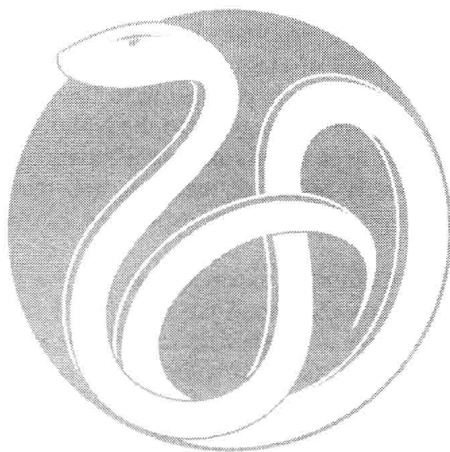
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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The serpent adopted as a logotype by the Institute of Medicine is a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

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*“Knowing is not enough; we must apply.
Willing is not enough; we must do.”*

—Goethe



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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this report:

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Sandra Smith, University of Washington Center for Health Education and Research in Seattle

Although the reviewers listed above have provided many constructive comments and suggestions, they did not endorse the final draft of the report before its release. The review of this report was overseen by **Hugh Tilson**, University of North Carolina School of Public Health. Appointed by the Institute of Medicine, he was responsible for making certain that

an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the rapporteur and the institution.

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The support of the sponsors of the Institute of Medicine Roundtable on Health Literacy made it possible to plan and conduct the workshop on innovations in health literacy research which this report summarizes. Sponsorship for the Roundtable comes from the Agency for Healthcare Research and Quality, GlaxoSmithKline, Johnson & Johnson, and the Missouri Foundation for Health.

The Roundtable wishes to express its appreciation to Michael Paasche-Orlow for preparation and presentation of a paper summarizing the Health Literacy Annual Research Conference. The Roundtable is also grateful to Lisa Cooper and Dean Schillenger for their presentations on the role of health literacy in health disparities research; to Joshua Seidman and Michael Wolf for their presentations on health literacy in health information technology; and to David Baker and Debra Roter for their presentations on building the field of health literacy research. Thanks also go to Cynthia Baur for presentation of the HHS National Action Plan to Improve Health Literacy; to Carolyn Clancy and Raynard Kingdon for their presentations on the importance of the National Action Plan; and to Terry Davis and Rima Rudd for their presentations on the role of health literacy research in the National Action Plan.

The Roundtable would also like to thank the members of the workshop planning committee for their efforts in developing an excellent workshop agenda. Members of the planning committee were Sharon Barrett, Cindy Brach, Julie Gazmararian, Jean Krause, and Michael Paasche-Orlow.

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Introduction

The past two decades of research in health literacy have done much to raise awareness about the problems associated with low health literacy. Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Ratzan and Parker, 2000). Nearly 9 out of 10 adults have difficulty using everyday health information that is available in health care facilities, retail outlets, media, and communities (ODPHP, 2010). The impact of low health literacy disproportionately affects lower socioeconomic and minority groups (Kutner et al, 2006). With knowledge of the effect of low health literacy, what does research say can be done to improve health literacy? Do interventions exist—aimed at either the consumer and patient or the healthcare system—that have been tested and shown to be effective? What research is needed to change the state of health literacy in the United States?

The Institute of Medicine Roundtable on Health Literacy focuses on building partnerships to move the field of health literacy forward by translating research findings into practical strategies for implementation. The roundtable serves to educate the public, press, and policy makers regarding issues of health literacy. The roundtable sponsors workshops for members and the public to discuss approaches to resolve key challenges in the field. A planning group designed a workshop to explore areas for research in health literacy, including the relationship of health literacy to health disparities and information technology applications. The role of the workshop planning committee was limited to planning

the workshop. Unlike a consensus committee report, a workshop summary may not contain conclusions and recommendations. Therefore, this summary has been prepared by the workshop rapporteur as a factual summary of what occurred at the workshop.

The workshop was moderated by George Isham. It began with a presentation about the first annual Health Literacy Annual Research Conference (HARC), held in October 2009. Discussion focused on two of the recurring themes of the HARC meeting: the integration of research on health literacy and health disparities; and the role of information technology and health literacy research. For the workshop summarized in this report, a panel was convened to address each of the two themes described above. The third workshop panel focused on professional development in health literacy research. In the fourth panel, leaders of three government agencies offered the first public presentation of the new National Action Plan to Improve Health Literacy. The final workshop panel addressed the role of health literacy research in the National Action Plan. The workshop ended with a discussion of lessons learned from the workshop.

Report on the First Annual Research on Health Literacy Conference

MICHAEL PAASCHE-ORLOW, MD, MA, MPH

Boston University School of Medicine

The problem of low health literacy has been acknowledged, Paasche-Orlow said. Now researchers are trying to figure out how to do something about it. A great deal of research is needed because, while there has been an increase in publications on health literacy, the majority of studies have been observational, with very few clinical trials.

The Health Literacy Annual Research Conference (HARC) was created as an interdisciplinary meeting for investigators who are dedicated to health literacy research with two aims: to advance the science of health literacy research and to serve as an engine to promote professional development in the field. The first meeting, held in October 2009, had two themes: the role of health literacy research in the elimination of health disparities, and health literacy and health information technology. After keynote addresses on the role of health literacy in patient education¹ and on the role of health literacy in health disparities,² four panels of invited speakers discussed measurement; health literacy and verbal interactions; health information technology (HIT) interventions; and organizational assessment and change. Current gaps in the research were examined by invited speakers and in breakout sessions relating to public health

¹ By David Baker, Northwestern University.

² By Anne Beal, Aetna Foundation.

approaches to health literacy, health disparities and health literacy, and health IT. All of the presentation slides are available on the conference website.³ A special issue of the *Journal of Health Communication*, guest edited by Paasche-Orlow, Lauren McCormack, and Elizabeth Wilson, reported on the HARC meeting and was published in September 2010, with free full text access online for 6 months.⁴ HARC II took place October 18-20, 2010, during the preparation of this report.

Limited health literacy has been linked to worse health outcomes for a range of medical conditions, Paasche-Orlow said. In addition, limited health literacy is more prevalent in specific racial and ethnic minorities. Although these findings have been widely acknowledged, little systematic research has been conducted to elucidate the role of health literacy in the creation of health disparities or to evaluate the possibility that interventions relating to health literacy may help eliminate health disparities.

In thinking about underlying contributions to health disparities, one perspective is that unneeded complexity in public health and health care systems transforms underlying educational disparities in our society into health disparities. Therefore, health literacy can be a roadmap to developing interventions to address health disparities. To differentiate the pathways through which people experience worse outcomes, both health disparities and health literacy need to be measured.

In a study of 204 patients with HIV, an initial analysis did not include literacy (Osborn et al., 2007). Results appeared to show that African American patients were much more likely to not adhere to their HIV medication regimen than whites. But when literacy was controlled for, the race effect diminished. The literacy variable was the only significant independent predictor of nonadherence. Those two very different results would lead to different types of interventions.

In a second study, patients were asked their preference regarding end-of-life care if they developed advanced dementia (Volandes et al., 2008). In an analysis that did not consider health literacy, African-American subjects appeared to be much more likely to want more aggressive care at the end of life. A handful of other studies support this conclusion. But the studies typically do not control for socioeconomic factors, and certainly not literacy. When controlling for health literacy in the study by Volandes and colleagues (2008), the race finding evaporated, and health literacy was found to be the dominant predictor of wanting more aggressive care at the end of life. Finally, when subjects were shown an educational video, differences by race as well as health literacy dropped. The preference for

³ See www.bumc.bu.edu/healthliteracyconference/2009-conference/.

⁴ See <http://www.gwu.edu/~cih/journal/>.