Roundtable on Health Literacy
Annual Report 2013
Message from the Chair

George Isham

With the implementation of the Patient Protection and Affordable Care Act (ACA), the issue of inadequate health literacy has become even more critical. Millions of Americans who had been uninsured became eligible on October 1, 2013, to enroll in health insurance plans. Yet, it is unclear whether these individuals possess the necessary skills to compare and choose the health plan best for them, to decide among treatment options, and to understand medication instructions. And the current system generally is not designed to accommodate the needs of such individuals. Health literacy interventions, at both the individual and system levels, play a foundational role in helping individuals make informed choices about their health and health care.

In 2013, the roundtable and many of its participants focused significant effort on creating health literate approaches to providing information about the ACA. Participants in the roundtable’s Collaborative on Health Literacy and Access, Health Care Coverage, and Care produced a series of papers, slides, and a consumer guide designed to help people understand and choose health insurance options. The roundtable commissioned a paper that describes numeracy challenges consumers face when considering health insurance and treatment options and what could be done to address those challenges. The paper was presented at a roundtable workshop along with approaches to simplifying numeric information for consumers.

The health of populations was another major focus of the roundtable. Most health literacy research and activity in the United States has focused on medical care interventions. Yet, research shows that other factors are major determinants of health, including health behaviors and the social and physical environments. Public health agencies provide essential services aimed at many of these factors in order to improve the health of populations. Health literacy can facilitate the work of these agencies.
This year saw some innovations for the roundtable. All 2013 workshops were webcast and videos and audio recordings are available on our website (www.iom.edu/healthliteracyRT). We also established a new Legal and Regulatory Issues working group and an Education Issues working group, which are planning activities in these two areas. The roundtable continues its efforts in the areas of international health literacy, implementation, and health reform. And, in November 2014, we will hold a meeting commemorating the 10-year anniversary of the publication of the groundbreaking Institute of Medicine (IOM) report Health Literacy: A Prescription to End Confusion.

We hope you will join us in the coming year to continue to work to improve health literacy—both in the United States and abroad.

George Isham
Chair
The Roundtable on Health Literacy brings together leaders from academia, industry, government, foundations and associations, and representatives of patient and consumer interests who have an interest and role in improving health literacy. The objective of the roundtable is to engage each sector in actively participating in developing policies, sharing knowledge, and building skills necessary to create a health literate society by providing a forum for discussion and exchange of knowledge and expertise. The specific aims of the roundtable are to

1. engage the public in advocating for patient–provider communication that delivers high-quality health care;

2. prioritize strategies that eliminate disparities in health literacy;

3. provide and facilitate expertise and guidance to develop policies, strategic goals, and procedures to promote health literacy;

4. facilitate collaboration to advance health literacy; and

5. establish a program that recognizes and rewards excellence in advancing health literacy.
Workshops and Meetings

Implementation of the Attributes of a Health Literate Organization
(Washington, DC, April 11)

In early 2012, a discussion paper authored by participants in roundtable activities detailed 10 attributes of a health literate health care organization and provided references and suggestions for how to achieve those attributes. Achieving the attributes requires not only knowledge about health literacy, but also a focus on system and organization change. On April 11, 2013, the roundtable hosted a workshop at which health literacy implementers were invited to present their experiences. Health literacy implementers are individuals who are responsible for implementing health literacy across their organizations; are involved as leaders or champions for health literacy within their organizations; or are involved in implementing health literacy in a “real-world” setting, that is, dealing with competing priorities, resource constraints, and organizational policies. Speakers addressed the following five questions:

1. What generated interest in improving health literacy in your organization?

2. What general strategies did you use to move health literacy forward? For example, did you recruit leadership support? Did you first focus on small
projects and then use the successes of those projects to convince others of the importance of health literacy?

3. What factors facilitated implementation of changes to improve health literacy?

4. What factors were barriers to implementation of changes to improve health literacy?

5. How will the implementation of changes to improve health literacy in your organization be maintained over time?


**Numeracy Issues and Challenges (Washington, DC, July 18)**

With the implementation of health care reform, there will be an influx of previously uncovered individuals who have limited knowledge, understanding, and ability to navigate the health care choices available. Health literacy interventions aimed at numeracy issues could enhance these individuals’ ability to make informed choices about which health plan best meets their needs; to make informed treatment decisions (for example, X treatment has a 5 percent greater risk than Y); and to understand medication instructions, among other benefits.

The roundtable held a workshop on the challenges of conveying numeracy information on July 18, 2013. The workshop began with an overview of what numeracy is. This was followed by the presentation of a commissioned paper, “Numeracy and the Affordable Care Act: Opportunities and Challenges.” The workshop then addressed whether numeracy issues and concepts are more difficult for patients to navigate when ill. Panels of speakers explored
numeracy issues and challenges for consumers; issues for communicators of information (including the media); and effective strategies for conveying numeracy information. The workshop webcast is available at http://www.iom.edu/Activities/PublicHealth/HealthLiteracy/2013-JUL-18.aspx.

Implications of Health Literacy for Public Health (Irvine, California, November 21)
Public health agencies and organizations in the United States provide essential services such as monitoring health status, investigating community health problems and hazards, developing policies and plans that support health efforts, enforcing laws and regulations that protect health and ensure safety, and ensuring a competent health care workforce, among others. Because health literacy is a product of the interaction between an individual and his or her environment, embedding health literate principles and actions into these essential services can empower people and communities to take greater control of their health and improve their health status.

During the workshop, a commissioned paper on current health literacy activities in public health was presented; a panel of three speakers from three different public health agencies described their work in the area; a second panel explored how health literacy facilitates public health work in the areas of preparedness, nutrition, school health, chronic disease, and oral health; and a final panel addressed workforce, academic, and professional development. A special guest presentation was made by Cecilia Doak, who, with her husband Leonard Doak, founded the field of health literacy more than three decades ago. The workshop webcast is available at http://www.iom.edu/Activities/PublicHealth/HealthLiteracy/2013-NOV-21/Videos/Panel1/Introduction.aspx
Reports and Papers

Visit the Roundtable’s website at www.iom.edu/HealthLiteracyRoundtable to access the full text of the 2013 reports and papers.

**Oral Health Literacy: Workshop Summary (February 2013)**
This is the report of a workshop held March 29, 2012. The report provides an overview of the importance of oral health and oral health literacy, discusses the role of health literacy in addressing oral health problems, examines how oral health literacy can be assessed within care systems and within the environment, presents effective oral health literacy programs, and describes national and state-based oral health literacy initiatives. The report is available at www.iom.edu/Reports/2013/Oral-Health-Literacy.aspx.

**“Helping Consumers Understand and Use Health Insurance in 2014” (Discussion Paper, May 2013)**
This is a paper prepared by participants in the roundtable’s Collaborative on Health Literacy and Access, Health Care Coverage, and Care. The paper offers basic information about health insurance options and is intended to be a resource for anyone whose role involves helping consumers make important decisions, such as navigators, community organizations, employers, members of the media, and educators. The paper describes both public and private options for health insurance, defines key health insurance terms, discusses major changes under the ACA, and reviews relevant financial facts, such as tax credits and subsidies. Links are provided for helpful resources such as online applications for various types of insurance, a map of state decisions about Medicaid expansion, and a list of preventive services covered by the ACA. The paper is available at www.iom.edu/understandhealthinsurance.
“Amplifying the Voice of the Underserved in the Implementation of the Affordable Care Act” (Discussion Paper, June 2013)

This is a paper prepared by participants in the roundtable’s Collaborative on Health Literacy and Access, Health Care Coverage, and Care and participants from the Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities. The paper describes how simplifying paths to obtain and use health insurance under the ACA can empower underserved communities to become involved in and take charge of their health. It highlights both the appetite of the underserved for information about obtaining health insurance under the ACA and the prevailing confusion regarding provisions in the new law. The authors suggest widespread dissemination of community-created messages that address not only health care coverage but also how to be an informed health care consumer, training of community-based organizations to conduct community outreach, and ensuring that the needs of limited-English-speaking communities are a core concern. The paper is available at www.iom.edu/~/media/Files/Perspectives-Files/2013/Discussion-Papers/BPH-AmplifyingtheVoice.pdf.

“Let’s Ask 4: Questions for Consumers and Providers About Health Insurance” (Discussion Paper, July 2013)

This is a paper prepared by participants in the roundtable’s Collaborative on Health Literacy and Access, Health Care Coverage, and Care. The paper focuses on four questions: (1) What are my choices for health insurance?, (2) How do I get it?, (3) How do I use it?, and (4) How much will it cost? The paper includes hyperlinks to four PowerPoint slide sets, each of which answers one of the four questions. It also links to a Consumer Guide that addresses the four questions in more depth. The paper is available at www.iom.edu/LetsAsk4.

This is the report of a workshop held September 24, 2012. The report begins by summarizing two presentations that set the stage for an international discussion, the first from Jo Ivey Boufford, the president of the New York Academy of Medicine and the second from Steven J. Hoffman, a representative of the United Nations Secretary General’s office. The report then explores health literacy perspectives and programs described by speakers from the World Health Organization and organizations in Australia, Canada, Ireland, Israel, and Italy. Also included are summaries of presentations on the results of the European Health Literacy Survey, corporate perspectives on health literacy, and visions for next steps. The meeting webcast is available at www.iom.edu/Activities/PublicHealth/HealthLiteracy/2012-SEP-24/September-24-2012/Boufford.aspx and the report is available at www.iom.edu/Reports/2013/Health-Literacy-Improving-Health-Health-Systems-and-Health-Policy-Around-the-World.aspx.

“Integrating Health Literacy with Health Care Performance Measurement” (Discussion Paper, July 2013)

This is a paper prepared by participants in roundtable activities. The paper describes opportunities for health care providers to link health literacy to quality measures and integrate health literacy performance measurement into every aspect of the patient experience. Effective health literacy–related performance measures and considerations important to measure development process are discussed. The overall objective of the paper is to contribute to the development of performance measures designed to improve care for people with low health literacy. The paper is available at www.iom.edu/Activities/PublicHealth~/media/Files/Perspectives-Files/2013/Discussion-Papers/BPH-IntegratingHealthLiteracy.pdf.
“Numeracy and the Affordable Care Act: Opportunities and Challenges”
(Commissioned Paper, July 2013)

Numbers are used to instruct, inform, and give meaning to information in order to help us make better judgments and healthier choices in our everyday lives. However, research has demonstrated that not all people can understand and use numbers effectively. In particular, people differ in terms of numeracy skills. Among uninsured adults, the authors estimate that 28.8 percent are at a “below basic” level of numeracy; 33.4 percent are at a “basic” level; 29.3 percent are at an “intermediate” level; and only 8.6 percent are at a “proficient” level of numeric literacy. The paper asserts that many complex informed health decisions (e.g., management of chronic diseases) require a “proficient” level of numeric literacy, given how much numeric information is often provided. The authors argue that if health providers present information to patients and consumers in an evidence-based manner, a greater proportion of the population will be successful in making informed health and health-related decisions. The authors identify five main communication themes and discuss evidence-based strategies for communication under each theme. The commissioned paper is available at http://www.iom.edu/Activities/PublicHealth/~media/Files/Activity%20Files/PublicHealth/HealthLiteracy/Commissioned%20Papers/Numeracy%20and%20the%20Affordable%20Care%20Act%20-%20Opportunities%20and%20Challenges.pdf.


The first section of this commissioned paper focuses on which organizations participated in the data-gathering process that underpins both Part 1 and Part 2 of the commissioned paper series on health literacy around the world (Part 1 is available at http://www.iom.edu/Activities/PublicHealth/~media/Files/Activity%20Files/PublicHealth/HealthLiteracy/2012-SEP-24/WorldHealthLit.pdf). Succeeding sections detail participants’ responses to a series of attitudinal queries about health literacy and questions concerning how health literacy is defined. The paper then examines U.S. health literacy efforts reported by participants, including a state-by-state summary of activities and
efforts within the U.S. government. Next, the paper focuses on efforts from nongovernmental organizations or nonprofit organizations on a regional or multistate basis, as well as efforts by the U.S. business and corporate communities. The commissioned paper is available at www.iom.edu/~/media/Files/Activity%20Files/PublicHealth/HealthLiteracy/Commissioned%20Papers/Health%20Literacy%20Around%20the%20World%20Part%202.pdf.

**Organizational Change to Improve Health Literacy: Workshop Summary** (October 2013)

Health literacy is the product of the interaction between individuals’ capacities and the health literacy–related demands and complexities of the health care system. Systematic changes are needed to better align health care demands with the public’s skills and abilities. In early 2012, members of the IOM Roundtable on Health Literacy published a discussion paper that focused on the attributes of a health literate health care organization or system. The paper detailed 10 attributes of a health literate health care organization, along with references and suggestions on how to achieve those attributes. To examine what is known about implementation of the attributes of a health literate health care organization, the Roundtable on Health Literacy held a workshop on April 11, 2013. Workshop participants discussed topics ranging from implementation approaches to the creation of a network of health literacy implementers who can share information about health literacy innovations and problem solving. This document summarizes the workshop. The report is available at http://www.iom.edu/Reports/2013/Organizational-Change-to-Improve-Health-Literacy.aspx.

**“A Prescription Is Not Enough: Improving Public Health with Health Literacy”**

*(Commissioned Paper, November 2013)*

Successfully integrating the best practices and knowledge of health literacy into the field of public health is likely the most significant opportunity that currently exists to improve individual, community, and public health. The benefits are not yet fully manifested, as it seems that public health organizations in the United States are not sufficiently interested in—or at least not engaged in—embedding health literacy into their efforts. This commissioned paper illustrates the many potential uses of health literacy in public health and the possible benefits of fully engaging the fields of public health and health literacy. It offers case studies in which public health departments have worked successfully to incorporate health literacy into efforts to fulfill their missions. The author also makes several recommendations aimed at achieving the goal of advancing health literacy to improve public health. The commissioned paper is available at www.iom.edu/Activities/PublicHealth/~/media/Files/Activity%20Files/PublicHealth/HealthLiteracy/Commissioned-Papers/A-Prescription-Is-Not-Enough-Improving-Public-Health-with-Health-Literacy.pdf.
Examples of Impact

Information taken from the discussion paper “Let’s Ask 4: Questions for Consumers and Providers About Health Insurance” and its accompanying materials has been posted on the Merck company website (knowyourhealthinsurance.com/index.html). The materials were prepared by roundtable members Ruth Parker, Winston Wong, Kavita Patel, and other participants in the Collaborative on Health Literacy and Access, Health Care Coverage, and Care. Merck is in the process of translating it into Spanish.

The German translation of the discussion paper “Attributes of a Health Literate Health Care Organization” has been posted on the website of the Austrian Network of Health Promoting Hospitals (www.ongkg.at/ueber-uns.html). The paper also has been widely distributed within Austria and has been used to define measures for fulfilling Austria’s Health Goal No. 3: improving the health literacy of the population. Tools to assess the status of health literate organizations are under development and will be tested in Austrian hospitals next year.

Future Activities

With support from the Agency for Healthcare Research and Quality, the roundtable commissioned a paper that identifies measures of the 10 attributes of a health literate health care organization. The goal is to obtain a set of measures that support quality improvement, reporting, transparency, and management. The paper will be available in 2014.

Three workshops are planned for 2014. The first, scheduled for March 17, will focus on the implications of health literacy for discharge instructions for both ambulatory and inpatient facilities. A workshop on July 28 will focus on legal and regulatory issues. On November 7, a workshop will be held to commemorate the 10-year anniversary of the publication of the seminal IOM consensus report Health Literacy: A Prescription to End Confusion.

The report Numeracy Issues and Challenges: Workshop Summary will be released in mid-2014. This is the report of a workshop held July 18, 2013.
Roundtable Members

George J. Isham (Chair)
HealthPartners, Inc.,
Minneapolis, MN

Wilma Alvarado-Little
University at Albany, NY

Cindy Brach
Agency for Healthcare Research and Quality, Rockville, MD

Gem Daus
Health Resources and Services Administration, Rockville, MD

Darren DeWalt
University of North Carolina at Chapel Hill

Benard Dreyer
New York University School of Medicine, New York

Elizabeth Fowler
Johnson & Johnson,
Washington, DC

Laurie Francis
Association of Clinicians for the Underserved, Portland, OR

Jill Griffiths
Aetna
Hartford, CT

Lori Hall
Eli Lilly and Company,
Indianapolis, IN

Linda Harris
U.S. Department of Health and Human Services, Rockville, MD

Betsy Humphreys
National Library of Medicine,
Bethesda, MD

Margaret Loveland
Merck & Co., Inc., North Wales, PA

Patrick McGarry
American Academy of Family Physicians, Leawood, KS

Ruth Parker
Emory University School of Medicine, Atlanta, GA

Terri Ann Parnell
North Shore–Long Island Jewish Health System, Lake Success, NY

Kim Parson
Humana, Louisville, KY

Kavita Patel
The Brookings Institution,
Washington, DC

Clarence Pearson
Independent Consultant, New York, NY

Susan Pisano
America’s Health Insurance Plans, Washington, DC

Andrew Pleasant
Canyon Ranch Institute, Tucson, AZ

Lindsey Robinson
California Dental Association, Grass Valley

Rima Rudd
Harvard School of Public Health, Boston, MA

Steven Rush
UnitedHealth Group, Minneapolis, MN

Paul Schyve
The Joint Commission, Oakbrook Terrace, IL

Patrick Wayte
American Heart Association, Dallas, TX

Winston F. Wong
Kaiser Permanente, Oakland, CA
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Merck & Co., Inc.
North Shore–Long Island Jewish Health System
Office of Disease Prevention and Public Health Promotion
UnitedHealth Group
About the Roundtable
The Roundtable on Health Literacy brings together leaders from academia, industry, government, foundations, and associations, and representatives of patient and consumer interests who work to improve health literacy. To achieve its mission, the Roundtable discusses challenges facing health literacy practice and research, and identifies approaches to promote health literacy through mechanisms and partnerships in both the public and private sectors.

About the Institute of Medicine
The Institute of Medicine was established in 1970 by the National Academy of Sciences to secure the services of eminent members of appropriate professions in the examination of policy matters pertaining to the health of the public. The Institute acts under the responsibility assigned to the National Academy of Sciences by its congressional charter to serve as an adviser to the federal government and, upon its own initiative, to identify issues needing attention in the areas of medical care, research, and education.

Roundtable Staff
Lyla M. Hernandez
Roundtable Director
Melissa French
Associate Program Officer
Andrew Lemerise
Research Associate
Angela Martin
Program Associate
Rose Marie Martinez
Director, Board on Population Health and Public Health Practice