



Integrating Health Literacy, Cultural Competence, and Language Access Services: Workshop Summary

DETAILS

114 pages | 6 x 9 | PAPERBACK
ISBN 978-0-309-44237-4 | DOI: 10.17226/23498

AUTHORS

Joe Alper, Rapporteur; Roundtable on Health Literacy; Board on Population Health and Public Health Practice; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine

BUY THIS BOOK

FIND RELATED TITLES

Visit the National Academies Press at NAP.edu and login or register to get:

- Access to free PDF downloads of thousands of scientific reports
- 10% off the price of print titles
- Email or social media notifications of new titles related to your interests
- Special offers and discounts



Distribution, posting, or copying of this PDF is strictly prohibited without written permission of the National Academies Press. (Request Permission) Unless otherwise indicated, all materials in this PDF are copyrighted by the National Academy of Sciences.

INTEGRATING HEALTH LITERACY, CULTURAL COMPETENCE, AND LANGUAGE ACCESS SERVICES

WORKSHOP SUMMARY

Joe Alper, *Rapporteur*

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

Health and Medicine Division

The National Academies of

SCIENCES • ENGINEERING • MEDICINE

THE NATIONAL ACADEMIES PRESS

Washington, DC

www.nap.edu

THE NATIONAL ACADEMIES PRESS 500 Fifth Street, NW Washington, DC 20001

This activity was supported by contracts between the National Academy of Sciences and AbbVie Inc.; the Aetna Foundation; the Agency for Healthcare Research and Quality (HHSP23337024); American Dental Association; Bristol-Myers Squibb; East Bay Community Foundation (Kaiser Permanente); Eli Lilly and Company; Health Literacy Missouri; Health Literacy Partners; Health Resources and Services Administration (HHSH25034011T); Humana; Institute for Healthcare Advancement; Merck & Co., Inc.; National Institutes of Health (HHSN26300054); National Library of Medicine; North Shore–Long Island Jewish Health System; Office of Disease Prevention and Health Promotion (HHSP23337043); and UnitedHealth Group. Any opinions, findings, conclusions, or recommendations expressed in this publication do not necessarily reflect the views of any organization or agency that provided support for the project.

International Standard Book Number-13: 978-0-309-44237-4

International Standard Book Number-10: 0-309-44237-0

Digital Object Identifier: 10.17226/23498

Additional copies of this workshop summary are available for sale from the National Academies Press, 500 Fifth Street, NW, Keck 360, Washington, DC 20001; (800) 624-6242 or (202) 334-3313; <http://www.nap.edu>.

Copyright 2016 by the National Academy of Sciences. All rights reserved.

Printed in the United States of America

Suggested citation: National Academies of Sciences, Engineering, and Medicine. 2016. *Integrating health literacy, cultural competence, and language access services: Workshop summary*. Washington, DC: The National Academies Press. doi: 10.17226/23498.

The National Academies of
SCIENCES • ENGINEERING • MEDICINE

The **National Academy of Sciences** was established in 1863 by an Act of Congress, signed by President Lincoln, as a private, nongovernmental institution to advise the nation on issues related to science and technology. Members are elected by their peers for outstanding contributions to research. Dr. Ralph J. Cicerone is president.

The **National Academy of Engineering** was established in 1964 under the charter of the National Academy of Sciences to bring the practices of engineering to advising the nation. Members are elected by their peers for extraordinary contributions to engineering. Dr. C. D. Mote, Jr., is president.

The **National Academy of Medicine** (formerly the Institute of Medicine) was established in 1970 under the charter of the National Academy of Sciences to advise the nation on medical and health issues. Members are elected by their peers for distinguished contributions to medicine and health. Dr. Victor J. Dzau is president.

The three Academies work together as the **National Academies of Sciences, Engineering, and Medicine** to provide independent, objective analysis and advice to the nation and conduct other activities to solve complex problems and inform public policy decisions. The Academies also encourage education and research, recognize outstanding contributions to knowledge, and increase public understanding in matters of science, engineering, and medicine.

Learn more about the National Academies of Sciences, Engineering, and Medicine at www.national-academies.org.

**PLANNING COMMITTEE ON INTEGRATING HEALTH LITERACY,
CULTURAL COMPETENCY, AND LANGUAGE ACCESS SERVICES¹**

MARIN P. ALLEN, Deputy Associate Director for Communications
and Public Liason and Director of Public Information, Office of the
Director, National Institutes of Health

WILMA ALVARADO-LITTLE, Principal and Founder, Alvarado-Little
Consulting, LLC

DENNIS ANDRULIS, Senior Research Scientist, Texas Health Institute,
and Associate Professor, University of Texas School of Public Health

IGNATIUS BAU, Independent Policy Consultant, Health Policy
Consultation Services

GEM DAUS, Public Health Analyst, Office of Health Equity, Office of
Special Health Affairs, Health Resources and Services Administration

ALICIA FERNANDEZ, Professor of Clinical Medicine, Department
of Medicine, Division of General Internal Medicine, University of
California, San Francisco

SUZANNE LELAURIN, Senior Vice President, International Institute

JANET OHENE-FREMPONG, President, J O Frempong & Associates

WINSTON WONG, Medical Director, Community Benefit, Disparities
Improvement, and Quality Initiatives, Kaiser Permanente

¹ The National Academies of Sciences, Engineering, and Medicine's planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published workshop summary rests with the workshop rapporteur and the institution.

ROUNDTABLE ON HEALTH LITERACY¹

- BERNARD ROSOF** (*Chair*), Chief Executive Officer, Quality in Healthcare Advisory Group LLC
- MARIN P. ALLEN**, Deputy Associate Director for Communications and Public Liason and Director of Public Information, National Institutes of Health
- WILMA ALVARADO-LITTLE**, Principal and Founder, Alvarado-Little Consulting, LLC
- SUZANNE BAKKEN**, Alumni Professor of Nursing and Professor of Biomedical Informatics, Columbia University
- CINDY BRACH**, Senior Health Policy Researcher, Agency for Healthcare Research and Quality
- GEM DAUS**, Public Health Analyst, Office of Health Equity, Office of Special Health Affairs, Health Resources and Services Administration
- TERRY DAVIS**, Professor of Medicine and Pediatrics, Louisiana State University Health Sciences Center
- CHRISTOPHER DEZII**, Director, Healthcare Quality and Performance Measures, Bristol-Myers Squibb
- JENNIFER DILLAHA**, Medical Director for Immunizations, Medical Advisor, Health Literacy and Communication, Arkansas Department of Health
- JAMES (JAY) DUHIG**, Head, Risk Communication and Behavioral Systems, Office of Patient Safety, AbbVie Inc.
- ALICIA FERNANDEZ**, Professor of Clinical Medicine, Department of Medicine, Division of General Internal Medicine, University of California, San Francisco
- LAURIE FRANCIS**, Senior Director of Clinic Operations and Quality, Oregon Primary Care Association
- LORI HALL**, Advisor-Health Literacy, U.S. Medical Staff, Eli Lilly and Company
- LINDA HARRIS**, Director, Division of Health Communication and ehealth Team, U.S. Department of Health and Human Services
- BETSY L. HUMPHREYS**, Acting Director, National Library of Medicine
- MARGARET LOVELAND**, Senior Director, Global Medical Affairs, Merck & Co., Inc.
- LAURIE MYERS**, Global Health Literacy Director, Merck & Co., Inc.
- CATINA O'LEARY**, President and Chief Executive Officer, Health Literacy Missouri

¹ The National Academies of Sciences, Engineering, and Medicine's forums and roundtables do not issue, review, or approve individual documents. The responsibility for the published workshop summary rests with the workshop rapporteur and the institution.

MARYLYNN OSTROWSKI, Executive Director, Aetna Foundation
MICHAEL PAASCHE-ORLOW, Associate Professor of Medicine, Boston University School of Medicine
TERRI ANN PARNELL, Principal and Founder, Health Literacy Partners
KIM PARSON, Strategic Consultant, Proactive Care Strategies, Humana
KAVITA PATEL, Managing Director for Clinical Transformation and Delivery, The Brookings Institution
ANDREW PLEASANT, Senior Director for Health Literacy and Research, Canyon Ranch Institute
LINDSEY A. ROBINSON, Thirteenth District Trustee, American Dental Association
STACEY ROSEN, Associate Professor of Cardiology, Hofstra North Shore–Long Island Jewish School of Medicine, and Vice President, Women’s Health, The Katz Institute for Women’s Health
RIMA RUDD, Senior Lecturer on Health Literacy, Education, and Policy, Harvard School of Public Health
STEVEN RUSH, Director, Health Literacy Innovations, UnitedHealth Group
PAUL M. SCHYVE, Senior Advisor, Healthcare Improvement, The Joint Commission
MICHAEL VILLAIRE, Chief Executive Officer, Institute for Healthcare Advancement
EARNESTINE WILLIS, Kellner Professor in Pediatrics, Medical College of Wisconsin
MICHAEL WOLF, Professor, Medicine and Learning Sciences, Associate Division Chief–Research Division of General Internal Medicine, Feinberg School of Medicine, Northwestern University
WINSTON WONG, Medical Director, Community Benefit, Disparities Improvement, and Quality Initiatives, Kaiser Permanente

Consultant

RUTH PARKER, Professor of Medicine, Pediatrics, and Public Health, Emory University School of Medicine

Roundtable Staff

LYLA HERNANDEZ, Senior Program Officer
MELISSA FRENCH, Associate Program Officer
EMILY VOLLBRECHT, Senior Program Assistant
ROSE MARIE MARTINEZ, Senior Board Director, Board on Population Health and Public Health Practice

Reviewers

This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the workshop summary 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 workshop summary:

SHARRON BARRETT, Health Literacy Staff Consultant
CINDY BRACH, Agency for Healthcare Research and Quality
ROBERT A. LOGAN, National Library of Medicine
YOLANDA PARTIDA, Hablamos Juntos

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this workshop summary was overseen by **Hugh H. Tilson**, University of North Carolina. He was responsible for making certain that an independent examination of this workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this workshop summary rests entirely with the rapporteur and the institution.

Acknowledgments

We are grateful to the sponsors of the Roundtable on Health Literacy who made it possible to plan and conduct the workshop on integrating health literacy, cultural competence, and language access services, which this report summarizes. Federal sponsors from the U.S. Department of Health and Human Services are the Agency for Healthcare Research and Quality, Health Resources and Services Administration, National Institutes of Health, National Library of Medicine, and the Office of Disease Prevention and Health Promotion. Nonfederal sponsorship was provided by AbbVie Inc.; the Aetna Foundation; the American Dental Association; Bristol-Myers Squibb; East Bay Community Foundation (Kaiser Permanente); Eli Lilly and Company; Health Literacy Missouri; Health Literacy Partners; Humana; Institute for Healthcare Advancement; Merck & Co., Inc.; North Shore–Long Island Jewish Health System; and UnitedHealth Group.

The workshop presentations were both interesting and stimulating, and we would like to thank each of the speakers for their time and effort. Speakers were Wilma Alvarado-Little, Dennis Andrulis, Marshall Chin, Sarah de Guia, Alicia Fernandez, Jessica Briefer French, Guadalupe Pacheco, Stacey Rosen, and Michael Wolf. Thanks also go to the excellent moderators, Ignatius Bau, Bernard Rosof, and Winston Wong, and small-group discussion facilitators, Gem Daus, Janet Ohene-Frempong, and Andrew Pleasant.

Contents

ACRONYMS AND ABBREVIATIONS	xvii
1 INTRODUCTION	1
Organization of the Summary, 2	
2 HEALTH SYSTEM TRANSFORMATION TO SUPPORT INTEGRATION	5
How the Affordable Care Act and Other Incentives May Support Integration, 6	
Concepts in Health Literacy, 10	
Concepts in Cultural Competence, 12	
Language Access Services, 14	
Discussion, 18	
3 ISSUES AND CHALLENGES	27
An Overview of Issues and Challenges, 27	
Moderated Panel Discussion, 32	
Discussion, 37	
4 ADDRESSING THE CHALLENGES	43
Integrating Health Literacy, Cultural Competence, and Language Access into Quality Improvement Standards and Activities, 44	
State Legislative Approaches to Integration, 48	

	How Cultural Competence, Language Access, and Health Literacy Are Integrated into Programs and Interventions Aimed at Reducing Disparities, 53	
	Effective Communication in Health Care, 59	
	Discussion, 62	
5	BREAK OUT SESSION REPORTS	67
	Research, 67	
	Policy, 68	
	Services and Care, 69	
	Discussion, 71	
6	REFLECTIONS ON THE DAY	73
	REFERENCES	83
	APPENDIXES	
A	Workshop Agenda	85
B	Biographical Sketches of Workshop Speakers and Moderators	89

Box, Figures, and Tables

BOX

- 1-1 Statement of Task, 2

FIGURES

- 2-1 Hypothetical scenarios for addressing language, literacy, and culture, 10
- 2-2 U.S. population trends, 13
- 2-3 State-level cultural competency legislation, 15

- 4-1 Reporting of data on race, ethnicity, and language needs, 2014, 46
- 4-2 Race/ethnicity of Medi-Cal enrollees, 49
- 4-3 IOM Model of Quality, 55
- 4-4 A conceptual model for health care disparities, 56

TABLES

- 3-1 Language-Discordant Care Leads to Suboptimal Communication, 31
- 3-2 The Present and Future of Language Barriers in Hospitals, 33

- 4-1 Results from Practices in the Patient-Centered Medical Home and Specialty Recognition Programs, 2014, 47
- 4-2 Limited English Proficient Population Enrolled in Medi-Cal, 49

- 4-3 Access to Primary and Specialty Care by English Proficiency, 50
- 4-4 Health Status by English Proficiency, 50

Acronyms and Abbreviations

ACA	Patient Protection and Affordable Care Act
ACO	accountable care organization
AHRQ	Agency for Healthcare Research and Quality
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CLAS	Culturally and Linguistically Appropriate Services
CMS	Centers for Medicare & Medicaid Services
CPEHN	California Pan-Ethnic Health Network
DMHC	California Department of Managed Health Care
DSRIP	delivery system reform incentive payment
EHR	electronic health record
HEDIS	Healthcare Effectiveness Data and Information Set
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HITECH	Health Information Technology for Economic and Clinical Health
HRSA	Health Resources and Services Administration
IOM	Institute of Medicine

NCQA	National Committee for Quality Assurance
PCORI	Patient-Centered Outcomes Research Institute
SAMHSA	Substance Abuse and Mental Health Services Administration

1

Introduction¹

“**O**ne of the six aims for improving health care in the Institute of Medicine (IOM) report *Crossing the Quality Chasm* (IOM, 2000) is to provide care that is equitable—that is, care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, or socioeconomic status,” said Bernard Rosof, Chief Executive Officer of the Quality in Healthcare Advisory Group, as an introduction to the topic of this workshop. “Increasing health equity and reducing health disparities requires aligning health care system demands and complexities with individual skills and abilities, and such alignment requires attention to the integration of health literacy, culture competency and language access.”

The aging and evolving racial and ethnic composition of the U.S. population has the United States in the midst of a profound demographic shift, Rosof said, and health care organizations face many issues as they move to address and adapt to this change. In their drive to adequately serve increasingly diverse communities, health care organizations are searching for approaches that will enable them to provide information and service to all persons, regardless of age, race, cultural background, or language skills, in a manner that facilitates understanding and use of that information to make appropriate health decisions.

¹ This section is based on the presentation by Bernard Rosof, Chief Executive Officer of the Quality in Healthcare Advisory Group, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

BOX 1-1
Statement of Task

An ad hoc committee will plan and conduct a public workshop on the integration of health literacy, cultural competency, and language access services. The workshop will feature invited presentations and discussions on topics that may encompass skills and competencies needed for effective health communication, including health literacy, cultural competency, and language access services; interventions and strategies for integration; and differing perspectives such as providers and systems, patients and families, communities, and payers. The committee will define the specific topics to be addressed, develop the agenda, select and invite speakers and other participants, and moderate the discussions. A summary of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

To better understand how the dynamic forces operating in health care today impact the delivery of services in a way that is health literate, culturally competent, and in an appropriate language for patients and their families, the Roundtable on Health Literacy established an ad hoc committee² to plan and conduct a public workshop on the integration of health literacy, cultural competence, and language access services (see Box 1-1).

Rosof noted that the complexity of health care delivery in today's ever-changing demographic environment requires more than an evidence-based approach, more than measures that matter, more than a robust information technology infrastructure, more than choosing wisely, and more than a learning health system. "To that very important list we must add person- and family-centered care and shared decision making, and to accomplish this we must understand certain basics, specifically, integrating health literacy, cultural competency, and language access services."

ORGANIZATION OF THE SUMMARY

The workshop was organized by an independent planning committee in accordance with the procedures of the National Academies of Sciences, Engineering, and Medicine. (See Appendix A for the agenda.) The planning

² The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteur as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants, and are not necessarily endorsed or verified by the National Academies of Sciences, Engineering, and Medicine, and they should not be construed as reflecting any group consensus.

committee's members were Marin Allen, Wilma Alvarado-Little, Dennis Andrulis, Ignatius Bau, Gem Daus, Alicia Fernandez, Suzanne LeLaurin, Janet Ohene-Frempong, and Winston Wong. This publication summarizes the workshop's presentations and discussions, and it highlights important lessons, practical strategies, and opportunities for improving the integration of health literacy, cultural competence, and language access services in the delivery of health care in the United States. Chapter 2 discusses some of the opportunities the Patient Protection and Affordable Care Act (ACA) and other incentives are creating to support the integration of health literacy, cultural competence, and language access services. Chapter 3 raises critical issues and challenges to integrating health literacy, cultural competence, and language access, and Chapter 4 explores some of the real-world approaches the health care enterprise is taking to address those issues and challenges. Chapter 5 reports on the discussions that took place in breakout groups focused on research, policy, and services and care, and Chapter 6 recounts the roundtable member's reflections on the key lessons learned at this workshop.

In accordance with the policies of the National Academies of Sciences, Engineering, and Medicine, the workshop did not attempt to establish any conclusions or recommendations about needs and future directions, focusing instead on issues identified by the speakers and workshop participants. In addition, the organizing committee's role was limited to planning the workshop. The workshop summary has been prepared by workshop rapporteur Joe Alper as a factual summary of what occurred at the workshop.

2

Health System Transformation to Support Integration

The workshop opened with a presentation by Dennis Andrus, senior research scientist at the Texas Health Institute and associate professor at the University of Texas School of Public Health, on the opportunities created by the ACA and other incentives for system transformation that support integration of health literacy, cultural competence, and language access services. This presentation was followed by a panel discussion to address two questions:

- What are the key concepts in this area?
- What three things have changed over time that facilitate integration?

The three panelists were Michael Wolf, professor of medicine and learning sciences and associate division chief of internal medicine and geriatrics, and director of the Health Literacy and Learning Program at Northwestern University's Feinberg School of Medicine; Guadalupe Pacheco, founder, president, and chief executive officer of the Pacheco Consulting Group; and Wilma Alvarado-Little, principal and founder of Alvarado-Little Consulting. Each panelist made a short presentation, which was then followed by an open discussion among the panelists and the workshop participants moderated by Bernard Rosof.

HOW THE AFFORDABLE CARE ACT AND OTHER INCENTIVES MAY SUPPORT INTEGRATION¹

As a prelude to his presentation, Dennis Andrulis recounted growing up in a three-language family of immigrants that faced numerous challenges associated with literacy, language, and culture. He called the richness of that background a gift and a reason to appreciate the importance of this workshop. He then listed some of the emerging issues that make today's efforts to integrate language, literacy, and culture different than in past times, starting with new financing and program initiatives, the new pressures and requirements around health contracts and insurance, and the reality of heightened competition. Andrulis said two important changes to the health care environment are contraction in the field through health system mergers and the simultaneous growth in the pool of insured Americans with increasing diversity of that pool. The new focus on population health and the social determinants of health create both opportunities and challenges, as does the increasing emphasis on community health needs. These and other factors create the greater complexity that Rosof noted in his introductory remarks, but they also set the context for opportunities that health care systems are starting to capitalize on as they transform themselves to succeed in the rapidly evolving U.S. health care environment.

Various provisions of the ACA are driving integration of language, literacy, and culture, Andrulis said, including

- Positive incentives, such as payments tied to implementation of the national standard for Culturally and Linguistically Appropriate Services (CLAS) and health literacy;
- Penalties, or negative incentives, tied to readmissions, hospital-acquired conditions, and other aspects of ineffective care;
- New requirements, such as community health needs assessments, CLAS, and nondiscrimination in marketplace activities;
- Support through grants and contracts, including research grants from the Patient-Centered Outcomes Research Institute (PCORI); and
- Symbolic support through unfunded initiatives that, with their very inclusion or explicit mention in the law, have symbolically elevated their priority and may have prompted related state focus or initiatives, such as the development of model cultural competence curricula.

¹ This section is based on the presentation by Dennis Andrulis, senior research scientist at the Texas Health Institute, and associate professor at the University of Texas School of Public Health, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

With regard to the ACA's health insurance provisions, Andrulis said that while much of the focus is on patient care and service systems, he has seen some interesting examples on the insurance marketplaces that are "thought provoking and have lessons for broader issues around literacy, language, and culture." The ACA's plain language requirements for benefit summaries, explanations of coverage, and claims appeals and the associated reporting requirements have triggered needed improvements, he noted, as have the navigator programs that require those working in those positions to have a language facility as well as literacy and culture training. Andrulis noted that he and his colleagues have studied some of the best training systems for enrollers and assisters and are in the process of documenting those efforts.

For health care systems, medical home and health home initiatives have provided states with incentives to develop evidence-based programs for communicating in a culturally and language-appropriate manner as part of their efforts to better coordinate care for Medicaid beneficiaries with chronic physical or mental illnesses. Iowa, New York, Ohio, and Oregon, for example, all require medical and health home providers to meet standards for communicating in health literate ways that meet the cultural and linguistic needs of the individual and family. Ohio is monitoring cultural competence using the Substance Abuse and Mental Health Services Administration (SAMHSA) National Outcome Measures. Several states also implemented programs to use evidence-based, culturally sensitive wellness and prevention programs with their Medicaid populations. Andrulis emphasized the importance of finding a point of focus for bringing health literacy, cultural competence, and language access services together in a synergistic manner. Otherwise, he said, efforts become fractured and fail to address all of the needs of patients. He also noted the opportunity to incentivize accountable care organizations to integrate health literacy, cultural competence, and access to language services by tying payments to measures of how well they communicate and the quality of the health education they provide to their patients.

Andrulis explained that the ACA's training requirements have a rich potential to build cultural and linguistic competencies in the health care workforce. When he and his colleagues examined the ACA, they found 62 provisions related to disparities, equity, race, ethnicity, language, culture, and literacy, including opportunities to facilitate integration of these concepts in primary care training and loan repayment programs, team-based care, and support for community health workers who deal with populations with low health literacy. However, the intent of these provisions have yet to be fulfilled, largely because of a lack of funding to support such programs.

With regard to data and research, standards for collecting race, ethnicity, and language data are embedded in the ACA and represent a critical

step to uniformly collecting data to track, assess, and monitor progress in ending disparities. This is especially important, said Andrulis, given that health data, including patients' race and ethnicity, are generally not collected in a uniform way (Weissman and Hasnain-Wynia, 2011). However, the implementation of this provision, particularly to authorize public programs, entities, and surveys to collect data using the standards, depend on appropriations, and the ACA states explicitly that without funding directly appropriated for this purpose, "data may not be collected under this section." Nonetheless, this provision and the progress made to date have value and relevance for private payers and sectors, including health plans, hospitals, and other health care providers, said Andrulis. In particular, the passage of the meaningful use provision in the Health Information Technology for Economic and Clinical Health (HITECH) Act requires physicians to record race and ethnicity for at least half of their patients to receive incentives to implement electronic health records (EHRs). He noted that ACA Section 4302 provided helpful implementation guidance on ways to effectively and cohesively collect these data.

PCORI offers opportunities for integration through its focus on disparities research, said Andrulis, and particularly through interventions addressing patient characteristics, strategies for overcoming cultural and linguistic barriers, and health communication models to improve outcomes among patients with low literacy and numeracy. So, too, does the federal government's focus on health equity in public health and prevention efforts that includes elevating the visibility and role of the Office of Minority Health at the policy level. One of the focus areas of the National Prevention Strategy is the elimination of health disparities, and toward this end, it has authorized a study of health literacy factors in patient safety; increased the use and sharing of evidence-based health literacy practices and interventions; mandated plain language patient information and labeling tailored to culture, language, and literacy; and required race, ethnicity; and language data collection.

Looking back 10 years, there were pieces of these programs and ideas floating around, said Andrulis, but today, efforts to integrate health literacy, cultural competence, and language access skills in all aspects of health care are more energized, supported, and seen as being more relevant. Looking ahead, it is important to frame integration of health literacy, cultural competence, and language access services in the context of today's health system priorities. Population health, for example, is now accepted as an area of focus for health systems, and addressing literacy, culture, and language issues is recognized as a critical feature of any successful population health program. Andrulis noted, though, that while many organizations are moving into population health, policies regarding reimbursement of population health programs aimed at tackling the social determinants of health from

a prevention, community-based perspective are lagging. He recounted a conversation he had with a leader of a foundation in California who said that what physicians and health plan officials focus on is not prevention but areas that generate revenues. “We’ve been trying to push health systems toward population health, but where is the money coming from?” asked Andrusis.

It should also be easy to tie integration to value-based care and patient safety, said Andrusis. He noted that rates of readmission and other aspects of patient safety are related to literacy, language, and culture. The Agency for Healthcare Research and Quality (AHRQ) is undertaking a demonstration at 10 hospitals as part of its Re-Engineered Discharge program to develop a tool to provide hospitals with guidance on providing education materials on diagnosis, home care, follow-up appointments, and medication adherence that are tailored to the patient’s culture and language. An English version of this program, said Andrusis, reduced readmissions by 30 percent. He repeated his earlier comments that it is important to draw on the lessons learned from the experiences of health insurance marketplaces in reaching and enrolling diverse populations (Jahnke et al., 2015).

Transformation-directed waiver programs at the state level also present opportunities for taking different approaches to integrate literacy, language, and culture. Texas and California, for example, pay for performance based on Consumer Assessment of Healthcare Providers and Systems (CAHPS) scores on patient perceptions of physician communication and health literacy skills and cultural competence. Texas also pays for performance based on engagement of community health workers in evidence-based programs to increase the health literacy of targeted populations and on the success of navigators in programs aimed at populations with low English proficiency, immigrants, and populations with low health literacy. In addition, Texas is expanding language access and implementation of CLAS standards—including some over and above those required by federal regulation—through workforce cultural competence trainings, while California is paying health systems to redesign patient education materials to be at the appropriate reading level, as well as paying for translations of those materials.

Going forward, said Andrusis, it is critical to build an evidence base both on the gaps in integrating health literacy, cultural competence, and language access services and on the beneficial effects on health that are realized when health systems address those gaps. This evidence base is essential for tying integration to payments and incentives. Also needed are programs to monitor health equity outcomes to ensure inequities are not an adverse outcome of related initiatives, which he explained using three hypothetical scenarios, one a desired scenario and the other two to be avoided (see Figure 2-1). In one undesirable scenario, individuals from advantaged and



FIGURE 2-1 Hypothetical scenarios for addressing language, literacy, and culture. SOURCE: Presented by Andrulis, October 19, 2015.

disadvantaged populations both benefit, but the already advantaged group benefits more and disparities increase. In a slightly less undesirable scenario, the effect of a program is equal to both groups, so there is no change in disparities. The desired scenario has individuals in both groups benefitting, but those in the disadvantaged group benefit more, reducing disparities. “I think without attention to literacy, language, and culture, you will have one or the other undesirable scenarios and you will not have the desired scenario,” said Andrulis.

In closing, Andrulis said that addressing shortcomings in literacy, language, and cultural competence is a necessary component for any system-level advance in terms of equity, quality, and value; without integration, progress will be limited. That lesson, he said, has been stated in earlier workshops held by the roundtable, and it continues to be true.

CONCEPTS IN HEALTH LITERACY²

What health literacy, cultural competence, and language access services have in common, said Michael Wolf, is stagnation and the challenge to have

² This section is based on the presentation by Michael Wolf, professor of medicine and learning sciences, associate division chief of internal medicine and geriatrics, and director of the Health Literacy and Learning Program at Northwestern University’s Feinberg School of Medicine, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

anyone pay attention to them. He also proposed that Russian dolls could serve as an appropriate analogy for thinking about these three topics in that they would be the innermost dolls—one could argue about the order of the three—nesting inside larger dolls that represent health care quality, safety, and equity. “We have been struggling for a while now to have our message heard that all of these issues really do matter to quality. What we need is a good business case,” said Wolf. “That is still something of a black box in that it is still unclear how we make that case.”

Health literacy, in Wolf’s opinion, is both a risk factor and an outcome, something the IOM recognized in its first report on the subject in 2004 (IOM, 2004). He acknowledged that health literacy has perhaps taken too much of a medical focus in that it identifies as a risk factor a group that is vulnerable to poorer health outcomes. However, health literacy is also an outcome, something to promote, and that, said Wolf, is why health literacy has two faces, both as an individual and societal trait. Health literacy is not just an individual skill set, an accumulation of knowledge or prior experience. It is also a reflection of how knowledge is presented by the health literate health care organization and how those organizations are increasing access to the services it provides to those it serves.

Health literacy is also context dependent and modifiable. “In many ways, we have framed health literacy in the context of health care equity and health disparities, which makes it conducive to integration with cultural competency and language access,” said Wolf. “It feels less formidable as a task to say that we can do better at communicating information, letting people understand what their options may be, and informing them about health care decisions than to think of health literacy in terms of socioeconomic factors that cause disparity.” At its core, though, health literacy is an emphasis on accessing, understanding, and applying information to make informed health decisions and, at its best, facilitating health behavior change. Health literacy has strong and obvious ties to socioeconomic status, race, ethnicity, and age that, according to Wolf, cannot be divorced from making changes in the health system and beyond.

He then made three points with regard to how to best integrate health literacy, cultural competence, and language access services. The first was that health systems must expect and prepare for diversity in the way they communicate about health care, train providers, and organize workflow. The Plain Writing Act of 2010 and the changes in health coverage triggered by the ACA are now forcing health systems to consider how they interface with patients. However, said Wolf, the health literacy community knew what needed to be done long before those mandates and has done a poor job of disseminating what it has learned. In the end, what is needed is for health literacy principles to be hardwired into the practice of health care. But the question that arises is whether the investment to do so is justifiable.

He noted that in the absence of a good business case, even wealthy health care systems such as the one he works for, will wonder if they should invest in health literate communications, provider training, workflow redesign, and developing a quality indicator to show how well they are communicating with patients.

The second point he made about integration was that all three of these topics reflect the needs of vulnerable populations with known disparities. They therefore warrant ongoing assessment to show that efforts to address these topics are reducing disparities and closing the gap between those with the lowest literacy skills and the rest of the population. The question then becomes how to measure health literacy, cultural competence, and access to language services. Wolf said that CAHPS can provide some information. He wondered, too, if EHRs either contain or could be used to collect relevant data on health literacy. He noted that while the health care system likes to think of itself as progressive, in some ways it is not because it still demands there be a business case for taking action.

Wolf's final point was that interventions must target improving access to understandable, actionable health information for everyone. The bottom line is that health literacy is a patient-centered approach to health information applicable to a diverse audience. From that perspective, cultural competence principles and access to language services become natural components of any effort to improve health literacy. Again, however, there needs to be a business case that links health literacy to behavior change and health outcomes, which is something he hoped the roundtable would explore further.

CONCEPTS IN CULTURAL COMPETENCE³

One definition of cultural competence, said Guadalupe Pacheco, is the ability of an organization or an individual within the health care delivery system to provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs of the patient. In essence, he said, cultural competence is about patient-centered care as discussed in the IOM report *Crossing the Quality Chasm* (IOM, 2000), though that report did not explicitly discuss cultural competence.

The key concept that health care practitioners need to address, Pacheco said, starts with looking at health beliefs through the lens of the patient.

³ This section is based on the presentation by Guadalupe Pacheco, founder, president, and chief executive officer of the Pacheco Consulting Group, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

Some patients, for example, view illness as a punishment from God, or the result of getting the evil eye from someone. Some cultures treat illness as an issue of fatalism, that illness and death are just part of life, that they happen for a reason, or that it was just someone's time to die. Another concept is to address the communication needs of the patient with regard to language preference and health literacy, as well as how different cultures treat authority figures and the effect that has on asking questions. As an example of the latter, Pacheco said he was raised to never question a doctor, priest, or teacher. The challenge, then, is to deal with those kinds of cultural perspectives in a way that breaks down communication barriers, he explained.

A third key concept is providing culturally competent care, which falls into the realm of providing patient-centered equitable care, Pacheco noted. The final concept he listed was developing a workforce that is inclusive of the demographics of the community, something that is taking on increasing importance with the changing demographics of the United States (see Figure 2-2). Pacheco called this population trend a game changer in terms of the strategies that health care providers are going to use to reach the different racial and ethnic minority groups that combined will account for 48 percent of the U.S. population by 2050. It is obvious, he said, that these strategies will have to be culturally competent to be successful.

Another game changer, said Pacheco, is the increasing recognition of the health disparities that affect many groups in the United States. "Why are we developing culturally competent programs and initiatives and health literacy initiatives? Because we want to deal with health disparities," said Pacheco. Half of the nearly 29 million Americans with diabetes belong to various minority groups, he noted, and the majority of children considered to be obese are Latinos and African Americans. In both cases, poverty,

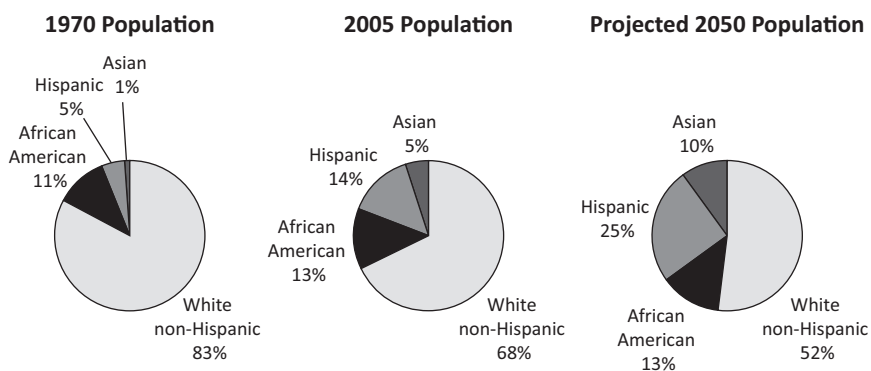


FIGURE 2-2 U.S. population trends.

SOURCE: Presented by Pacheco, October 19, 2015.


lifestyles, and environmental factors are to blame for these major drivers of health care costs, which again ties back to health inequities. Pacheco cited a 2006 study (LaVeist et al., 2011) estimating that limiting health disparities would reduce direct medical expenditures by almost \$300 billion and that premature deaths from health disparities cost the nation some \$1.24 trillion. He also noted that approximately 35 million U.S. residents are foreign born, approximately 55 million people (19.7 percent of the U.S. population) speak a language other than English at home, and more than 25 million people (8.7 percent of the U.S. population), speak English less than “very well” and are considered to have low English proficiency.


With regard to policies pushing the cultural competence and health literacy agenda, Pacheco referred to the CLAS standards that were first issued in 2000 and reissued in 2013. The 15 standards in CLAS provide pathways for the delivery of culturally competent care to diverse populations. He also cited the U.S. Department of Health and Human Services (HHS) Office of Civil Rights guidance, issued in 2000 and again in 2003, regarding Title VI of the Civil Rights Act’s prohibition against national origin discrimination affecting those who have low English proficiency, and the ACA, which has 19 provisions addressing culturally competent care and health literacy. Another driver was the established standards of The Joint Commission and the National Committee for Quality Assurance addressing communication, cultural competence, patient-centered care, and the provision of language assistance. At least seven states have passed legislation mandating some form of cultural competency requirements in their health care delivery system, another eight states are considering such legislation, and in five states legislation was introduced but died in committee or was vetoed (see Figure 2-3). As a final comment, Pacheco noted that the number of publications on cultural awareness and the number of citations has risen since 2001. “If you pick up any report dealing with health equity, you will find reference to cultural competency trends and progress,” he said in closing.


LANGUAGE ACCESS SERVICES⁴

To illustrate the central challenge that language access presents in the health care environment, Wilma Alvarado-Little began her presentation with a quote from George Bernard Shaw, who said “The single biggest problem in communication is the illusion that it has taken place.” She then addressed the difference between language access and language assistance. According to the HHS Language Access Plan issued in 2013, language

⁴ This section is based on the presentation by Wilma Alvarado-Little, principal and founder of Alvarado-Little Consulting, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

 denotes legislation requiring (WA, CA, CT, NJ, NM) or strongly recommending (MD) cultural competence training that was signed into law.

 denotes legislation that was referred to committee and/or is currently under consideration.

 denotes legislation that died in committee or was vetoed.

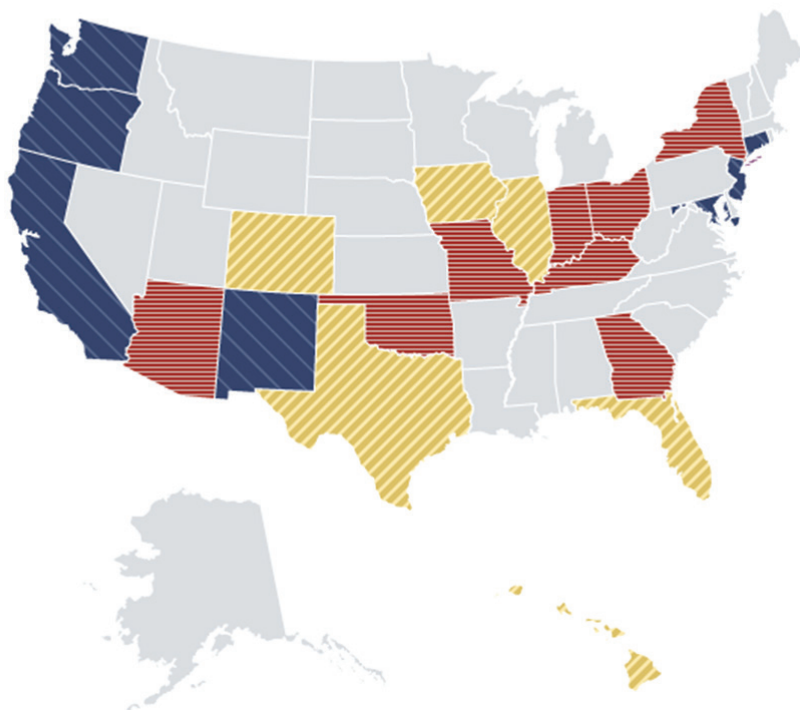


FIGURE 2-3 State-level cultural competency legislation.
SOURCE: HHS Office of Minority Health, 2015.

access is achieved when individuals with low English proficiency can communicate effectively with HHS employees and contractors and participate in HHS programs and activities. Language assistance refers to all oral and written language services needed to assist individuals with low English proficiency to communicate effectively with HHS staff and contractors and gain meaningful access and equal opportunity to participate in the services, activities, programs, or other benefits administered by HHS. In summary, language access, explained Alvarado-Little, focuses on equity, and language assistance focuses on the methods of service delivery, whether

it be in-person sign language or spoken language interpreters, video remote interpreting, or remote simultaneous medical interpreting.

Alvarado-Little noted that when she speaks about language access services, she is often surprised by how many people are unaware of Title VI of the Civil Rights Act, the Office for Civil Rights, the Americans with Disabilities Act, Executive Order 13166, and the U.S. Department of Justice guidance for agencies for developing language access plans to ensure meaningful access to services for individuals who have low English proficiency and includes what is known as the four-factor analysis⁵ for assessing whether recipients of federal funds and federal agencies meet the requirements. She also tries to drill down to find out more information regarding her audiences' knowledge by asking, for example, what they know about the policies of their own states or organizations, the demographics of those they serve, and the top five languages their clients or patients speak. She recounted how she recently asked officials at a hospital in rural upstate New York if they were complying with The Joint Commission accreditation requirements on language access and their response was that they were not accredited by The Joint Commission so they were off the hook. Though not true, that response illustrates a glaring lack of knowledge about relevant regulations and policies concerning language access services.

Another key concept, said Alvarado-Little, is the need to educate health systems about the role of the interpreter or translator, roles that are not interchangeable. Interpreting, she explained, applies to oral communication and requires strong listening and speaking skills, while translating applies to written communication and involves reading and writing skills. Alvarado-Little noted that a good interpreter is not part of the conversation between two individuals. She also explained that members of the health care team should brief the interpreter about specialized vocabulary they might be using before meeting with the patient or family.

There are several certifications available for health care interpreters, such as the Certification Commission for Healthcare Interpreters, the Registry of Interpreters for the Deaf, and the National Board of Certification for Medical Interpreters, and for the medical translators who deal with discharge instructions and other written materials. Certification, however, is

⁵ Four-factor analysis is the first step in determining whether individuals with limited English proficiency (LEP) have meaningful access to programs. The factors considered are (1) the number or proportion of LEP persons eligible to be served or likely to be encountered by the program or grantee; (2) the frequency with which LEP individuals come into contact with the program; (3) the nature and importance of the program, activity, or service provided by the recipient to its beneficiaries; and (4) the resources available to the grantee/recipient and the costs of interpretation/translation services (<http://www.hhs.gov/civil-rights/for-providers/laws-regulations-guidance/guidance-federal-financial-assistance-title-VI/index.html> [accessed June 7, 2016]).

not available for all languages. Therefore, health care systems need to look closely at the level of formal education and type of training an individual has had. Alvarado-Little noted that interpreters also follow a code of ethics and standards of practice.

Having a certified interpreter and not merely a family member present is particularly important when interpreting preoperative instructions and working with terms such as *health proxy*, *advance directives*, and *living wills*, concepts that do not exist in some countries and cultures, as well as terms such as *copay*, *deductible*, *out-of-network*, and *out-of-pocket*. Medication regimes can often be complicated, and having a certified interpreter who is experienced in dealing with different levels of health literacy and culture, different measurement systems, and knows that some medications go by different names in different countries can mean the difference between a patient and family truly understanding what is being said to them and misunderstanding instructions that are given at a particularly stressful moment. When trained interpreters and translators are not used, the result is often miscommunication. Some institutions, for example, attempt to turn English words into Spanish by adding an *o* to the end of the English word, with the English word *exit* becoming the Spanish word *éxito*, which actually means successful, rather than *salido*, the real Spanish word for exit.

Turning to her third key concept, community engagement and empowerment, Alvarado-Little said that the main focus here is educating end users—the patient, provider, workforce, and community member—about the need to understand what is involved in providing or using language access services and the mandates to do so. It is important, she said, to empower communities to know it is their right to have an interpreter present in any interaction with the health care system and for providers to know that interpreters are there to be their partners in providing health care to those who need such services. Communities need to feel empowered, she added, to ask that the materials they receive from the health care system be reviewed for cultural competence and to expect that health care providers will make use of an interpreter rather than just speaking more slowly and louder when talking to someone who does not speak English or who is hard of hearing or deaf. Alvarado-Little also said interpreters expect to be treated with respect as professionals and to be called by the appropriate title. “We are not interpreters, interpretators, or interpolators, and we are not translators,” she said.

She then cited three resources that she said have helped her move the discussion forward when she speaks with health care systems about turning policy into practice:

- Patient Protection and Affordable Care Act: <https://www.healthcare.gov> (accessed June 3, 2016)

- *Attributes of a Health Literate Organization*: <http://nam.edu/perspectives-2012-attributes-of-a-health-literate-organization> (accessed June 3, 2016)
- HHS Office of Minority Health's National Standards on Culturally and Linguistically Appropriate Services: <http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=53> (accessed June 3, 2016)

These three documents, she said, enable her to say that this is not just about the health literacy community saying that providing language access services and culturally competent communications is something that health care systems should be doing, but that there is substance involved. What still needs to happen, she said, is for the health literacy community to get the message out about the importance of integrating health literacy, cultural competence, and language access services and for there to be continued enforcement and evaluation. "Patient-centered care is communication based and is about addressing issues contributing to health disparities," Alvarado-Little said in closing. "When we do not speak the language of the individual, we must use an additional set of skills to continue to provide excellent patient care."

DISCUSSION

Rosof began the discussion by wondering if *business case* was the wrong term to use when thinking about cultural and language competence, and if the field should be talking about *return on investment*. He illustrated this difference by saying that when North Shore–Long Island Jewish (LIJ) Health System opened the Dolan Family Health Center 20 years ago, the chief financial officer said there was no business case that would justify investing in a facility to provide care for a largely vulnerable and uninsured population with a variety of cultural competency issues. He was right, said Rosof, because to this day, North Shore–LIJ still loses about \$600,000 per year. He estimated, though, that the return on investment in terms of a healthy community, healthy population, and thousands of healthy children must be sizable.

Wolf agreed with Rosof and said health systems are starting to look at what would be an acceptable cost for realizing those community health benefits. He recounted that when he was in the process of convincing one of the largest national pharmacy chains to undertake a health literacy initiative, the executives of this company had several questions they wanted answered: Are we getting ahead of an eventual mandate? Are we going to sell more product? Is there a way to frame this as a safety initiative? With regard to this last question, Wolf said while some health systems are framing health literacy, cultural competence, and access to language services in terms of

a risk-mitigation strategy for specific subgroups, he thought this is a bad strategy for the health literacy field. “We want to have people thinking that this is a right thing to do, that they are going to get return on investment, and that it is a matter of improvement in health care quality,” said Wolf. Yes, he added, there will be some safety-related benefits, but in his mind health literacy, cultural competence, and language access services should be viewed as quality indicators and an integral part of value-based design.

Andrulis agreed with Wolf and noted the importance of getting past a pure dollars-and-cents, bottom-line business case and looking instead at bigger issues that can lead to an expanded version of the business case. Examples he cited included the cost of hospital readmissions and physician follow-up visits resulting from the health care system not paying attention to health literacy or cultural or language issues, the expense of not complying with regulations, or the penalties for performing poorly on metrics of patient satisfaction and quality of care. Pacheco added that a key element in building an expanded business case is data collection. “Analytics is driving policy and programs,” he said. If health care systems started documenting how health literacy, cultural competence, and language issues are acting as barriers for patients getting to a clinical encounter and following care plans, it would provide the leverage to build a business case that more accurately reflects the larger value of health literacy, cultural competence, and language access services.

Ruth Parker from Emory University School of Medicine asked the panelists if they knew of anyone who was writing about literacy, language, and culture from the perspective of value, given how value is high on the agenda of health care systems. Andrulis said that he did not know of anyone who has approached the business case in that way. “That is why I think the timing of this workshop is important in the sense of reevaluating the visibility of language, literacy, and culture and grounding them in data,” said Andrulis. He proposed that the National Institutes of Health (NIH) should fund a series of demonstration projects or assessments comparing results from experimental and control groups to produce a foundation grounded in data and real-life experience, not just anecdote and advocacy. He added that with all of the projects going on today involving enrollers and assisters, who he assumed are engaging in health literate, culturally competent, language-appropriate outreach activities, he has yet to see any studies looking at those efforts. Alvarado-Little noted both the importance and the difficulty of capturing the effect of providing language access services compared to not providing them. As an example, she cited a recent instance in which a patient had been briefed in the absence of an interpreter prior to surgery. This patient had not understood the instructions and was missing a laboratory test required by New York State. Fortunately, an interpreter encountered this patient and informed him about the need to have this test

run, and so the patient was ready for surgery on the appointed day. “But how do we capture what would have happened if he had shown up and had the surgery cancelled?” asked Alvarado-Little. “That is a question I know we are not going to answer today, but it is one we need to think about.”

Rima Rudd from the Harvard School of Public Health offered a brief comment on why she has not successfully grappled with the issues of culture, language, and literacy and integrating them. With issues of culture, it seems to her that the health care system takes for granted its interpretation of health, medicine, and nursing as the base culture and then tries to learn the culture of its patients. “I think we need a deeper analysis of what our culture is and to understand what our biases are, what our limitations are, and what our values and assumptions are before we can really understand another culture,” said Rudd.

To her, these are issues of explaining and negotiating, which is about good communication. “When we think about interpretation, the ethics of a good interpreter is to be true to the statement that is being made,” said Rudd. Being true to the statement requires negotiating for the extra time and effort required beyond that needed for the mere change from one language to another given the complexities of explaining the meaning of medical jargon. She often thinks of the scene in Lewis Carroll’s *Through the Looking-Glass* when Humpty Dumpty says to Alice that when he uses a word it means exactly what he wants it to mean, which to Rudd means there is no room for interpretation or explanation. “Of course, we know what happened to Humpty Dumpty, and I am worried that the same thing will happen to us.” In some ways, she continued, integrating health literacy with culture and language services cannot happen without a lengthy, detailed explanation, negotiation, and respectful dialogue.

Given that context, Rudd asked Alvarado-Little what she means by language access. Alvarado-Little explained that interpreting for providers can be tricky given that whatever she hears, she is obligated by her code of ethics to interpret. To answer Rudd’s question in what she characterized as a roundabout way, she described how she was interpreting for a complex patient in the intensive care unit who was heavily sedated for his protection. The patient’s family arrived and she was interpreting for his sister, who was his health care proxy. The nurse asked if the family had any questions and the sister asked why her brother’s hand was so swollen. The nurse replied it was the result of a physiological response, and Alvarado-Little interpreted that even though she herself did not know what it meant. “The sister looks at me, the nurse looks at me, and I am supposed to be transparent, so I say nothing,” said Alvarado-Little. Finally, the nurse looked back at the family and said that was the only explanation she had. At that moment, Alvarado-Little stepped out of her role as a transparent conduit and asked for permission to clarify something with the nurse. Turning to the nurse,

she asked, “As an interpreter, is there something else you would like me to interpret, such as do you have any other questions?” Her position was that she did not want to do anything that would cause the nurse to lose face. The nurse then turned to the sister and asked if she understood, which Alvarado-Little interpreted, and the sister replied no, she did not know what a physiological response meant.

In that instance, Alvarado-Little explained, she applied her cultural competence and knowledge about health literacy while still adhering to her code of ethics to help bridge a gap that was preventing effective communication. “I am not responsible, nor would I pretend to be responsible, for the words of others,” she said, “but what I can do as somebody who is trained in this area and always learning is to try to be a resource when I am the only one in the room with a foot in both worlds.” What would help avoid this type of situation, she added, would be for the health care professional to be aware of what they are presenting and the challenges that someone outside of the profession might have understanding that information.

Pacheco responded to Rudd’s question by noting that health literacy and cultural competence are about communication and making sure the patient understands all of the information being conveyed. Addressing Rudd’s comments about culture, he said the culture of a federally qualified health center is much different from that of a typical hospital. The federally qualified health center has staff that represents the surrounding community, it has interpreters and materials translated into the languages used in the surrounding community, and it has community health workers and patient navigators who know about and understand the cultural and language diversity in the surrounding community. It would be useful, he said, to study the strategies and interventions these federally qualified health centers use to address the needs of those diverse populations and think about how those practices might be adopted or adapted for the hospital setting to address the needs of those patients that have chronic diseases. Rosof summarized this part of the discussion by referring to the earlier Shaw quote, saying that the biggest problem in communication is the illusion that it is taking place.

Laurie Francis commented that she works exclusively with federally qualified health centers in her role with the Oregon Primary Care Association and that she is mildly and chronically irritated with how much work still remains to bridge the health literacy world with the patient-centric world. She then remarked that culturally competent providers would be better listeners, inquirers, and interviewers, particularly for patients who come from cultures that would never think of questioning a doctor or other provider given the inherent power differentials in health care. Her question for the panel was whether they thought it was time to go from lecturing gently about the need to be health literate, culturally competent, and pro-

vide language access services to calling out the provider team, particularly their need to listen and not just lecture, in the same way that health care systems are being brought to task around issues of equity.

Andrulis replied that yes, it is time to do just that because this is at its heart an issue of being conscious about these issues. It is time for health care professionals to recognize that health literacy, cultural competence, and language access services have to be a part of the narrative around patient care. Bringing these elements to a discussion should not be an assumption, but a requirement that gets documented, which in turn would begin generating the data that Pacheco said are needed to develop more effective approaches for communicating with patients, families, and communities. Andrulis suggested the health care marketplaces created by the ACA may have some important lessons for how to integrate these three concepts, particularly with regard to training, documentation, customer satisfaction, and measurement. He suspected, in fact, that the marketplaces may be further ahead than the rest of the health care field because they have been forced to by the plain language requirements in the ACA. He also repeated Parker's point about documenting where value is playing out in new initiatives to better understand how to develop more effective programs.

One challenge regarding patient-centeredness, said Wolf, is that little is known about the characteristics of patients, including their health literacy skills, language preferences, and cultural backgrounds, that affect their engagement in health care, which in turn makes it difficult to create a more efficient and patient-centered health care system. Getting this kind of information goes beyond the 15- to 20-minute encounter and requires building a real relationship between the patient and the provider and a recognition from the health care system perspective that this is a worthwhile endeavor. Until that happens, he said, there will continue to be stagnation in terms of truly creating a more efficient and responsive health care system.

Michael Paasche-Orlow from the Boston University School of Medicine echoed Francis's suggestion that it is time for the health literacy field to drop the gentle approach to convincing health systems to become health literate and culturally competent, and provide language access services as the standard of practice. He acknowledged that some changes will require data, and he applauded Andrulis's call to learn from approaches that work. Other changes, however, require direct advocacy. "What are we thinking when we see patients that we cannot talk to in the same language? What are we doing in that appointment?" asked Paasche-Orlow, who places the blame for what is obviously wrong with that situation on the provider-centric cultural belief that dominates physician attitudes. He acknowledged that the health literacy community needs to learn how to be more forceful in its advocacy, and the time to learn how to do so is now. He noted it is still uncommon for clinicians to call upon professional interpreters when meet-

ing with patients who speak a different language, and that while it is important to hear about how a professional interpreter such as Alvarado-Little will step out of her role as interpreter to make sure effective communication is occurring, it is the exception rather than the rule that she even had the opportunity to be in the room with the patient and provider. “This should be a matter of a patient’s civil rights in this country,” said Paasche-Orlow.

Pacheco said what has been missing is the progressive element in health care, and looking at this issue in terms of civil rights is a promising approach. He called on the workshop attendees to push the Office for Civil Rights at HHS to start enforcing its guidance and laws that affect the civil rights of individuals who are trying to access health care but cannot because of issues involving health literacy, cultural competence, and language access services. He added that he believes there is movement in the direction of more forcefully addressing these issues. Paasche-Orlow said this community needs to bring anger in addition to advocacy to bear on addressing these issues, though Andrus said that what is needed is passion, not anger. “My goal is to find the tools that you, I, and others can use to advocate passionately and in a way that convinces people,” said Andrus.

Alvarado-Little said that when she goes into a room as an interpreter, she also goes in wearing her masters in social work hat when she works with those providers who have fragile egos regarding self-assessment and language. When she deals with medical students, she reminds them to think about whether they ask their patients what language they get sick in and to access their emotions. She commented that nutrition is a hard area in which to interpret because food names can vary tremendously even within one language, such as Spanish, because of cultural factors. Speech pathology is another area where interpreting is difficult because of how the tongue and lips are used in different languages. The key, she said, is preparation, of learning what words make sense to a patient and that are diagnostic for the speech pathologist. Mental health appointments can also be challenging because conversations can be “word salads” rather than linear. She recounted one instance when she was interpreting for an adolescent who was having visual and auditory hallucinations. The provider said, “This is Wilma. You can touch her. She is real.” Alvarado-Little had to interpret that.

She agreed with the call to bring passion to this community’s advocacy efforts and noted that in some cases clinicians do not call for interpreters because they are not even aware that service exists in their health care system. She added that what she tells medical students is to use her to help them work smarter, not harder, and noted that interpreters often have to walk a fine line to avoid doing anything to undermine a patient’s confidence in his or her provider. “I have to be careful because if I do something that taints that relationship, the provider might not call me back and instead

use their own skills because they have generalized that interpreters are difficult,” Alvarado-Little explained.

Marshall Chin from the University of Chicago asked Wolf to comment more on why he thinks the three fields being discussed at this workshop have stagnated and what the single most important new direction he thinks these fields should take. Wolf replied that two important causes of stagnation, at least from the perspective of health literacy, are the health literacy community continues to do a poor job at disseminating best practices and the lack of a strong evidence base to support those best practices. In addition, he believes there are too many factions in the field. “We need to have a united voice,” he said. Wolf also commended the roundtable for talking about evaluation and laying out the characteristics of a good health literacy intervention.

Andrew Pleasant from the Canyon Ranch Institute commented that when it comes to making policy change, “numbers get you in the door, but stories win hearts and minds.” The ACA and PCORI, he explained, “are providing fabulous opportunities to advance health literacy, language access, cultural competency, yet they go out of their way to defer people—some would say prevent people—from using metrics such as the quality-adjusted life year to achieve the ends this group is trying to achieve.” He said that he has used the quality-adjusted life year metric to demonstrate clearly that health literacy and integrated health prevention interventions can create health at lower cost than most other medical interventions, but PCORI is prevented from funding research that makes cost comparisons. Given that situation, he asked the panelists how these fields can align strategically to change that discussion and enable the use of specific metrics to make the business case or show a return on investment.

Andrulis responded that there are some efforts to work around those restrictions, and the National Prevention Strategy and other initiatives are trying to address this roadblock. He noted this is a hard area for foundations to tackle because they do not want to spend the money. As an example, he said he is involved in the Robert Wood Johnson Foundation’s work to create a National Health Equity Index, and when he raises the need to include literacy, language, and culture in that index, the response is lukewarm because the focus is on other areas. He and his colleagues Brian Smedley of the Joint Center for Political and Economic Studies and Steven Woolf at Virginia Commonwealth University are making it a point of advocacy to step up and make the case, but so far they have been unsuccessful at engaging those at the foundation who are creating this index. With regard to other efforts to produce supporting data, he suggested turning to Congress and finding allies within federal agencies to raise the visibility of the need for metrics and data. Pacheco noted there are sympathetic ears in Congress and also suggested approaching the White House about using

executive orders to address this issue strategically without harming entities such as PCORI. Alvarado-Little said the New York state legislature could not pass a language assistance bill, but the governor issued an executive order mandating supervision of language access services for the top six languages as identified by the 2010 U.S. Census. She and her colleagues are also working with the provisions of the New York State Pharmacy Act that require chain pharmacies to provide these services.

3

Issues and Challenges

In the workshop's second panel, Alicia Fernandez, professor of clinical medicine at the University of California, San Francisco, and an attending physician in the General Medical Clinic and the Medical Wards at San Francisco General Hospital, provided an overview presentation on the issues and challenges for integrating health literacy, cultural competence, and language access services. Following her presentation, Winston Wong, medical director for Community Benefit, Disparities Improvement, and Quality Initiatives in the National Program Office at Kaiser Permanente, moderated a discussion among Fernandez, and the members of the first panel, Dennis Andrulis, Michael Wolf, Guadalupe Pacheco, and Wilma Alvarado-Little.

AN OVERVIEW OF ISSUES AND CHALLENGES¹

Alicia Fernandez began her remarks by presenting four cases to provide a common reference for the later discussion. The first case, illustrating the challenge of interpretation versus communication, involved a 62-year-old, Spanish-speaking woman who was newly insured under the ACA and was seeking care at the university-affiliated medical center after a recent heart attack. Using a phone interpreter, her young, earnest, and wonderful physi-

¹ This section is based on the presentation by Alicia Fernandez, professor of clinical medicine at the University of California, San Francisco, and an attending physician in the General Medical Clinic and the Medical Wards at San Francisco General Hospital, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

cian begins to tell her about the merits and drawbacks of combined anti-coagulation therapy using clopidogrel and aspirin, emphasizing the higher percentage bleed with combination therapy over single-agent treatment on the one hand, and the better protection conferred by combination therapy and low chance in absolute numbers of a major bleed on the other hand. After 4 minutes, he finishes by asking her which drug she wishes to take. Thoroughly confused, the patient looks at him and says, “*Si?*”

In the second case, illustrating the challenge of talking to the right people, an oncology team is conducting rounds at a teaching hospital and is happy to catch its elderly Cantonese-speaking male patient alone. He has had family continuously at the bedside, but the team needs to inform him of the pathology results showing lymphoma, and obtain his consent to initiate chemotherapy. A team member pulls up a speaker phone and calls for a professional interpreter. Impatient with the arrangements, the lead oncologist starts in: “I am glad we can talk with you now. We need to tell you about your cancer and have you decide on the treatment.” The patient turns away and barely responds.

The third case, illustrating how interpretation can go awry, involved the instructions that a member of the health care team was giving a mother regarding how to give her baby an antibiotic. “Please give the baby 1 teaspoon of the antibiotic three times a day for 7 days. Give it to her even if the fever is gone,” explained the well-meaning pediatrician. “*Dele al bebe una cucharita de antibiotico tres veces al dia por siete dias, aunque ya no tenga fiebre,*” the interpreter says. There is only one problem—what is a *cucharita*?

Case four, involving use of the wrong word, has a physician telling a patient, “You can enter hospice, and they will help your family take care of you.” The interpreter says, “*Puede entrar al hospicio, y ellos ayudaran a su familia a cuidarlo.*” The problem is that while *hospice* is a program for terminally ill patients focused on palliation of symptoms, a *hospicio* is a home for abandoned children or the poor elderly.

These cases, and the many others like it, are not egregious. “This is bread-and-butter clinical medicine in an extraordinarily and increasingly complex clinical panorama of care, and yet they illustrate the tip of the iceberg of how difficult it is for patients and clinicians to overcome the language, literacy, and cultural barriers to achieve effective, equitable patient-centered valuable care,” said Fernandez. To illustrate why this is the case, she started by providing some statistics. Using the strict definition of a low English proficiency—those who report speaking English “not well” or “not at all”—there are about 14 million people living in the United States, 11 million of whom speak Spanish. Seventy percent of the 14 million people with low English proficiency have less than a high school education, and 6.6 million have family incomes under the federal poverty line. In addi-

tion, many if not most of these individuals are less acculturated to U.S. health practices, including practices around informed consent and having a dialogue with their physicians. There is also a diversity of views in the low English proficiency population about how a patient and family should make decisions, some of which Fernandez said she was hinting at in her story about the elderly Chinese man with lymphoma.

Patients with low English proficiency, she explained, report more medication errors (Wilson et al., 2005), have a lower level of understanding of prescription labels (Masland et al., 2011), are less likely to know the medications they need to take when discharged from the hospital (Karliner et al., 2012a), and are less likely to know about follow-up appointments (Karliner et al., 2012b). Language barriers, she added, have been implicated in patient safety (Divi et al., 2007) and are associated with worse outcomes in diabetes care (Fernandez et al., 2011), though not with patients who have had a heart attack (Grubbs et al., 2008) or other conditions for which care is heavily regimented. “There is widespread agreement that things are not working,” said Fernandez.

Fernandez and Yael Schenker from the University of Pittsburgh Division of General Internal Medicine conducted a national survey of interpreters on their experiences with end-of-life discussions. These were experienced, certified interpreters, yet only half reported that the discussions usually went well. Some 80 percent of the interpreters surveyed said they would like additional training in end-of-life interpreting, and 81 percent reported that physicians need more training in working with interpreters in general, not just on end-of-life discussions (Schenker et al., 2012).

Discussing the common challenges to overcoming literacy, language, and cultural barriers, Fernandez said that determining the health literacy of a patient can be challenging, particularly when physicians do not take a social history that might tell them that the patient sitting in front of them has less than a high school education, is a highly trained engineer, or is someone who can truly understand risk percentages. As a result, information sharing can easily be too much or too little, she said, or can go on for too long when all the patient wants to know is when can he or she go back to work.

Another challenge is the belief that equitable care means the same care and the offer of similar information to all patients. As examples, Fernandez noted that some physicians might believe it is equitable to offer genetic counseling to all pregnant patients regardless of cultural background, or to let the patient choose between two different medication regimens regardless of their level of health literacy. On the other hand, she added, substituted judgment or paternalism can rob patients of agency and autonomy, yet an emphasis on shared decision making can leave patients feeling confused, left alone, or deprived of professional services (Penchaszadeh, 2001). A final

common challenge, said Fernandez, is that the cultural value of individualism is seen by Americans as universal, yet in many cultures decision making is never done alone but involves the family.

The current standard of care for patients with low English proficiency is to use a professional interpreter, whether that be in person, by phone or video link, or through the use of bilingual staff, but there is no data about how often conversations with hospitalized patients with low English proficiency include an interpreter. What is known is there is no mandate for physicians to be trained on how to work with an interpreter, and there is no testing required to demonstrate proficiency in working with an interpreter. Her institution, a recognized leader in medical education, did not have mandatory classes in interpreter training until 2015, she noted, and added that a few hospital systems are starting to test and certify bilingual physicians. “This is an important route if we want physicians to speak directly with their patients without the use of an interpreter,” said Fernandez.

The underuse of interpreters and the use of inappropriate interpreters, such as untrained staff or family members, is one of the biggest barriers, she noted, but so too is the fact that so few physicians and other members of the health care team are trained to work effectively with an interpreter. The fact that interpreters are trained to value a role as language conduit rather than as cultural advocate can be a barrier, and Fernandez wondered if interpreters should be trained to speak up when they sense that the patient and clinician are not understanding each other.

Another health system barrier is the lack of some means to facilitate family meetings with the clinical care team. She experienced a rather simple solution to this last barrier when she went to Argentina when her father was hospitalized there. When she asked to speak with her father’s doctors, she was told to come to “doctor time,” the twice-daily, hour-long periods set aside for families to meet with their loved ones’ physicians, ask questions, and even bring along a family friend who is a physician. “This kind of simple solution is not integrated within the U.S. health care system,” said Fernandez.

These barriers, she said, lead to the situation demonstrated in multiple studies that patients with low English proficiency have lower levels of comprehension, patient satisfaction, and trust in their physicians when they receive language-discordant care (Schenker et al., 2010) (see Table 3-1). Studies also show that while interpreters provide a valuable service, the best situation is to have physicians who speak the language of their patients. In one study Fernandez conducted using data from Kaiser Permanente in northern California (Wilson et al., 2005), she and her colleagues found that even patients who are treated by physicians who use trained interpreters and certified bilingual staff still feel as if they are treated poorly because the physician is not showing them respect by speaking their language, a

TABLE 3-1 Language-Discordant Care Leads to Suboptimal Communication

	English- Proficient N = 8116	LEP N = 522	P Value	LEP-LC N = 210	LEP-LD N = 153	P Value
Lack of trust in MD	26%	25%	0.37	16%	35%	<0.0001
Treated poorly because of language	2%	12%	<0.001	9%	20%	0.001
MD not showing respect	28%	30%	0.31	29%	39%	0.04
MD not listening	33%	28%	0.02	26%	32%	0.24

NOTE: LC = language concordant, LD = language discordant, LEP = low English proficiency.
SOURCES: Schenker et al., 2010, presented by Fernandez, October 19, 2015.

finding that Fernandez said did not vary according to language. Another study she cited (Rivadeneira et al., 2000) found that communication is likely to be more patient centered when delivered by a language-concordant physician compared to an interpreter. Observational studies have found that interpreter-mediated conversations, compared to those involving a language-concordant physician, have fewer open-ended questions and less elicitation of questions and values, and one study has shown that patients cared for by language-concordant physicians can have better clinical outcomes (Fernandez et al., 2011).

With regard to what can be done, Fernandez offered several possible solutions to the challenges and issues she described. One solution is to structure health systems to require professional interpreters for patients with low English proficiency, and, at a minimum, every hospitalized patient with low English proficiency should have at least one conversation per day with the treating clinician mediated by an interpreter if the clinician does not speak the preferred language of the patient. This requirement, she said, could be integrated easily into a patient's EHR. "This is not rocket science," said Fernandez. "It does not require a single payer. It does not require a full reassessment of the U.S. health care system. This is an easy floor to establish."

Two other obvious solutions, she said, are to do a better job training interpreters in high-risk communication scenarios such as end-of-life discussions and genetic counseling and to train not only physicians but all member of the health care team on how to work with an interpreter. Such training should be incorporated into medical and nursing school curricula, for example, and in all residencies. Clinical care team training should also incorporate skills in eliciting patient questions and concerns that reflect a

patient's cultural background. Fernandez also called for better enforcement of the requirement that all translated materials be written at the fifth-grade level. Finally, she said, the workforce needs to be diversified. "At the end of the day, it is easier to ask people appropriate questions when they know from their own experiences and those of their family members how difficult it is to be a patient in poverty," said Fernandez. She also recommended that common foreign language skills should be a plus or even a requirement for medical school admissions. She noted that some health systems, such as Kaiser Permanente in Southern California, are facilitating language matches for patients and providing differential pay for language skills. Some systems, she said, are investing in interpreter technology, but that technology, she cautioned, is only good if it is used with the recognition that patients are likely to have low English proficiency and health literacy.

Health systems are starting to experiment with ideas such as "teamlets" that match a primary care physician with language and culturally competent medical assistants or phrasing modules or grouped care. Health systems are also using language-appropriate health coaches and *promotoras* with some success. All of these approaches have to come to scale, however, and the requirement for language access services needs to be incorporated into the EHR. All of these ideas also need to be paid for, and while they certainly provide a return on investment in terms of equitable care, Fernandez noted that she performs many tasks as part of routine medical care for which she is not asked to justify a business case. "I think that there will be a return on investment in terms of a healthier community, but for now we need to hold the line around patient-centeredness, safety, equity and simply doing the right thing," said Fernandez. She said she believes there will be a future in which the language barriers within hospitals will be broken down (see Table 3-2), but realizing that future will take a great deal of time. She noted in closing that she has the privilege of working at San Francisco General Hospital, where language, literacy, and culture are inexorably entwined, but that she sees the difficulty patients experience when they move to other systems.

MODERATED PANEL DISCUSSION

Winston Wong opened the discussion period by saying that he was struck by the fact that "we have tended to look at these cases from the perspective of being the provider, but maybe it is important for us to go to a place where we have felt marginalized in the discussion about something important, whether it had to do with a medical issue or a social family issue, and where we felt alone and disempowered. That might give us an understanding of the interventions that need to take place." He then added a fifth example to the opening cases that Fernandez presented. In

TABLE 3-2 The Present and Future of Language Barriers in Hospitals

	Now	Future
Technology	Inadequate	VMI in every room
Interpreters	Insufficient numbers	Adequate, trained, certified, integrated, funded
Residents/Students	Underuse of interpreters common	No underuse
	Training inadequate	More language skills Trained, consistent, professionally committed
Attendings	Hit or miss on language access	Professionally committed More language skills
Nurses/Staff	Hit or miss on language access	Trained, consistent, professionally committed, diverse language skills
Patients	Accept care as given	Drive improvement

NOTE: VMI = Videoconferencing Medical Interpretation.

SOURCE: Presented by Fernandez, October 19, 2015.

this instance, he had a patient who was a Cantonese-speaking, first-time mother-to-be who was being evaluated for thalassemia, a genetic disorder that is more prevalent among Southeast Asians. Indeed, this woman, a recent immigrant from rural China with perhaps a sixth-grade education, did have a mutation that put her baby at risk for having serious sequelae, and Wong, who was the supervising physician, and the rest of the clinical staff were trying to communicate to her what the issues were with regard to carrying a child that might be seriously compromised. He recalled walking by the exam room and seeing the genetic counselor from Children's Hospital in Oakland working with an interpreter to explain dominant and recessive genes using a pile of pegs and being impressed that these professionals were truly trying to enable this patient to be empowered. Wong noted that because this woman had recently emigrated from China and had a fairly low level of education, he perceived at the time that much of her value to her family and community was being a mother who could bring a first child into the family. "That was critical for her sense of being valued and being part of a bigger set of community propositions and social value," explained Wong.

After telling this story, Wong asked each panelist to identify which one of the five cases they heard struck a chord, explain why, and talk about the critical issues that came into play in that case. Wolf said the scenario with the Cantonese man is something he saw frequently in a study he conducted some 15 years ago where he was trying to understand how to start a conversation with a patient when little is known about what was said previ-

ously or about what is going on with that patient. He then said that case and the one involving the discussion of different medication regimens and shared decision making both point to the difficulty of interpreting complex elements of medical jargon, pathology, and disease in the context of literacy, language, and cultural difference, and breaking them into “digestible units” for a family and patient to understand. This is particularly challenging given that each situation is unique, and what these two cases illustrate to him is the need to better support providers, not just through medical education and training, but with point-of-care support to help them navigate the information needs of each specific patient. Such an approach, he said, would be low-hanging fruit that health care systems could address while taking longer-term steps to increase workforce diversity and hire clinical care staff that is fluent in various languages. One possible way to provide support would be to leverage the EHR and use it to provide simple words and straightforward explanations that would be appropriate for a specific patient based on the information that Fernandez suggested should be included in a patient’s record.

Alvarado-Little, commenting on the case involving the Cantonese man being given a lymphoma diagnosis, said that too often information on a serious disease such as cancer is conveyed too rapidly, regardless of language, for a patient to assimilate and use to make a rational decision. With cancer in particular, patients usually stop listening after hearing the word *cancer*. She also noted that in some cultures, talking about cancer is taboo or at a minimum a very sensitive subject, and in some cultures it is important to consider the provider’s gender when speaking about anything relating to childbearing. “Providers are doing what they have been trained to do, and then here comes this health literacy, cultural, and linguistic piece being added to situations that are complex in and of themselves,” said Alvarado-Little. The five cases also made her think about the spiritual and nonverbal components of giving patients a serious and perhaps sensitive diagnosis.

Pacheco was struck by the limited time that physicians have to deliver a diagnosis and prescribe a treatment and how that time can be compromised by issues of literacy, language, and culture. He also commented on the crucial role that empathy plays in dealing with serious illness, particularly cancer, and how challenging it can be to convey empathy when language and cultural barriers exist. The cases presented also raised in his mind questions about how to navigate from diagnosis to treatment, how to provide patients with the information they need to understand all of the steps in their treatment, and how to involve in those discussions family members who may provide a strong support structure for the patient within that family’s culture. For Pacheco, the case Wong presented highlighted how the first birth in a family is such a milestone in so many cultures and how receiving news that something may not be right with the child can affect

not only the mother- and father-to-be, but also the extended family, which may believe that its members did something that caused this particular health outcome. In this particular case, said Wong, the mother-to-be could feel the baby moving inside her and asked him how he could tell her that her unborn child was going to have a bad outcome when she could feel its viability in her body.

Fernandez then asked the other panelists if they could talk about some structural solutions, separate from workforce diversification and training, that would require either payment reform or new regulations. One example, she said, could be certifying providers for demonstrating proficiency in working with an interpreter or being conversant in a second language. Wong added that it would be useful to consider structural solutions that go beyond the triad of doctor–interpreter–patient to include the entire multi-disciplinary team that cares for patients.

Wolf suggested that the point of care might be the place to start looking at structural solutions because in his mind those solutions would take hold more quickly. He commented that when the discussion turns to provider training, the claim is made frequently that training does not seem to have a lasting impact on provider behavior, and one way to address that issue is to include provider behavior in meaningful quality indicators that have regulatory or payment consequences. He expressed the frustration that he said many in the health literacy field experience about how much longer it will take to convince regulators and payers that the evidence base is sufficient to mandate certain best practices. He reiterated earlier comments that health information technologies such as EHRs should be used to support these best practices and to demonstrate that implementing them does not take as big of an investment as many health systems believe. Returning to the analogy of nesting dolls he used in his earlier presentation, Wolf said he sees culture being the biggest of the three, then literacy, then language when it comes to cost. “Many health care systems view the language piece as the most burdensome in terms of cost, whether that is right or not,” he said, and he worries that efforts to integrate these three components may fail because of some “inappropriate thinking” about the investment required.

Pacheco said that implementing structural solutions requires a systems approach and that starting with point of care and continuum of care are key places to begin such an effort. To take a systems approach, quality indicators and data are essential, and he believes that each of the cases presented is a data point. He agreed that health information technologies can collect the necessary data to inform quality indicators and that execution is now the issue. Upcoming programs from the Centers for Medicare & Medicaid Services (CMS) offer the opportunity, he said, to embed the quality indicators that this community wants and tie them to reimbursement.

Alvarado-Little called for more education about and enforcement of existing policies, such as Title VI of the Civil Rights Act or New York State Executive Order 26, and to revisit those policies to see where they can be improved and strengthened. Pacheco noted that the EHR could be used to capture the data needed to determine whether health systems were meeting regulatory requirements. What is needed, he said, is to determine the new data elements required to develop patient-specific profiles relevant to health literacy, cultural competence, and language access. Once collected, these data could also help make a business case by demonstrating the value of providing patient-centered quality care.

Alvarado-Little also commented on the resistance she gets whenever she talks about cultural competence or interpreting services because some of the requirements are thought of as unfunded mandates. However, federal agencies take the position that anyone accepting federal funding agrees as part of the funding agreement to provide language access services and meet all regulatory requirements concerning literacy, language, and culture. If that is the case, she said, then this community should look hard at raising awareness of existing regulations, calling for better enforcement of those regulations, and advocating at the state level for state legislators to take advantage of the incentives that exist to move initiatives forward.

At the same time, she said, this community could educate and work to empower communities and providers to advocate for health systems to meet all existing requirements. She noted that medical students or residents often do not learn about these issues until they are put in a situation where they require an interpreter and at that moment are unsure of what to do. As an aside, she noted that it is important to teach students about body language—someone may not understand English or be able to hear, but they see someone sigh or roll their eyes without the need for an interpreter.

Wong then asked the panelists to put themselves in the position of a hospital administrator or director of patient services. What metrics would they need to put before their boards that captures the confluence of language access, health literacy, and cultural competence of the sort that arose in the five cases presented in this session? Fernandez thought that patient-reported metrics, such as comprehension, satisfaction, and trust in the provider and system on a per-encounter, per-hospitalization, or per-procedure level, might be the best bet. Wolf agreed that patient-reported outcomes would be key measures that would provide a more detailed picture of the quality of care being delivered than simply looking at readmissions and other currently collected information. He cited as an example, a study he conducted on medication adherence in which patients were asked to demonstrate how they understood they were supposed to take their medications. A high prevalence of those patients did not understand what they were supposed to do. Using simple measures such as readmissions does not provide a clinical signal

that this lack of understanding exists. “I would love to have these patient-reported metrics in place,” said Wolf. “The question is how do we do that.”

Wolf also suggested that appropriate metrics could serve as the basis for a value-based model that bundles reimbursements for services related to literacy, language, and culture into payments for treatments. For example, Wolf said he is building a reimbursement model for the new hepatitis C treatments that includes measures on the proper use of these medications. Services supporting adherence to the medication regime could be embedded in that kind of bundled reimbursement.

In addition to using the metrics Fernandez and Wolf proposed, Alvarado-Little suggested involving risk management and patient relations as partners in these discussions. She noted that one of the tenets of the CLAS standards is to provide patients and health care systems with the ability to address grievances and complaints. The metrics Fernandez suggested could be used to determine if the CLAS standards are being met and if grievances and complaints are handled well. Other steps Alvarado-Little suggested were to ask the interpreters and translators how best to capture this information and ask them about the role they play in creating partnerships with other aspects of their organizations. “Once you open that door with interpreters and translators, many of them are happy to share that kind of information,” said Alvarado-Little.

Before opening the discussion to the workshop attendees, Wong made two points. First, use had not been discussed as a measure of how effective providers are at communicating what patients need and what the health care system asks them to do. Second, there was little discussion about waste, though there is certainly waste in the system because of poor communication, and reducing waste could be part of a business case.

DISCUSSION

Steven Rush from UnitedHealth Group remarked that the discussions about interpretation focused on the words being said, and he wondered to what extent interpreters can insert empathy and feelings into their work. Alvarado-Little responded by saying that when she interprets, she uses the same inflection in her voice as she heard in the provider’s voice in order to deliver a message in the spirit and with the meaning intended by the provider. For example, if a provider says, “I’m sure you don’t understand that,” she would interpret the message that way instead of “I’m sure you didn’t understand that.” However, if she senses the atmosphere in the room is getting spirited because not everyone in the room agrees with whatever message they are receiving she is going to use what is called the “luxury of two seconds,” the time she has to figure out how to interpret a message without tainting the outcome. If during that time she decides that a

phrase she is about to interpret is going to damage the provider–patient or provider–family relationship, she may decide to change the exact wording of her interpretation with the knowledge that she will be held accountable according to her code of ethics. Afterward, she will have to meet with the provider and explain why she changed the wording and altered the tone of that message. “There are some complexities that are nuanced, but what hits my ears is what I am obligated to interpret,” said Alvarado-Little.

Rush also said that he agreed that the first year of residency is too late for a young clinician to first learn to work with an interpreter. Other members of the clinical care team, including pharmacists and nurses, need to be involved in interpreter training as well. Rush then mentioned a metric called the net promoter score,² a measure of patient satisfaction, and wondered if that metric could be tied into cultural competence. The CAHPS measure, for example, includes a health literacy component, and he suggested looking at CAHPS and other measures, such as the Healthcare Effectiveness Data and Information Set (HEDIS) and net promoter scores, to help drive the business case.

Pacheco agreed with Rush’s comments about using existing metrics and data collection structures. “Why not adapt health literacy, cultural competency, and language access as key components of these metrics?” he asked.

Andrulis then asked Fernandez two questions about language concordance. First, he wondered if there were something interpreters could learn from working with language-concordant providers that would improve their interpretation skills. Second, he asked if she had any insights on what language-concordant physicians are missing that leads to less than perfect understanding by patients. Fernandez replied to the first question by saying there is some understanding of the difference between an interpreted conversation and a language-concordant conversation, the biggest of which is that concordant conversations are more likely to elicit a patient’s values than an interpreted conversation. She explained that she sees many patients with whom she is language concordant and many with whom she works with an interpreter. In the latter case, she focuses hard on making sure that the patient is understanding the specifics of the instructions that she is providing via the highly capable interpreters with which she works. “Somewhere in there, I forget to ask the patient what he or she thinks about taking all of these medicines, for example,” said Fernandez.

From watching video and listening to audio tapes of these kinds of interactions, she knows that her concordant conversations are more patient-centered than her interpreter-mediated conversations. Becoming more

² More information about net promoter scores can be found at <http://www.peoplepulse.com/resources/useful-articles/net-promoter-score-nps-implement> (accessed June 3, 2016).

patient centered in interpreter-mediated conversations is a skill that she can learn and practice. She and her colleagues have been teaching that skill and are slowly improving interpreter-mediated conversations. Another difference she has noticed when interacting with a language-concordant patient is the level of social noise is higher. Social noise, she explained, is the chatting she engages in with the patient or family members when she walks into a patient's room, the "Hi, how are you? How's your family? Did you watch the Giants game last night?" banter that engages people. Again, audio recordings show that the amount of social noise is directly related to the number of questions a patient asks and how much information a physician shares.

Wong then commented that it would be interesting to look at the effects of cultural and literacy concordance, in addition to language concordance. Fernandez said there are some data available to show that language concordance has the biggest effect on the provider-patient interaction. Her institution, she explained, has many providers who have learned to speak excellent Spanish. "For those things we have been able to measure, it is actually language concordance that makes a very big difference," said Fernandez. She pointed to a recent study showing that 70 percent of the patients with low English proficiency seen in an outpatient setting were cared for by members of an ethnic minority, which she said is another great reason to diversify medical schools.

Rima Rudd asked if it would be appropriate to expand the notion of culture and language to include the millions of Americans who now have health insurance for the first time and are essentially new to the culture and language of health care. "Are we thinking about orientations for these new patients to tell them something about us and our culture?" asked Rudd. "Are we going to do that for cultural competency?" She also commented on the number of different accents in the United States and the challenges that can present even for those whose native language is English. As an illustration, she told of an encounter with her son's first-grade reading teacher who thought he might have a hearing problem. When Rudd asked why, the teacher said that when she asked him about a *cab*, he did not know what she was talking about and did not know the letters in the word *cab*. Rudd apologized for the misunderstanding and told the teacher that his father comes from California and she is from New York, they both say *car*, and he knows how that word is spelled. Similarly, she said, there are many people from parts of the United States, but not from other regions, who greet everyone with "Hi, sugar." To her, these examples suggests that the concepts of language and culture need to be expanded beyond just considering individuals who are new to this country. She worries, however, that such an expansion would lose something essential that the field is focused on and that it is working hard to achieve.

Pacheco thought such an expansion would be good, and while it would present challenges, he sees them as opportunities, much like the challenges and opportunities created by the ACA and the influx of newly insured Americans. He said that when he worked in the Office of Minority Health at HHS there was a big push to increase enrollment of Latinos and other minorities. Latino enrollments lagged because there was little understanding of what it meant to have health insurance. For reasons such as this, it is still a challenge to fully implement the ACA in a number of underserved communities, said Pacheco, but there are also opportunities to work in those communities to increase access and knowledge about health and quality health care.

Wolf remarked that these discussions raise the importance of recognizing there is waste in the way the health care system operates that creates challenges for communicating well. In terms of expanding how the field looks at culture and language, he raised the issue of preconceived notions—that even though someone speaks fluent English and “looks American,” their prior experience with and knowledge about the health care system may be limited. Becoming more productive, he said, means more time to have more meaningful experiences with patients; to find out about the literacy, language and cultural issues a patient might have; to learn about their preferences and prior experiences; and to form a real relationship with the patient that is not possible today in the typical 15-minute encounter. Wolf said that while he thinks of himself as an optimist, he is pessimistic about the near-term possibilities of health care systems trying to balance payment reforms with making a greater investment in the relationship with patients. He noted there is a substantial amount of data showing the benefits of integrating health literacy, cultural competence, and language access services, which is why it is important to make the case that spending more time with patients will pay off in terms of increased satisfaction and better care. “This is what *patient centered* means,” said Wolf.

Andrew Pleasant wondered why nobody had mentioned an objective indicator of health status as a measure of outcomes for addressing issues of literacy, language, and culture. Fernandez said that including such an indicator can be a good idea, but only if it measures those health outcomes that are sensitive to the process of care and not to those factors external to the process of care. Wolf agreed with Fernandez and noted, for example, how much of the work he does with medication adherence has to do with socioeconomic factors and not those related to the process of care. It is important to find measures that will demonstrate improvements in outcomes that are more proximal to the intervention. Pacheco voiced a similar concern with regard to the impact of social determinants of health that affect many high-risk patients and can negate any benefits that could come from improving communication between provider and patient. “If we do not address those

kinds of issues, we are still going to be talking about eliminating health disparities for the next 20 or 30 years,” he said.

As the last comment of the session, Alvarado-Little agreed that the negative effect of the social determinants of health, such as living in a food desert or a neighborhood plagued by violence, can be tremendous. The hope, though, is that because the patient feels respected and heard and treated with dignity, a better relationship is formed between patient and provider. The hope is also that by communicating information in a way that resonates with the patient, by impressing upon the patient the need to return for additional services, then health care systems can improve compliance and the overall health of the individual.

4

Addressing the Challenges

The workshop's third panel provided four examples of programs that aim to integrate health literacy, cultural competence, and language access services. Jessica Briefer French, senior research scientist with the National Committee for Quality Assurance (NCQA), addressed how issues of health literacy, cultural competence, and language access are being incorporated into national quality standards and measures. Sarah de Guia, executive director of the California Pan-Ethnic Health Network (CPEHN), spoke about some of the legislative proposals and administrative advocacy that her organization has been involved with to advance integration. Marshall Chin, the Richard Parrillo Family Professor of Healthcare Ethics in the Department of Medicine at the University of Chicago, discussed his experiences directing the Robert Wood Johnson Foundation's Reducing Health Care Disparities through Payment and Delivery System Reform program office and some of the successful interventions incorporating concepts of health literacy, cultural competence, and language access. The final speaker, Stacey Rosen, associate professor of Cardiology and vice president for Women's Health at the Katz Institute for Women's Health, Hofstra North Shore-LIJ School of Medicine, described ways her health system and how some state-level health transformation efforts have been incorporating these concepts into their operations. An open discussion, moderated by Ignatius Bau, an independent health care policy consultant with Health Policy Consultation Services, followed the four presentations.

INTEGRATING HEALTH LITERACY, CULTURAL COMPETENCE, AND LANGUAGE ACCESS INTO QUALITY IMPROVEMENT STANDARDS AND ACTIVITIES¹

NCQA is a nonprofit organization that measures and evaluates health care quality with the mission of improving the quality of health care, explained Jessica Briefer French. NCQA is probably best known, she said, for its accreditation programs for health care plans and accountable care organizations (ACOs), the HEDIS, and its recognitions programs for patient-centered medical homes and specialty practices. Its accreditation programs for some 1,200 health plans and ACOs, including a multicultural health care distinction program focused specifically on issues of cultural competence, language access, and health care disparities, are probably the most relevant for this workshop. She noted that the HEDIS data set includes submissions from more than 1,100 health plans, including commercial, Medicare, and Medicaid plans. Approximately 950 of these are publicly reporting health plans, and the rest are nonpublicly reporting plans that allow NCQA to include their data in aggregate but without identifying them individually. NCQA's recognition programs for patient-centered medical homes covers 11,000 operations and approximately 100 specialty practices. All of these programs integrate NCQA's CLAS standards.

For its health plan accreditation program, NCQA uses standards included in its multicultural health care distinction program, though the health plan program has a broader focus and addresses standards in other areas, too. The multicultural health care distinction program focuses on standards that address CLAS and disparities, but it does not address health literacy. The health care accreditation plan has fewer standards related specifically to CLAS, but it does address health literacy throughout in the form of requirements to provide information in understandable language. Both plans have a strategic focus, explained French. The health plan accreditation program specifies objectives for serving a culturally diverse membership, as well as eight other objectives. The multicultural health care distinction program has the same objective for serving a culturally diverse membership as well as additional requirements such as a process to involve members of the diverse community and a list of measurable goals for improving CLAS.

Both programs, said French, have comparable standards for cultural competence of the health care network requiring assessment of cultural, racial, and linguistic needs of its members and adjusting the availability of practitioners based on that assessment. The multicultural health care dis-

¹ This section is based on the presentation by Jessica Briefer French, senior research scientist with the National Committee for Quality Assurance, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

inction program also requires a network to collect and publish information about its practitioners' language skills and the network's language services to ensure that the right languages are represented in the network and that there is transparency for the network's members.

The two programs also have different levels of specificity with regard to language services, French added. The health plan accreditation program requires plans to provide language services for members and for complaints and appeals processes, and to provide information on how to obtain language assistance. The multicultural health care distinction program goes further in requiring translation of vital documents and provision of competent interpreter or bilingual services. She noted that at the time these requirements were written, interpreter and translator certification programs were just getting started, so it would have been premature at the time to specifically require certification. "Certainly, we intended through the language of the standards to allow for certification to satisfy that requirement," said French. The multicultural health care distinction program standard also requires networks to support practitioners in providing effective language services.

With regard to quality improvement, the health plan accreditation program requires improvement, but it does not focus on CLAS, nor is it prescriptive about where health plans focus their improvement efforts. In contrast, the multicultural health care distinction program requires a focus on measurement and improvement of linguistic and cultural competency and includes a mandate to evaluate the effectiveness of the interventions to improve language and cultural competency.

Data collection standards are included in both programs, said French. The health plan accreditation program requires reporting on a long list of selected HEDIS measures related primarily to effectiveness of care but not specifically related to CLAS. The multicultural health care distinction program requires data collection on race, ethnicity, and language needs, and it requires reporting on the two HEDIS measures of diversity, which are the preferred language for spoken communication and written materials and the racial and ethnic composition of the membership. The intent of having plans capture those data is to enable them to measure and report on disparities and conduct studies involving stratification, explained French.

French noted that reporting on these two HEDIS measures of diversity is voluntary for the health plan accreditation program, and NCQA has had "less than exciting results on these measures," with low levels of information reported by health plans about race, ethnicity, and languages of their members (see Figure 4-1). Medicare plans, she added, have done better at reporting race, ethnicity, and language needs than commercial plans. She noted that it is a continuing challenge to capture these data.

The patient-centered medical home and specialty recognition programs also include standards related to cultural and linguistic appropriateness.

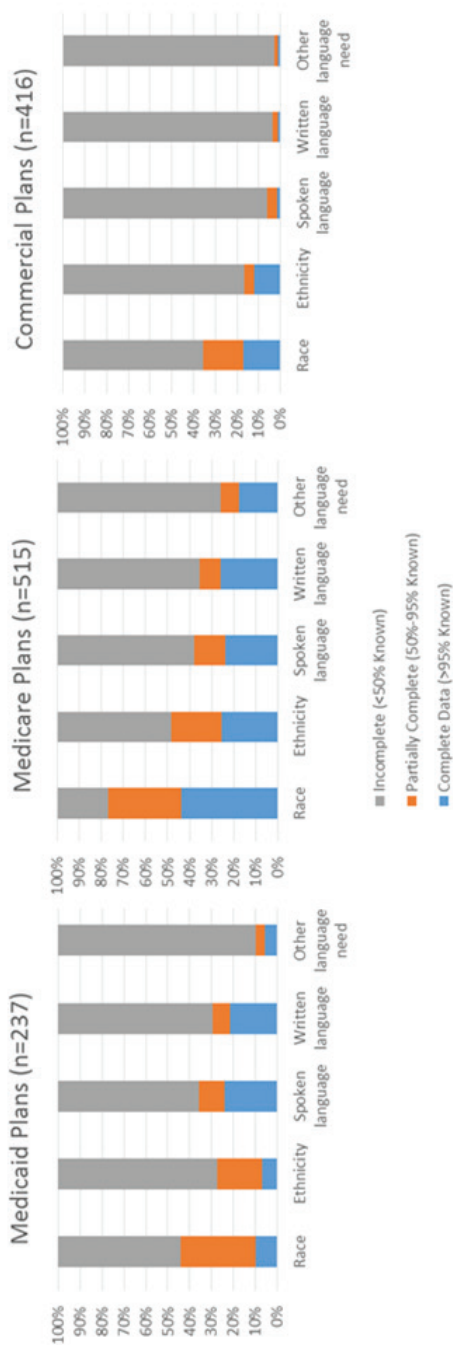


FIGURE 4-1 Reporting of data on race, ethnicity, and language needs, 2014. SOURCES: NCQA, 2015, presented by French, October 19, 2015.

To receive recognition, a practice must understand and meet the cultural and linguistic needs of its patients and families by assessing the diversity and language needs of its population, providing interpretation or bilingual services to meet the language needs of its population, and providing printed materials in the languages of its population. Practices also must use an EHR to record patient information as structured data on race, ethnicity, and preferred language, and to assess health literacy. The most recent data, explained French, were collected for standards issued in 2014 (see Table 4-1). She noted that a survey of some 1,100 practices based on the 2011 standards had slightly lower but still high performance on these measures. The key takeaway, said French, is that providers are doing a good job of capturing information about race, ethnicity, and language needs, but not quite as good a job of assessing health literacy, though more than half of the providers are assessing health literacy. She noted that it helps that these measurement requirements are part of the meaningful use incentive program.

The lesson from these results is that there are measures and standards related to cultural competence, language access, and health literacy. These standards, said French, are available and are embedded in popular, long-standing voluntary programs. “What we have found is that purchaser and regulatory incentives make a huge difference in the uptake of these programs. On the provider side, the alignment with meaningful use makes a huge difference.” There is a synergy, she added, when there are incentives for doing things that are part of an otherwise larger and potentially dilutable set of standards. She noted that California is considering making the multicultural health care distinction program a requirement for its

TABLE 4-1 Results from Practices in the Patient-Centered Medical Home and Specialty Recognition Programs, 2014

Functional Requirement	Patient-Centered Medical Home (N = 420)	Patient-Centered Specialty Practice (N = 95)
Assessing the racial and ethnic diversity of its population.	96.7%	87.9%
Assessing the language needs of its population.	98.3%	80.2%
Providing interpretation or bilingual services to meet the language needs of its population.	98.6%	94.5%
Providing printed materials in the languages of its population.	77.1%	63.7%
Assessing health literacy.	58.3%	N/A

SOURCE: Presented by French, October 19, 2015.

health plans. Currently, only 16 organizations hold the distinction of being recognized by this program, making it clear, she said, that more leverage is needed. However, a recent study NCQA conducted for the Office of Minority Health at CMS found that there is delivery system reform fatigue. “There are so many reforms under way, so much effort to transform the health care system, and many of these efforts have incentives attached to them, such as pay-for-performance and a variety of value-based purchasing incentives,” said French. In this environment, organizations reported they are “following the money,” which she said means that systems will be more likely to focus on issues of culture, language access, and literacy when there are incentives that are at least equal to those for all of the other reforms they are being asked to make.

In closing, French said there is real opportunity from a regulatory and purchaser perspective to channel efforts and raise awareness of these issues, but not without advocacy. “As we heard earlier in the discussion, passion and advocacy are what is going to make purchasers and regulators bring these issues into their incentive and value-based purchasing programs,” said French.

STATE LEGISLATIVE APPROACHES TO INTEGRATION²

The 23-year-old CPEHN was founded during an era of health care reform by four partners—the Asian & Pacific Islander American Health Forum, the Latino Coalition for a Healthy California, The California Black Health Network, and the California Rural Indian Health Board. These organizations felt that communities of color or ethnicity needed to come together to provide a unified voice on health care reform, explained Sarah de Guia. Today, CPEHN is engaged in implementing the ACA with the goal of not just improving access to health care but also ensuring the data are available to inform decisions about where to deploy resources and to support reform efforts. CPEHN is also looking at the provision of culturally and linguistically appropriate health care services and addressing some of the social determinants of health, de Guia added.

As a means of providing context for why CPEHN believes its work on legislative and administrative advocacy to promote change is important, de Guia briefly reviewed some pertinent demographic data. California, she said, has one of the most diverse populations in the nation, which is reflected in both ethnicity (see Figure 4-2) and language (see Table 4-2) of the state’s Medi-Cal (the California Medicaid program) enrollees. In

² This section is based on the presentation by Sarah de Guia, executive director of the California Pan-Ethnic Health Network, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

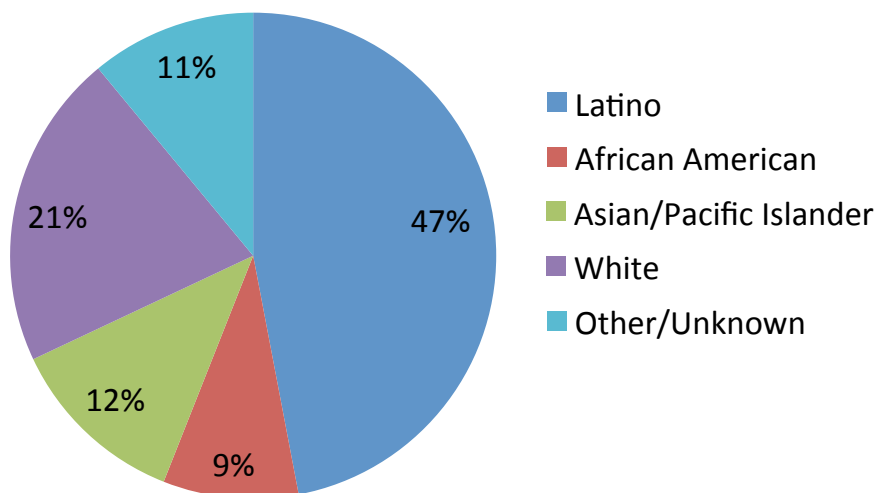


FIGURE 4-2 Race/ethnicity of Medi-Cal enrollees.

SOURCES: California Department of Health Care Services, 2015, presented by de Guia October 19, 2015.

TABLE 4-2 Limited English Proficient Population Enrolled in Medi-Cal

English Proficiency	Covered by Medi-Cal
Speaks English Very Well	19.6%
Speaks English Well	26.8%
Speaks English Not Well/Not at All	34.7%

SOURCES: 2014 California Health Interview Survey, presented by de Guia, October 19, 2015.

addition, communities of color account for 60 percent of the state's residents who have purchased health insurance through Covered California, the state's health insurance exchange, with Spanish, Chinese, Korean, and Vietnamese as the top four non-English languages spoken by Covered California enrollees.

The 2014 California Health Interview Survey found that individuals with language issues have limited access to both primary and specialty care (see Table 4-3), and as a result individuals with limited English proficiency tend to rate their health as being poor or fair more often than their English-speaking counterparts (see Table 4-4).

Taken together, these demographic data point to why CPEHN advocates for the importance of language assistance standards in California's Medi-Cal

TABLE 4-3 Access to Primary and Specialty Care by English Proficiency

English Proficiency	Difficulty Finding Primary Care	Difficulty Finding Specialty Care	Does Not Have Usual Source of Care
Speaks English Very Well	5.4%	13.7%	18.7%
Speaks English Well	6.6%	8.7%	20.4%
Speaks English Not Well/Not at All	3.8%	16.7%	27.2%

SOURCES: 2014 California Health Interview Survey, presented by de Guia, October 19, 2015.

TABLE 4-4 Health Status by English Proficiency

English Proficiency	Fair or Poor Overall Health
Speaks English Very Well	15.9%
Speaks English Well	20.3%
Speaks English Not Well/Not at All	43.9%

SOURCES: 2014 California Health Interview Survey, presented by de Guia, October 19, 2015.

program and commercial health plans, said de Guia. The Medi-Cal program, for example, has translation thresholds based on the number of enrollees in a county or zip code, as well as a requirement for interpretation services at any time in any language. Commercial plan translation thresholds are based on enrollment numbers, while interpretation services are required in any language during business hours, which de Guia said has presented challenges at times. Legislation regulating commercial health plans also requires the plans to collect race, ethnicity and language data, which de Guia noted gets to the point that French made about incentivizing or mandating data collection. There is some flexibility in this data collection requirement in that plans can impute some of the ethnic and racial percentages based on Census data, so CPEHN is working with plans to ensure they build race and ethnicity data collection into their systems so they can report actual figures rather than imputing them. She also pointed out plans are now required to report these data to the California Department of Managed Health Care (DMHC), and that DMHC surveys the plans to ensure they are actually providing the required translation and interpretation services.

Noting that it took several years and quite a bit of work to achieve these successes, de Guia said one thing in their favor was that the state's public programs had some of these standards in place. "With 3.4 million enrollees with low English proficiency in private coverage, we were able to make the case that rather than just letting the market decide, we should

have standards in place about how plans would provide their language assistance services,” said de Guia. She also credited the strong leadership within the newly created DMHC for its role in pushing for the adoption of these standards and for legislative leadership in enacting California SB-853, which included the translation thresholds, language assistance, and data collection requirements for commercial plans. Recently, she added, the state codified into law the Medi-Cal thresholds, which since the mid-1990s had been included in contract language. “This provides us with more leverage for enforcement,” explained de Guia.

Unfortunately, de Guia noted, there was little in SB-853 regarding health literacy standards. “All of the culturally competent provisions were taken out of the bill during a very difficult negotiation process, and the new head of DMHC was not quite as consumer friendly as was the original director,” she explained. In addition, public programs were exempt from the requirements in SB-853, which points to the fragmentation that exists in the system. “We cannot get everything aligned,” said de Guia.

One thing CPEHN has been able to accomplish is to get the state to provide advance copies of applications, marketing materials, and notices so members of the coalition and the community-based organizations they work with can review them and provide some guidance. For example, a review of the Covered California application found that the Hmong translation was completely inaccurate and that the term *marketplace* was difficult to translate into Tagalog and Spanish. Concepts such as family size and lawful residency, key inputs that determine the type of coverage an individual or family was eligible for, were not accurately conveyed in Vietnamese. Based on these reviews, the state made changes to the translated application forms, de Guia said.

The broad coalition of organizations that CPEHN works with has been engaged in California policy making for several years now and has built a good, responsive relationship with DMHC. This coalition was involved in creating Covered California and helped include diversity provisions in Covered California’s board and set its goal to have its enrollees reflect the racial and ethnic diversity of the state. “We’re still working on that, but that goal is in the law,” said de Guia. CPEHN was also instrumental in creating a consumer workgroup that builds community engagement into Covered California’s operations and creates the mechanism by which notices are regularly reviewed by advocates. Nevertheless, the notices still continue to be too complex, largely because of statutory requirements to include certain information in every notice. In addition, the community engagement piece is not funded and is conducted largely by volunteers.

Over a decade ago, a study was conducted in California that raised concerns about medication adherence, and a task force was convened to examine this issue. While the initial focus was on the population at

large, the study and the task force noted the importance of low English proficiency and health literacy issues as contributors to poor medication adherence. California passed legislation in 2006 addressing some of these issues, but the compromise bill that was signed into law did not mandate translated prescription drug labels.

However, in 2010, the ACA was set to add 1.5 million individuals with limited English proficiency to the state's health care system, which enabled CPEHN to once again raise this issue. At the time, said de Guia, the California Board of Pharmacy was working with researchers, including Michael Wolf, to identify health literacy issues with prescription labels and medication instructions. The idea, she explained, was to develop a set of standardized, simple instructions that would be easy to translate into other languages. In fact, the Board of Pharmacy worked with the California Endowment to provide translations of these standardized instructions in five languages. CPEHN helped write legislation that would have required pharmacies to use these translations, and when this bill did not go forward, the Board of Pharmacy took the issue on and did get legislation passed that was signed into law in 2015. Going forward, translated prescription drug labels are required in Spanish, Korean, Chinese, Vietnamese, and Russian. De Guia noted that California's fifth most common language is Tagalog, but the bill included Russian based on national numbers.

A key issue CPEHN now hopes to address is that while there are standards in place for data collection and language assistance, enforcement is still a challenge. "Where is the hook to make sure providers understand their responsibilities, that health plans are complying with these standards, and that the departments themselves have the resources to be able to ensure that compliance is taking place?" asked de Guia. Also needed, she said, are evaluations of the programs that have been created. One evaluation did show that translated labels did increase comprehension for simple drug regimens.

CPEHN is also working to create alternative methods for surveying consumers with low English proficiency about their needs and experiences that go beyond CAHPS and similar surveys, particularly for individuals who do not speak the languages for which translated surveys are available. The organization is also focusing on developing a culturally appropriate workforce by incorporating *promotoras* and community health workers who can better address cultural competency in the health care system. As a final comment, she noted the importance of using community partners. "We do not have to be experts in all cultures and all languages," said de Guia in closing. "There are many organizations that understand their communities' needs and that can provide important insights into the needs of those communities that we are all seeking to serve."

HOW CULTURAL COMPETENCE, LANGUAGE ACCESS, AND HEALTH LITERACY ARE INTEGRATED INTO PROGRAMS AND INTERVENTIONS AIMED AT REDUCING DISPARITIES³

Before turning to the main topic of his presentation, Marshall Chin said he agreed with Michael Wolf that the three fields of health literacy, cultural competence, and language access have the potential dangers of stagnating, being too insular, and too siloed. He also said that these fields have to do more in terms of integrating with existing quality and equity initiatives and do better at creating a business case while at the same time nurturing the inherent motivation and values people have for reducing disparities. He then noted that much of his presentation is based on the work of the 33 grantees and 12 systematic reviews of the health care disparities intervention literature funded by the Robert Wood Johnson Foundation Finding Answers: Disparities Research for Change, as well as the experience gained from providing technical assistance to a variety of organizations.

Based on the lessons learned from the Finding Answers program, Chin and his colleagues have developed a six-step roadmap for reducing racial and ethnic disparities in health care (Chin et al., 2012):

1. Recognize disparities, and commit to reducing them.
2. Implement a quality improvement infrastructure and process.
3. Make equity an integral part of quality.
4. Design interventions.
5. Implement, evaluate, and adjust the interventions.
6. Sustain the interventions.

The focus nationally, said Chin, has been on the first and fourth steps, but if the goal is sustained change, all six are needed. “We are not going to get there if we just focus on two of them,” he said.

Chin made two points about the first step, recognizing disparities and committing to reducing them. The first point was that performance data stratified by race, ethnicity, language, and socioeconomic status can be used to increase people’s motivation to change. “People have to see their own data to acknowledge there are disparities in their own practice,” said Chin. “They will not be motivated to change unless they are convinced there is actually an issue with their own particular patients.” His second point is that cultural competency programs have sometimes been too narrow and too insular, and that perhaps the emphasis should be on state-of-the-art

³ This section is based on the presentation by Marshall Chin, the Richard Parrillo Family Professor of Healthcare Ethics in the Department of Medicine at the University of Chicago, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

disparities training. The Society of General Internal Medicine, for example, has developed goals for health disparities courses that include discussing the existence and causes of disparities and working through various solutions for addressing mistrust, subconscious bias, and stereotyping. The courses should also work on communication and trust building and building a commitment to reduce disparities (Smith et al., 2007). Chin noted that while it is easy to get people to accept that addressing disparities is important, it is actually difficult to teach these courses well. “They can even be counter-productive if not taught well,” said Chin.

At the University of Chicago Pritzker School of Medicine, the first two courses that first-year medical students take are anatomy and health care disparities. The disparities course (Vela et al., 2008) has been taught for some 10 years by Monica Vela, the associate dean for Multicultural Affairs, and on the first day of class she has the students go through a self-insight exercise that is an entrée into subconscious biases. The course includes field trips to Chicago’s south side, the home of most of the patients the students will see, so they can learn about their patient’s living environment, and a section on Chicago history where a sociologist talks about why housing in Chicago is segregated. The students learn that segregation did not occur by chance but because of a conscious set of policy and business decisions. The course also includes a group disparities project, in which small groups of students develop a disparities reduction process, as well as reflective essays and discussions that cover a gamut of topics including working with interpreters to learn about Medicare policy. Over the past 2 years, Vela has added a new segment on advocacy when she learned that without the advocacy component, students felt disempowered, which was counterproductive.

On a sobering note, Chin said, stratified data and cultural competency training alone do not improve clinical performance measures (Sequist et al., 2010). “Disparity interventions are helpful in raising awareness, and improving attitudes and knowledge, but they do not move the clinical numbers,” said Chin. “These interventions are helpful, but you have to combine them with other methods.”

Before describing some of those methods, he recounted a conversation reported in *The New York Times* (Haberaman, 2015) between Hillary Clinton and Black Lives Matter activist Julius Jones. Secretary Clinton said, “You can get lip service from as many white people you can pack into Yankee Stadium and a million more like it who are going to say: ‘We get it, we get it. We are going to be nicer.’ That’s not enough, at least in my book. I don’t believe you change hearts. I believe you change laws, you change allocation of resources, you change the way systems operate.” Chin believes her statement may also apply to health care disparities, though he added that she does get some things wrong in that statement. “What

she gets wrong is that it is important to change hearts, to change people's motivation. They have to really believe it and feel it is part of their social values to improve equity."

"At the same time," said Chin, "she is right that you have to change the laws, the allocation of resources, and the way systems operate." He recalled speaking with some people from industry who made the point that to prevent disparity-reduction programs from becoming marginalized, they have to be embedded into the basic operating structure of people's jobs. Doing so means making equity an integral component of quality improvement efforts. The challenge, though, is that too often the people who work on quality are not the same people who work on equity.

In 2010, the IOM reworked its Model of Quality and elevated equity from one of the six pillars of quality to something that cuts across all dimensions of quality (see Figure 4-3). This fundamental conceptual change says that equity needs to be a part of everything done to improve quality.

The fourth step on the roadmap calls for designing interventions that address the root causes of disparity and considers six levels of influence. Chin made the point that there is no substitute for talking to patients and community members, as opposed to talking to proxies such as minority health care providers. Too often, he said, the assumption is that African-American doctors or nurses are going to know what to do, but in fact, there is a good chance they come from different socioeconomic backgrounds

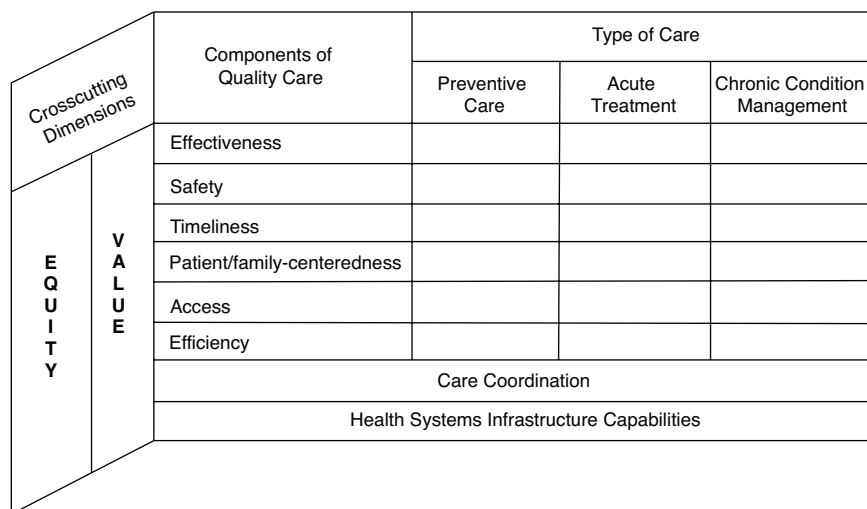


FIGURE 4-3 IOM Model of Quality.

SOURCE: Presented by Chin, October 19, 2015.

than the patients that will be the focus of a program. As an example, Chin described a depression telephone intervention aimed at Latino patients that was designed after talking to Latino nurses and doctors. The intervention had trouble enrolling patients and the reason was that the target patients had pay-by-the-minute cell phone plans, as opposed to the unlimited minute plans that the doctors and nurses had.

Chin then described a conceptual model for health care disparities (Chin and Goldmann, 2011; Chin et al., 2007) in which a person embedded in a community deals with access challenges to become a patient interacting with the clinician and health care organization (see Figure 4-4). Above that sits a policy superstructure that includes financing, regulation, and accreditation. Underlying the interaction between the patient, the health care organization, and the provider are processes and outcomes. Together, this model highlights six levels of influence: policy, the health care organization, the microsystem, the provider, the patient and family, and the community.

The policy level includes clinical performance standards linked to reimbursement or mandated by legislation. Such standards can be structural measures of culturally competent organizations such as interpreter use or clinical outcomes, or they can be equity index tools to rate organizations. At the level of the health care organization, there are various diversity, inclusion, and equity initiatives that institutions create, but the key is making these a true priority of senior leadership and providing the resources

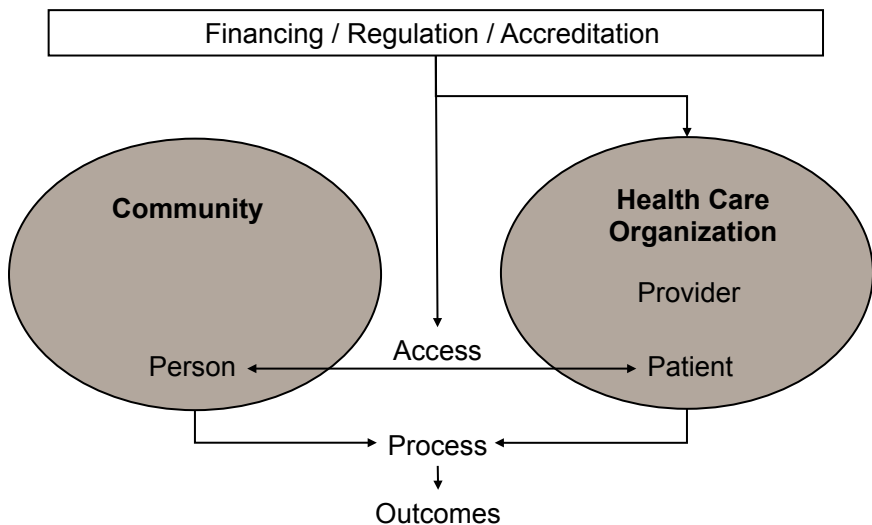


FIGURE 4-4 A conceptual model for health care disparities.

SOURCES: Chin et al., 2007, presented by Chin, October 19, 2015.

and core team to facilitate change within organizations. These initiatives have to be embedded within existing committees and departments. Having a core team dedicated to an initiative makes a big difference in realizing the goals of the initiative, said Chin.

The microsystem is the immediate care team, and steps that can be taken at this level include integrating language services and interpreters more immediately into care teams. In these circumstances providers have easy access to these services and to training on how to be culturally competent, and on shared decision making. Patients and families also need help being empowered to participate in shared decision making and accessing language services. Finally, at the community level, it is important to empower the community through the more effective use of community health workers and to help communities address the social determinants of health.

An examination of 400 different interventions, Chin explained, shows there are not many magic bullets for success, though he and his colleagues identified six common themes among successful, evidence-based intervention strategies:

- Multifactorial interventions attacking different levers;
- Culturally tailored approaches are better than generic approaches;
- Team-based care, particularly when the teams are led by nurses;
- Involving families and community partners;
- Patient navigators; and
- Community health workers, along with interactive skills-based training.

The important point, said Chin, is that off-the-shelf tools are not going to work. Any successful intervention has to be embedded in the quality improvement process because there has to be adaptation to the individual context, culture, and patient setting. “There is going to be an important role for demonstrations and model programs, but there is always going to have to be adaptation,” said Chin.

He then briefly described a consolidated framework for implementation research (Damschroder et al., 2009). This framework comprises five major domains:

1. Intervention characteristics that convey a relative advantage over the status quo,
2. The external incentives,
3. The culture of the organization,
4. The characteristics and beliefs of the targeted individuals, and
5. The process for planning, executing, and evaluating.

He also briefly discussed behavior change theory, which usually starts with educating people about why they should change and how it will solve a problem. However, said Chin, this is not how things work in the workplace, so it is necessary to consider the peer pressure and social norms that come with being part of a work culture. Other components of behavior change theory include environmental factors such as incentives and self-efficacy, which includes coaching, quality improvement collaboratives, and various approaches to give people the confidence they can change. Both internal motivations—professionalism and an appeal to do the right thing—and extrinsic motivations, including financial and other rewards, also play an important role in behavior change.

The final step on Chin's roadmap is to sustain interventions, and that starts with institutionalizing them by ingraining them in the organizational culture, providing incentives, and integrating them into daily operations. It is also essential, though, to build the societal business case that reducing disparities will improve direct and indirect medical costs and help build a healthy, diverse national workforce. The direct business case aligns incentives with policy goals through global and bundled payments, and population health and pay-for-performance reimbursement models to reduce disparities is also key. He suggested other avenues for aligning policy with incentives would include better linkages between the community and the health care system and the community needs assessments required of non-profit hospitals. Chin noted the Robert Wood Johnson Foundation has a program looking at using payment and delivery system reform to reduce disparities.

Recently, Chin attended a CMS conference. His impression from the discussions he heard is that CMS is doing great things with value-based purchasing, but not enough in terms of equity. He had a number of recommendations for CMS that he also thought were important for the roundtable. His first recommendation was to require public reporting of stratified disparities data, something that CMS is going to start in several of its programs over the next year. The second was to strengthen incentives for prevention and primary care. The current global payment and shared payment savings plans have been relatively modest, he said, and they need to be more aggressive to create more incentives to actually do prevention and primary care. "I think most of us know the relative value payment schedule for physicians is part of a political process as opposed to an evidence-based process, so the cognitive specialist and primary care physician are grossly undervalued," said Chin.

To produce a greater financial incentive to work on disparities, Chin's third recommendation was for CMS to encourage intersectoral health partnerships, explicit equity accountability measures, and provide specific reimbursements for reducing disparities. Fourth, CMS needs to align equity

measures across public and private payers and provide more support and more equitable reimbursement for safety net providers. “There needs to be risk adjustment for both clinical and social demographic factors to create a level playing field,” said Chin. “The bottom line is having an explicit equity lens both for quality efforts and payment efforts so we can think about how we design systems to reduce disparities.”

He concluded his presentation by stating that leadership matters (Chin, 2014). “It is our professional responsibility as clinicians, administrators, and policy makers to improve the way we deliver care to diverse patients. We can do better.”

EFFECTIVE COMMUNICATION IN HEALTH CARE⁴

In the day’s final formal presentation, Stacey Rosen described what North Shore–LIJ Health System is doing to realign and integrate its efforts in health literacy, cultural competence, and language access. North Shore–LIJ Health System, which in 2016 will be renamed Northwell Health, is the 14th largest health care system in the United States. It comprises 20 hospitals, more than 400 ambulatory practices, and other health care, home care, long-term care, and hospice facilities. It is New York State’s largest private employer, and its 62,000 employees, including 10,000 physicians and 11,000 nurses, serve 8 million people on Long Island, the 5 boroughs of New York City, and Westchester County.

In 2008, the health system opened Hofstra North Shore–LIJ School of Medicine, the first new allopathic medical school established in New York State in 40 years. She noted that rather than immerse its new students in basic science classes, the medical school has them ride along with ambulance crews for the first 12 weeks, enabling them to learn about the social determinants of health in the underserved neighborhoods from which many of the health systems’ clients come. Rosen added that its newly opened nursing school for advanced nurse practitioners, and ultimately bachelor’s degree nurses, “turns nursing education on its head.” She noted, too, that North Shore–LIJ’s Center for Learning and Innovation is the largest corporate university in health care in the nation; it also runs the nation’s largest patient safety center. In New York City, the system recently opened the city’s first freestanding emergency department, as well as what Rosen characterized as a state-of-the-art community-based clinical practice in the Greenwich Village neighborhood.

⁴ This section is based on the presentation by Stacey Rosen, associate professor of cardiology and vice president for women’s health at the Katz Institute for Women’s Health, Hofstra North Shore–LIJ School of Medicine, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

Rosen noted that in Queens alone, some 175 languages are spoken on a daily basis, and until the system's recent acquisition of two community-based hospitals that serve a predominantly white population, more than 40 percent of the system's covered individuals did not speak English as their primary language, which she said is double the national average for health care systems. To address this diversity and also support the system's business case, North Shore–LIJ Health System created the Office of Diversity, Inclusion, and Health Literacy in 2010. "There has been discussion today about the business case and return on investment, and you do have to align that with doing the right thing, but when margins get smaller and competing needs become an apparent financial concern, the business case is very important," said Rosen.

The mission of the Office of Diversity, Inclusion, and Health Literacy, she explained, is to promote, sustain, and advance an environment that supports the principles of equity, diversity, inclusion, health literacy, and community. When this office opened, it began with a multiyear strategic plan to establish goals and steps to embed a culture of diversity, inclusion, and health literacy across the complex North Shore–LIJ system, including among its medical students and in the community it serves. As a first step, the office performed the American Medical Association's community climate assessment toolkit survey at several of the system's hospitals to better understand their cultural competency and health literacy awareness and readiness. The results of this initial survey informed the strategic plan, which focused initially on education and awareness. Rosen said that when this process started in 2010, diversity, inclusion, and health literacy efforts in the system were somewhat siloed, with health literacy efforts focused predominantly on education and awareness at several of the system's larger hospitals and diversity and inclusion activities embedded in the new medical school curriculum.

While North Shore–LIJ was developing its strategic plan, HHS announced the new National Prevention Strategy focused on increasing the number of Americans who are healthy at every stage of life. System administrators decided then, said Rosen, to align two of the National Prevention Strategies four strategic initiatives—empowering people and eliminating health disparities—with the activities of the Office of Diversity, Inclusion, and Health Literacy. Health literacy fit into this focus because individuals who have access to actionable and easy-to-understand information become empowered to make healthier choices. Working toward eliminating health disparities, North Shore–LIJ focused on identifying communities at risk and engaging leaders in those communities when it developed programs with the goal of truly aligning those programs with local cultures in a way that reflected the unique features of the vast communities the system serves. With this new focus, the Office of Diversity, Inclusion,

and Health Literacy expanded its purview to include language access and cultural competency activities in addition to diversity, inclusion, and health literacy. Under the banner of effective communication, these activities aim to improve the interaction between an individual's ability to access health care and the demands of the health care system itself.

One result of this new strategic focus was that the Office of Diversity, Inclusion, and Health Literacy took over all health literacy activities and evaluated every piece of patient education material used in the system. The office also expanded the system's diversity, inclusion, and health literacy programs to include cultural competence and language access, and it initiated a program to empower the system's employees to become involved in empowering communities. This led to the office decentralizing its activities and partnering with the system's facilities-based experts to empower them, as Rosen explained, "to do right by their individual communities and the complex clinical needs in their areas, but also so they would feel that they were a part of something important." Because the system encompasses so many different communities, programs were designed to use many different modalities to educate employees about relevant topics and in turn educate and involve their patients.

In 2013, the Office of Diversity, Inclusion, and Health Literacy became a division in the Office of Community and Public Health, which runs the system's public health, community benefit, Community Benefit Excellence Council, and Katz Institute for Women's Health activities. Rosen noted that a guiding principle of the Katz Institute is that all of its community initiatives, events, fact sheets, presentations, and other activities would all include the tenets of health literacy, cultural competence, and language access.

Rosen then discussed a few examples of the programs run out of the Office of Diversity, Inclusion, and Health Literacy. One program run in partnership with the Long Island Regional Adult Education Network includes a course called the ABCs of Health Literacy. This course trained the education network's faculty to incorporate health literacy tenets into the classes taught at the network's approximately 80 literacy sites on Long Island. In 2014, the office held a systemwide book drive that collected more than 4,000 books for literacy programs in the New York City area. Its public health initiative established a partnership with the underserved Spiney Hill community that established what Rosen called "traditional opportunities" to engage the community in health literacy and prevention strategies. Through this program, the office learned about cultural competence in a way that led to refocusing its efforts to involve the community in creating these initiatives.

The commitment of leadership to these types of activities is crucial, said Rosen, for without that commitment it is impossible to embed these

principles in the culture of the organization before demonstrating they produce a return on investment. At North Shore–LIJ, the system’s chief executive office and president chair an executive diversity, inclusion, and health literacy council, and the chief medical officer and chair of the department of medicine are cochairs of a physician leadership group. The system’s language access activities are now overseen by a systemwide committee, which coordinates activities conducted by the system’s 20 hospitals and its larger ambulatory practices that reach into their surrounding communities in a spoke-and-hub model. Rosen noted that these activities have recently won several innovation awards and recognition from various organizations dedicated to diversity and inclusion.

Rosen said that the system’s health literacy strategy has been able to expand thanks to New York State’s delivery system reform incentive payment (DSRIP) program that promotes community-level collaborations and focuses on sustainable system reform. In fact, North Shore–LIJ is leading the health literacy cultural, linguistic, and competency activities for the New York State DSRIP activities on Long Island. “We are proud of this, and it shows that our ability to bring initially siloed activities into one integrated program is going to have an impact on the communities that we serve,” said Rosen.

In her final comments, Rosen noted that North Shore–LIJ became the first large health system in the New York tristate area to take the American Hospital Association pledge to eliminate health disparities, even though this pledge includes what she called aggressive expectations and aggressive timelines. This pledge requires North Shore–LIJ to increase its collection and use of race, ethnicity, and language preference data, which Rosen said sounds simple but in fact is not. At Long Island Jewish Hospital, where she does most of her clinical work, 90 percent of the surrounding community’s population is listed as white and English-speaking, which she said is “dead wrong” given that the hospital serves the residents of Queens and their 175 languages. “So even with something that should be simple, there is an opportunity to do much better,” said Rosen.

Another requirement of the pledge is to increase cultural competency training, which North Shore–LIJ plans to accomplish with the same strategy it employed successfully in 2010 to address health literacy issues in the system. The third pledge is to increase diversity in leadership and governance, which system leaders have acknowledged is a critical feature of an equitable health system.

DISCUSSION

Ignatius Bau began the discussion by asking French if she knew of other examples, beyond Covered California and the New York State DSRIP

program, of opportunities to engage purchasers and providers in activities that align delivery system transformation with efforts that support culturally and linguistically appropriate services and health literacy. French said the marketplaces are great environments in which these activities can play out and that Medicaid will be an important innovator given that it serves diverse communities. CMS, which has the greatest clout, has begun efforts in this direction and has the opportunity to be a convener of a multipayer initiative. “Alignment and integration across payers is going to create the best opportunity for consistent, aligned efforts and common payment incentives with purchasers defining value in similar ways where measurement sets can also be aligned,” said French.

Bau then asked de Guia for ideas on how patients and consumers might engage in supporting community-based partnerships and how CPEHN is supporting integration activities in community-based and consumer-based organizations. De Guia replied that CPEHN began recruiting community-based organizations as early as 2007 when it realized that the voices at the policy table in California did not represent the diversity of the state’s population. She noted that The California Endowment and the California Wellness Foundation provided generous support enabling CPEHN to help its community-based partners build capacity to engage beyond the local level. CPEHN was also able to provide small grants to individuals to travel to Sacramento and testify to legislative committees. She reminded the workshop of the important role that individual stories play in changing hearts and minds and said, “Being able to bring individuals to Sacramento to talk about what the direct impact of policy actions would be in California has been a model that continues to work.”

Today, in the context of health care system transformation efforts, there is an important emphasis on engaging community and stakeholders, she continued. “The basic idea is we need to hear from the population itself and that proxies can provide one perspective but not necessarily the right perspective,” de Guia said. Going forward, it will continue to be important to ensure that community members have capacity and resources to continue to participate in transformation efforts, and doing so will require strong leadership and governance, as Rosen noted, and for programs to be transparent with regard to how consumers can participate.

Chin, in his presentation, mentioned the need to pay special attention to the role safety net providers play. Bau asked him to say more about addressing the additional burdens that safety net providers and community health centers might have to integrating health literacy, cultural competence, and language access services. Chin replied that despite the ACA, the system still creates more challenges for safety net providers in terms of having the most challenging patients, in terms of morbidity and socioeconomic and cultural challenges, and with respect to limited resources. “We have to

make sure they have the resources to do their mission, and also to create incentives in systems that do not make things worse,” said Chin. Doing so will require thinking specifically about policies and resource allocations that will maximize the chances that these safety net providers and community health centers will “make good things happen” in the populations they serve.

Bau then asked Rosen if she could say more about what has motivated the leaders of North Shore–LIJ to so strongly support transformative integration efforts. Rosen replied she believes it is a combination of “doing things right and doing things smart.” The doing right part comes from the system’s President and Chief Executive Officer, Michael Dowling, an immigrant and social worker by background. “But I also think he and our leadership team, both clinical and administrative, see that the business case to do this is critical and that jumping across the chasm too late will put us in financial jeopardy,” added Rosen. She believes that the timing for supporting these integration initiatives, which do not have an easy and early return on investment, has been brilliant.

Upon opening the discussion to the workshop participants, an unidentified participant asked how health literacy is assessed and if a patient assessed for health literacy skills is a health-literate patient. French replied the NCQA standard for its patient-centered medical home program is for the practice to systematically assess the health literacy of its patients and not to be prescriptive about how the practice does that assessment. Clearly, though, an assessed patient is not necessarily a health literate patient, she said. “What we are asking the practices to do is understand their literacy capacity and then to appropriately tailor their communications to the patient.” She noted, though, that if practices apply something akin to universal precautions—use plain language at low reading level for all patients—they do not have to do the specific patient assessments.

Ernestine Willis from the Medical College of Wisconsin asked the panelists to comment on her belief that while it is certainly possible to engage, motivate, and educate a community, to provide it with resources, and to build its capacity to engage, she is not sure that it is possible to empower a community because that has a paternalistic implication. Responding first, de Guia said she agreed absolutely with Willis and is conscious about not using the term empowerment. It is not her organization’s role to empower, she added, and she believes that the organizations CPEHN works with have the same attitude. “Our role is about education and awareness,” said de Guia. She said that she even hesitates to talk about capacity building. “Everyone has capacity. It’s more about sharing knowledge,” she added.

In working with many community groups on implementing the ACA, she has found that the health care system’s culture of coverage is confus-

ing and fragmented to many individuals and organizations. For those who do not speak English well or who are new to this country, it can be nearly impossible to understand copayments and deductibles or to choose between multiple different health plans and access coverage. As a result, CPEHN sees itself as an educator and information conduit, both to the community-based organizations and also to government agencies, policy makers, and research partners to make sure they understand the obstacles individuals face and why they need to have consumers at the table.

Chin agreed that information is important, but that it is not enough. “We also have to work on the self-efficacy piece so people feel more confident acting on that information,” said Chin. He used diabetes as an example, where proper self-management can address the great majority of potential health problems. Chin wondered if there really is agreement on this issue of empowerment and whether there is just confusion about the exact words. Rosen said she thinks of empowerment in terms of sharing knowledge and providing both access and insights as opposed to the top-down paternalistic meaning that Willis implied in her question. When she uses the word *empowerment*, she sees it as a way of leveling what was a particularly patriarchal process in years past, of changing a system that is not particularly good at producing good patient health outcomes. As an example, she said she empowers her obstetrician–gynecology partners by providing them with data that enables them to better care for their hypertensive pregnant patients, improving the end result for the patient.

Another unidentified participant identified an issue related to the use of the EHR, that is how physicians often face their computer screens more than they face the patient in the exam room. Rosen responded by acknowledging the problem and said that much of the patient education material embedded in the EHR is difficult to find and often inaccurate and ineffective. North Shore–LIJ’s Office of Community and Public Health has developed its own set of patient education materials, in partnership with various organizations such as the American Heart Association and WomenHeart, that are acceptably well written and health literate. Chin noted that someone at his institution has developed a method of teaching patient-centered care using the EHR that includes forming a triangle with the patient so the physician and patient can look at the screen together, asking questions that use data on the screen, and not looking at the screen when talking about a sensitive issue or mental health issue, for example.

5

Break Out Session Reports

Upon conclusion of the panel presentations and discussions, the workshop participants divided into three preassigned small break-out sessions to discuss research, policy, or services and care. Janet Ohene-Frempong, president of J O Frempong & Associates, facilitated the research discussion session; and both Michael Paasche-Orlow, associate professor of medicine at Boston University School of Medicine, and Rima Rudd, senior lecturer on health literacy, education, and policy at the Harvard T.H. Chan School of Public Health, served as the rapporteurs. Gem Daus, public health analyst in the Office of Health Equity at Health Resources and Services Administration (HRSA), facilitated the session on policy, and Michael Villaire, chief executive officer of the Institute for Healthcare Advancement served as the rapporteur. Andrew Pleasant, senior director for health literacy and research at the Canyon Ranch Institute, facilitated the services and care discussion and also acted as the rapporteur. After the rapporteurs delivered their summaries of the discussions to the reassembled workshop participants, Bernard Rosof moderated an open discussion.

RESEARCH

Michael Paasche-Orlow reported there was a great deal of discussion about the need to break out of the silos dominating these three fields, at least in part because of how poorly funded these areas have been. One reason for the limited funding may be that there is no good home at NIH or other federal agency from which funding for integrating literacy, language, and culture could originate. One suggestion was that AHRQ could serve as a

home agency for integration research, but so far, AHRQ has not taken a lead in this area. Paasche-Orlow said that he wanted to emphasize the point that if integration research is going to take off, there must be adequate funding.

He then reported discussing a broad range of options for developing a common research agenda for literacy, language, and culture, with much of the discussion focusing on communication, systems, health outcomes, and building a business case. Rima Rudd also noted the discussion about the need for more research to support the value argument, and in particular, about the need to improve the quality of the data collected using available metrics. Paasche-Orlow added that those in the session were generally shocked by how poor data quality has been, and reminded the workshop of the NCQA data showing that perhaps as few as one-quarter to one-third of hospitals report on basic measures. Rudd commented that this is an issue of rigor, and that there are many important questions ready to be addressed if researchers can do better at producing high-quality data.

Rudd reported the discussion raised the point that while there is intervention research, there are too few interventions to study, at least in part because there has not been enough research to inform the design and development of interventions. This session also talked about the need to look at concordance within the larger context of different attributes and qualities of a system, and about the need when doing research to understand not only the patient, but also the provider, the quality of the interaction between patient and provider, and the context in which that interaction occurs.

POLICY

Michael Villaire reported that this breakout session discussed a wide range of policies and the challenges of moving some of these policies forward. He said one of his takeaway messages from the discussion was that boldness and leadership play a strong role in getting new policies in place. “I think the area in which there’s going to be movement and traction are going to be those put forward by the visionaries, by the leaders, the ones who have the great ideas,” said Villaire. He cited a phrase that came up during the discussion: “Policies are for followers, not leaders,” and he said leaders are the ones who initiate change on their own. He cited North Shore–LIJ being a good example of how strong leadership can lead to integration of programs to reduce disparities and encourage inclusion, and he commented that the motivating factor for North Shore–LIJ was the carrot rather than the stick, that policy change happened because leadership felt it was the right thing to do. Villaire also reported the issue of unfunded mandates came up frequently in the discussion. “It is difficult if not impossible to put out a mandate for which there is no funding and expect there to be complete compliance with it,” said Villaire.

Another thread in the policy discussion dealt with the differences between NCQA's standard accreditation policies and the ones tied to its Multicultural Healthcare Distinction accreditation. Some of the participants wondered whether these two sets of policies could be homogenized, and the discussion noted that cost was the main barrier to homogenization.

The policy session had some discussion about possible approaches to engage with those groups that are most affected by health disparities and inequities and learn from their experiences in order to provide care services that would more effectively meet the needs of those groups. The discussion cited Massachusetts's listening sessions as an example of positive engagement and learning. At these sessions, individuals can discuss concerns and steps they would like to see the state take to improve services, and in some but not all cases, new policies result from those comments. Similarly, he reported, Arkansas has created patient advisory committees as another means of interacting more effectively with affected populations.

The theme of community involvement also came up, Villaire noted, when the discussion tried to identify additional approaches for submitting desired changes or tweaks to existing regulations to help incentivize practitioners to implement some of those changes. "In the end, we said we need more voices from the populations that are affected," said Villaire in summarizing that part of the discussion. He added that there are different ways to bring the community voice to policy discussions, but that bold solutions are truly needed. "To put it in a different perspective, we have been using a transactional approach of tinkering with policies," said Villaire, but his takeaway from the discussion was that the current system is untenable and needs more complete systems change. Again, he said, participants in the session noted the importance of leadership, and the suggestion was made to approach the head of CMS with a list of changes that need to happen and then have a discussion on how to implement those changes.

SERVICES AND CARE

Andrew Pleasant reported on the discussion of services and care, noting that health literacy has come a long way, particularly in terms of an attitudinal shift regarding the power of health literacy to improve health. At the same time, some members of this breakout session noted that the effort to integrate health literacy with language access and cultural competence to create effective approaches for improving outcomes for all patients is still in its infancy. The session tried unsuccessfully to identify terms that could sum up these three areas with some participants noting that there is a need for new language to describe this effort. Many pointed out that "what gets measured gets managed," but identifying what should be measured was beyond what the discussion could accomplish. There was also some dis-

cussion about how, where, and who to measure and noted that what gets measured is a dynamic state.

Pleasant said his takeaway from the discussions is that though health literacy is perhaps furthest along in development, it still has a long way to go, as do language access and cultural competence. Members of the session noted that health literacy includes both communication and navigation, requires a strong skill set, and can suffer from unconscious bias. He reported that there had been a good discussion about two aspects of cultural competence, one of which was that *cultural competence* and similar terms are often used as a surrogate for race, racism, and ethnicity without having to have a frank and proper discussion. At the same time, he said, while there is much diversity in training, the core issue of racism and ethnic discrimination needs to be elevated to “decompress the privilege of cultural competency” so it can be truly tackled in a sufficient and effective manner.

During the course of the discussion it became apparent, Pleasant reported, that many of the those in the session did not believe the nested dolls metaphor given earlier was appropriate. Several felt that integration of literacy, language, and culture leads to talking with someone rather than talking to them, and leads to the individual receiving appropriate information rather than simply being told something. There was a challenging discussion about what *appropriate* means in terms of appropriate to whom. He summarized that discussion by posing a set of questions: “If it is appropriate to the patient, is that a valid outcome? If it is appropriate to the health system is that then an invalid outcome? And what does an informed decision really mean if the patient says no to what the health care system thinks is ‘appropriate?’” he asked. As an attempt to identify the master rubric for this area, some members in the session suggested the phrase *bidirectional communication*, but Pleasant said they did not come up with a real answer.

The possibility of going after low-hanging fruit was discussed, with attempts to identify some of those. One was time—the goal should be to change the amount of time a health care professional has to spend with people. As an aside, Pleasant said he is on a personal campaign to eliminate the word *patient* and to use the word *person* instead. He then reported that one person suggested “providing rational enlightenment by honoring all people and asking them what is important.” Another person suggested the solution was to conduct a thorough examination of all the policies that relate to these three areas, collect input on them through engagement with individuals and communities, evaluate them to identify which ones are working and which are not, and promote those that do work and make changes to those that do not. A final suggestion was to look at accreditation across the range of health services and health professions and identify where health literacy, cultural competence, and language access are and are not being adequately represented and change those for which they are not.

DISCUSSION

Christopher Dezii from Bristol-Myers Squibb asked if the research session discussed the concept of relevant outcomes. “Can a health literate person be identified as an outcome that can be codified?” he asked, adding that his impression from the day’s presentations and discussions was that cultural competence and language access activities are about improving bidirectional input and patient understanding. Ohene-Frempong said they did discuss this, and one suggestion to come out of that discussion was to measure health outcomes, not health literacy, to take the focus off the person and put it more on the provider. The discussion raised the point that if providers are effective in the way they communicate with people across health literacy levels, across languages, and across different cultural perspectives, then they should be managing their hypertension or diabetes more effectively and that is something that can be easily measured.

Paasche-Orlow added that some roundtable members are working on what he called a “definitions paper” that, among other topics, aims to define the nature of the outcomes that could be measured. “This is a fair topic and something we should be talking about, and it gets, more broadly speaking, into the definition of health literacy,” said Paasche-Orlow.

Jennifer Dillaha from the Arkansas Department of Health commented that the importance of strong leadership was a common thread in the three breakout discussions and wondered if one should promote health literacy leadership, particularly given the example of how North Shore-LIJ took action through strong leadership rather than because of a policy mandate. This idea, she said, prompted her to reflect on her view that health literacy is a skill set used outside of the health system and one linked closely to social determinants of health. That, in turn, led her to the idea that there needs to be an effort to increase the health literacy of policy makers so they can get, understand, and use health-related information to make decisions not just for their own health but for their constituents, too. In the end, she said, this comes back to a leadership issue—leadership by people at her level of government who can try to influence legislators in her state, and leadership at the level of health systems and in the community—and wondered if there were something the roundtable could do to ignite an effort to address health literacy among policy makers.

Paasche-Orlow thought this was an intriguing idea and asked if any of the workshop participants had any experience in developing leadership at the state level to inform policy on health in that state. Catina O’Leary from Health Literacy Missouri said her organization works at the state level and agreed with Dillaha’s comment about the importance of leadership. In Missouri, she said, leadership at the highest levels of state government say that addressing health literacy is very important and as a result,

change is happening, though not universally. “Every policy is dictated by the people who put their hands on it and make things go forward or not,” said O’Leary, which makes broad-based partnerships so important to turning policy into action. She explained that Health Literacy Missouri has an 18-month contract with the state to work with advocates on redesigning forms and processes, particularly for the state’s Medicaid program. Her experience shows that it is all about the people in Missouri Department of Health and Human Services who decide which forms are problematic and the people in the print shop and what they allow to happen. So while leadership from the top is important, so too is leadership at other levels in the process of change.

Jessie Sherrod, a practicing physician and former Robert Wood Johnson Foundation clinical scholar, commented that there are so many variables that affect health that leadership from the highest levels—perhaps the surgeon general—is needed to ensure that health considerations are part of a broad range of policy discussions, including those on environmental policies, nutritional policies, and education. Rosof, who noted that the policy discussion raised the idea of involving the surgeon general, thought there was an opportunity for the roundtable to advocate for the surgeon general to create a bold initiative, just as was done for smoking, to make the integration of health literacy, cultural competence, and language access a national priority and get ahead of the demographic changes occurring in the United States.

As a final comment, Alicia Fernandez said she was troubled by the fact that the NCQA is having difficulty getting commercial plans to collect and report data on race, ethnicity, and language despite the fact that the community has been saying for the past 15 to 20 years that these data are essential to moving forward. She was also struck by the challenging discussions about making a business case for integrating literacy, language, and culture versus making integration a matter of return on investment or value or equity or part of a patient safety initiative, or all of these. She said she would feel more optimistic if there could be a discussion about how the National Academies of Sciences, Engineering, and Medicine and other organizations could move more boldly and think about which levers need to be pushed to truly move these efforts forward.

6

Reflections on the Day

To conclude the workshop, Bernard Rosof asked the roundtable members to provide one or two points of reflection on the day's proceedings. Catina O'Leary offered two thoughts, the first being that the discussion on making a business case is one that Missouri has been struggling with for 6 years. Her organization has been funded primarily by the Missouri Foundation on Health, but that line of funding is shifting significantly and her organization needs to figure out how to identify significant sources of new funding. Sitting in Missouri, she had been thinking that she was the only person who could not identify a strong business case for health literacy, so in a sense she was reassured to hear that nobody has an answer yet. Her suggestion was that this is a key area to pay attention to, and creating a business case that everyone can use is needed. "It would be nice to have one story that we all felt good about and put the pieces of research and policy together so that we could all speak the same language over and over and not compete with one another," said O'Leary. "There is one story here somewhere, and it would be good to figure that out."

Her second thought was that while she heard about funding, initiatives, and policies, she did not hear as much as she thought she would about the disciplines of language access and cultural competence as they affect individuals, perhaps because these fields are still in their infancy. She suggested that the roundtable should revisit these topics again.

Michael Villaire commented that the health care system has been aware of inequities for many years, and while there have been approaches based on policy, legislative, and regulatory payment reforms, the needle has only moved in small increments. "In my opinion, we are essentially not much

further down the road toward a state of health equity in this country,” said Villaire. He recounted Andrew Pleasant’s comment that stories are what win people’s hearts and Rosof’s statement about taking bold steps to move the needle and wondered if a bold initiative might be to engage and activate that segment of the population that is most affected by literacy, language, and culture issues; to collect those stories that can win people’s hearts and get those populations to use their voices to enact change. He noted that the marketplaces have mechanisms in place to rate the services they receive and the places they receive them, and activating consumers of health care to use those mechanisms, just as they do now through Consumer Reports, Angie’s List, Yelp, and other rating sites, could be a powerful approach to forcing systems to change. This approach, he said, would not require prescribing which approaches to use to improve a health system’s performance. “Let the marketplace figure that out,” said Villaire. “That is who we are as a country. We allow this notion of competition to let the good practices bubble to the top. I think there’s a great power in that, and I think we may be able to find a role to play there.”

Lori Hall from Eli Lilly and Company offered an approach to operationalizing literacy, language, and culture from her perspective of someone who has to collect information and best practices and turn those into actions that can be implemented across her organization. Noting that in many cases her organization spends so much time analyzing that it becomes paralyzed, and one way of breaking out of that mode is to look for a few steps that can be taken to get the ball rolling. She referred to the “Ask Me 3” campaign that aims to improve communication between patients and health care providers, encourage patients to become active members of their health care team, and promote improved health outcomes, and wondered if there was a similar campaign that could be aimed at providers to give them one or two tools they could implement immediately with a couple of patients per day. She suggested a repeatable message that providers could memorize quickly as one possibility, or a simple technique for engaging in active listening, or perhaps three questions that providers could ask their patients, such as How do you feel about what we just talked about? What questions or concerns do you have? What is your understanding of your condition? The idea would be to create a campaign with a marketing spin, something memorable or even funny, that could be quickly and easily disseminated and not feel like a burden to providers who are already feeling overwhelmed by so many competing priorities. “We talked about low-hanging fruit earlier, and I think this could be a place to start,” said Hall.

Terri Parnell from Health Literacy Partners said she was struck by the concept of social noise and the effect that it can make in the provider–consumer relationship and effective communication. She also suggested looking at data needs from the perspective of the consumer and using the

EHR to record if a patient had teach-back, the time it took to get language access services, or any culture-related challenges the patient faced. She also remarked that the day's discussions made her think of the book *The Spirit Catches You When You Fall Down* by Anne Fadiman that documents one tragic outcome of a collision between cultures in the health care system.

Christopher Dezii said the only way he knows to hold people accountable is to measure something, and that what gets measured gets managed and reimbursed. He believes there needs to be incentives to move these fields forward. "I don't think Adam Smith's invisible hand is working," said Dezii. In his opinion, implementing performance measures is the key.

Robert Logan from the National Library of Medicine acknowledged hearing during the workshop's discussions that the NIH could better support cultural competence, language access, and intervention research; the development of more comprehensive, evidence-based best practices; and research demonstrating a return on investment from intervention efforts, similar to the work it funds on effectiveness research. He said he would mention these suggestions at future meetings where NIH staff collectively discusses funding priorities. After reminding the workshop that there are other agencies, particularly PCORI, that could fund this type of work as well, Logan said what he would truly support would be the creation of a home to fund the integration of multidimensional research that addresses how to enhance assessment at all levels of measurement of health literacy, health disparities, cultural competence and language access; how to enhance health literacy, health disparities, cultural competence, and language access interventions; and how to encourage the diffusion of findings or their translation into practice.

Logan then suggested "addressing the need for the creation of a research center with those goals and objectives in mind, as well as the creation, dissemination, and professional diffusion of integrated health literacy, cultural competence, health disparities, language access research, and practice." He also suggested, in keeping with Rosof's call for a bold initiative, that this roundtable's efforts would be "10 times more effective" if it collaborated with the National Academies of Sciences, Engineering, and Medicine's Roundtable on Population Health Improvement, which he thought was in the realm of possibility. "If we could get such an ally to come to the same conclusion, we will have a far bolder statement to make," said Logan.

Rima Rudd commented on a theme that she thought emerged over the course of the workshop, which was the feeling of discouragement, despair, and anger she heard from several of the panelists and participants. She noted that the general strategy has been to take a logical, sustained effort, to create a strategy, make the business case, and speak the language of those who need to be in alignment with these ideas to bring about change. She wondered, though, if what is needed is to bring more passion and audacity

to the effort. One might think about the Black Lives Matter movement that convinced the nation of the need to collect data on how many people are killed nationwide by police officers and the Occupy Wall Street movement that made the issue of equity a central theme in the 2012 presidential campaign. “Perhaps we need a little more focus on the issue of social justice and truly make the values argument and not simply the logical argument of the business case,” said Rudd.

Laurie Francis from the Oregon Primary Care Association agreed with Rudd and, thinking about the six steps that Marshall Chin discussed in his presentation, suggested a way to operationalize that idea over the next year or two. The operational plan would include a policy dimension, a care dimension, a payment dimension, and perhaps a community dimension, and she would call it Triple LC, for *listen, language, literacy, and culture*, with *listen* at the beginning. She would also weave social justice throughout the process. She also recounted a small project her organization conducted that was relevant to the idea that Lori Hall had about having providers to ask patients a standard set of questions. She and her colleagues at 10 clinics in Oregon asked 10 patients three questions about social issues, connectivity, economics, and stress. The result was that 5 of the 10 clinics changed their model to embrace the social issues people are facing. Oregon now calls this simple intervention of having providers ask about a patient’s life, about asking how they can serve the patient today, “radical customer orientation.”

Earnestine Willis agreed with Francis’s emphasis on listening and then said that in her mind, the health status of many people depends on the social determinants of health, with literacy, language, and culture being just one of the dimensions of those social determinants. In her opinion, “The discussion here is somewhat superficial, and we do not do the heavy lifting that we need to hear from the people who are most impacted by health inequities and to engage them in our process.” Her other concern is that there are so many systems and complex entities, including schools of public health, schools of health education, universities, and others, that affect those who experience the health inequities and who need to be involved in this effort. She said she appreciated the real-world examples of working at the state level to produce change presented in the final panel session and suggested spending more time thinking about how to operationalize true action agendas and strategies. Willis added that while there are good data available, they do not come from the people who are most affected by issues with literacy, language, and culture and will not necessarily help with efforts to operationalize what needs to happen in a patient-centered, culturally sensitive, and adaptable manner.

Kim Parson from Humana agreed with both Rudd and Willis and added two things to consider. The first was that culture is not just about race and ethnicity, and the second was that the culture of the health care

enterprise—payers, providers, the pharmaceutical industry, and others—is also an important factor to consider. She then gave an example of how important it is to listen, and noted that while it was about a physician, it could apply to any other part of the health care enterprise. A physician had seen a homeless man, who clearly had mental health issues, come in to the emergency department for treatment many times, but the emergency department had no luck convincing this man to take his medications. Sometime later, the physician starting working in a clinic that served the homeless and over time he saw this man and eventually was able to have a conversation with him. This was the first time the physician had ever heard the man speak, even though he had encountered him many times in the emergency department, and he asked him what he was most focused on regarding his health. The homeless man responded that he needed to get some sleep. Through that opening, the physician was able to prescribe medications for the man’s mental health issues that also enabled him to sleep better. Not long after that, the man returned and said the medication was working and that he wanted to continue taking it. The end of this story was that this man was able to leave the streets and live in supportive housing for more than 20 years. That story, said Parson, shows how listening and having real conversations can produce better outcomes, and that is the return on investment.

Lindsey Robinson, a pediatric dentist and the American Dental Association’s 13th District Trustee, also agreed with the call to bring more passion and energy to these issues. “In my thinking, the business case is more about a call to action, and it is a call to action because people are dying,” said Robinson. “That should be the motivation for us to make an impact.” She noted the stories she heard during the workshop showing the real-world impact of paying attention to health literacy, language, and culture should be a call to action. She endorsed the idea of calling for a surgeon general’s report that would highlight the importance of health literacy, but also noted the need to make sure its effect filters down through all segments of the health care system, including professional education, health policy, and funding. “It all needs to be aligned, and that is what I am taking away from this meeting,” said Robinson.

She then said that she appreciated the nested dolls metaphor discussed earlier because to her it represents how her profession has been siloed from the rest of the health care system. She believes there are opportunities to be mutually supportive of each other in terms of consistent messaging on health literacy, language, and cultural competence. “It is about listening to the person and supporting their self-efficacy whether they’re in a dental chair or in a medical office,” said Robinson.

James Duhig from AbbVie Inc. said he was struck by the possibility of taking systems-level approaches to addressing health literacy, language, and

culture given the different functional areas and professions that need to be involved for any effort to have a real effect. He also noted the importance of the comment about the need to know more about who patients are and what their lives are like and Wolf's questions about how to apply what is already known about health literacy to address culture and language issues. He added the questions that he was looking forward to addressing would examine what a systems-level approach would look like and how systems research could be brought to bear on these issues. He noted the consumer products area, where innovations are incorporated so rapidly into product and consumers provide feedback through the choices they make, could offer some lessons on how to use market pressures and consumer feedback to produce change in the health care system through incremental but rapid-cycle and continuous innovation.

Wilma Alvarado-Little remarked that she did not want to lose sight of the resources that the ACA and CLAS standards provide, at least from the language access perspective, to move the field forward, and she thanked Guadalupe Pacheco, during his tenure with the federal Office of Minority Health, for giving language access a voice. She then spoke about research on the prevalence of various health conditions in communities and how these studies often do not include individuals whose primary language or preferred language is not English. The usual excuse given for excluding those individuals, said Alvarado-Little, is that it is too expensive to translate surveys into different languages or to hire interpreters, but having worked in an institutional setting and translating and interpreting documents for institutional review boards, there are ways to do this that are affordable. "If we are going to talk about research, let us do it in a way that is inclusive and not just convenient," said Alvarado-Little, who also noted the importance of including individuals who are hearing impaired in research.

Andrew Pleasant said he wanted to tackle the depression and pessimism that seemed to be spreading among the workshop participants by recounting some stories about real people in the real world who had positive health outcomes resulting from the power of health literacy and addressing culture and language. The Canyon Ranch Institute, he explained, has hosted a health literacy program for many years in multiple cultural settings, in multiple languages, and in multiple regions and setting across the United States, with the same health literacy approach tailored to each community. His organization's view is that health literacy prescribes one action—engage people early and often. "If you do that, you will learn about them," said Pleasant. "You will learn about their histories, their families, their children, and the children they do not yet have and want, and that means you have inherently taken an integrative approach to health that includes mind, body, spirit, and emotion," the latter of which, he said, is often ignored but is real and important.

Taking such an approach, he said, regardless of how a provider was trained, immediately changes the model from a sick-care model to a preventive one that helps people turn their lives around before they get sick. “We’ve seen this numerous times,” said Pleasant, noting the many diabetics seen in the program who become compliant through lifestyle management and without drugs, and the people who come into the program suicidal and leave with a new outlook on life and a new role in the community. “Think about that—a health literacy program improving civic engagement across cultures so that people are more active in their communities,” said Pleasant, who added that these individuals become teachers, they go back to school, and they not only help themselves but their friends, families, and community members make changes that improve their health. All of this, he emphasized, is possible using what is already known. “It is not enough to study what people with low health literacy do not have in their lives; because, what are we going to learn that we do not already know?” asked Pleasant. Rather than be pessimistic, he added, there should be optimism because the tools that have been developed are powerful and will change lives.

There is one obstacle, however—the nation’s perverse payment system. “Can I prove the value of those changes in people’s lives? Absolutely, because we do it every day,” said Pleasant. “Is the valuation perfect? Of course not, but it is good enough to make comparisons so we can say to the payer system, ‘You are reaping these benefits without having to sow anything so how about sharing some of those savings?’”

He then told how the chief executive officer of one of his organization’s partners, Urban Health Plan, a federally qualified health center in one of the poorest congressional districts in the United States, went to neighborhood stores, asked them to start selling fruits and vegetables, and said that she would buy them if they had not sold by the end of the day. Pleasant said she had to buy that produce for a week and a half, but 7 years later that community now has farmers’ markets and stores that exclusively sell tabletop fruits and vegetables.

“What we can do,” said Pleasant, “is create leaders from the bottom up. It can be the participants, the people who we have worked with who become teachers, and it can be that chief executive officer who works every day to change the structure of health in her community.” What is truly amazing, he added, is that when the program starts, communities with different cultures have statistically significant differences in mind, body, spiritual, and emotional health outcomes, but when the program ends, those difference disappear. The lesson, he said, is that there is a place called *health* that is culturally blind. “We can help everybody get there with health literacy, so please do not be so gloomy,” said Pleasant.

Gem Daus commented that he was glad to hear there are examples in the real world where health literacy, cultural competence, and language

access are integrated in the real world. He suggested looking at case studies to find out how the health system failed individuals or helped them be successful on a number of measures. “If we can tell the story on that level, it will become easier to understand what systems can do, and then become part of the carrot to create an incentive for systems to change,” said Daus. He also thanked the participants for reminding the roundtable about how important it is to understand both the patient’s and the provider’s cultures.

Jennifer Dillaha remarked that the discussions at this workshop have prompted her to take action herself in her sphere of influence in the Arkansas state health department, particularly with regard to immunizations, but for other areas as well. She, too, acknowledged the importance of learning about the health system’s culture in order to produce change and said she was going to redouble her efforts and commit to understanding the effects of health literacy, language, and culture as a leader, encourage their integration and incorporation in all that her department does, and find others in her agency working on areas and partner with them. “It’s a daunting task because it means that I cannot continue doing things the way I do them now, but I will change,” said Dillaha.

Winston Wong was struck by the need to come to grips with what the ACA offers as opportunities and what it does not, and to understand that the United States still has not embraced the notion that health care is a right. He noted that of the 35 million Americans who were uninsured before the ACA was passed, only 11 million have been insured since, meaning there are 20 million Americans who have been effectively shut out of the health care system. The fact that the nation does not yet embrace health care as a right is what enables the country to rationalize why people who enter the health care system can face challenges in terms of accessing care. If health care is a privilege, not a right, then people who come into the system have no right to expect certain behaviors, explained Wong. “What happens is if you have a physician or health care system that is indifferent, disrespectful, dismissive, or callous, well, you had just better be happy you got something at all,” he said. Given that attitude, those who want to change the system need to be forceful and deliberate about creating a narrative that says health care is a right and that is different than appealing to the underlying decency of Americans with regard to saying people need to be treated in a way that enables them to have the full fruits of what a first class health care system can provide. As a final comment, Wong said, “All of the things we deal with did not happen by accident. They happened because of an etiological framework that rationalized the behavior we see in the system,”

Michael Wolf wondered if something could be done to bring back the Translating Research into Policy and Practice Conference that AHRQ used to hold. The goal of that conference was to learn what became of the projects that the agency funded and to find out if a program had a legacy

product that translated into something that stuck. In this case, such a conference could be used to highlight examples such as North Shore–LIJ, to identify best practices that others can adopt, and to provide a roadmap for systems that want to change but do not know how to start and what measures and evaluations they need to assess outcomes.

Steven Rush agreed that collecting stories and creating narratives is important and should continue, and that developing a business case is also necessary. He noted that changing the health care system, which has billions of dollars invested in the status quo, will require additional dollars, which would be the function of the business case. He said that it will be the combination of stories and a business case that will lead to success.

Michael Paasche-Orlow said that he agrees with Wong that there is the philosophical problem of health care as a right versus a privilege that needs to be resolved, and as an example, he noted the perverse situation in several states where the best way to receive treatment for hepatitis C is to commit a felony and get treated in prison. In a rights framework, it would be obvious that everyone should be able to have language-appropriate services and culturally competent, health literate care. He then commented that breaking down silos between these three areas is happening largely because research on language access and cultural competence is so poorly funded that investigators in those areas are being forced to join with health literacy. He also noted that the health literacy program at NIH has to be reauthorized, which is not a *fait accompli*, and that the last time that program was up for reauthorization, several of the NIH institutes dropped out of the program. “So even though I think the brand is strong, I also think we have to be vigilant and worried,” said Paasche-Orlow.

MaryLynn Ostrowski from the Aetna Foundation commented that Wolf’s suggestion to provide patients with navigation support at the point of care was a good one and something doable. She noted that the Aetna Foundation is focused on using technology to create health equity, and she is sure there must be some strategy that would enable navigation support in real time. Her hope is that some entrepreneur would address that opportunity. Ostrowski also commented on the importance of nonverbal communication and of keeping it part of the discussion, and of the need to take a more holistic approach to health that does not treat the mouth or the brain separately from the rest of the body.

Then, addressing the subject of social determinants of health, she wondered where the outrage is over the fact that there can be two communities 3 miles apart—Roxbury, Massachusetts, and the Back Bay neighborhood of Boston—with life expectancies that differ by more than 30 years. The life expectancy in Roxbury is 59.3 years, while in Back Bay it is 91 years. “That is a huge issue of health equity and should not be tolerated,” said Ostrowski. “Yet people are walking in and out of these neighborhoods,

passing each other on the street, with no realization of what is happening because of the social determinants of health.” In her mind, efforts to address issues of health literacy, language, and culture will not succeed unless the medical community and the public health community come together to truly address the social determinants of health.

Ostrowski’s final comment was the policy regarding immigrating medical professionals that restricts who would be able to continue to practice without having to recertify or go back to school for further training. She believes that this policy has had detrimental effects with respect to the diversity of the health care workforce and wondered if there were some way to perhaps fast-track those professionals as one way of creating a medical system that reflects the overall population of the country.

Marin Allen from NIH offered the final comment electronically. She hoped the roundtable would be able to come up with a picture of an ideal transaction in a full system that works and weaves all three of these threads together.

To conclude the workshop, Rosof noted that he did not hear a unified theme, but neither did he hear pessimism. “In fact, my thinking was that there is commitment and optimism going forward as to what we can and cannot do to make a difference,” said Rosof. In closing, he suggested that a next step for the roundtable would be to develop an action agenda that would enable the roundtable and other interested organizations to speak with a consistent voice.

References

- California Department of Health Care Services. 2015. *Medi-Cal managed care performance dashboard, September 2015*. Sacramento, CA: California Department of Health Care Services.
- Chin, M. H. 2014. How to achieve health equity. *New England Journal of Medicine* 371(24):2331-2332.
- Chin, M. H., and D. Goldmann. 2011. Meaningful disparities reduction through research and translation programs. *JAMA* 305(4):404-405.
- Chin, M. H., A. E. Walters, S. C. Cook, and E. S. Huang. 2007. Interventions to reduce racial and ethnic disparities in health care. *Medical Care Research and Review* 64(5 Suppl):7s-28s.
- Chin, M. H., A. R. Clarke, R. S. Nocon, A. A. Casey, A. P. Goddu, N. M. Keesecker, and S. C. Cook. 2012. A roadmap and best practices for organizations to reduce racial and ethnic disparities in health care. *Journal of General Internal Medicine* 27(8):992-1000.
- Damschroder, L. J., D. C. Aron, R. E. Keith, S. R. Kirsh, J. A. Alexander, and J. C. Lowery. 2009. Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science* 4:50.
- Divi, C., R. G. Koss, S. P. Schmaltz, and J. M. Loeb. 2007. Language proficiency and adverse events in US hospitals: A pilot study. *International Journal for Quality in Health Care* 19(2):60-67.
- Fernandez, A., D. Schillinger, E. M. Warton, N. Adler, H. H. Moffet, Y. Schenker, M. V. Salgado, A. Ahmed, and A. J. Karter. 2011. Language barriers, physician-patient language concordance, and glycemic control among insured Latinos with diabetes: The Diabetes Study of Northern California (DISTANCE). *Journal of General Internal Medicine* 26(2):170-176.
- Grubbs, V., K. Bibbins-Domingo, A. Fernandez, A. Chattopadhyay, and A. B. Bindman. 2008. Acute myocardial infarction length of stay and hospital mortality are not associated with language preference. *Journal of General Internal Medicine* 23(2):190-194.
- Haberman, M. 2015. Hillary Clinton, pressed on race, issues her own challenge. *The New York Times*, August 19, 2015.

- HHS (U.S. Department of Health and Human Services) Office of Minority Health. 2015. *CLAS legislation map*. <https://www.thinkculturalhealth.hhs.gov/Content/LegislatingCLAS.asp> (accessed November 16, 2015).
- IOM (Institute of Medicine). 2000. *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.
- IOM. 2004. *Health literacy: A prescription to end confusion*. Washington, DC: The National Academies Press.
- Jahnke, L. R., N. J. Siddiqui, and D. P. Andrulis. 2015. *Evolution of health insurance marketplaces: Experiences and progress in reaching and enrolling diverse populations*. Austin, TX: Texas Health Institute.
- Karliner, L. S., A. Auerbach, A. Napoles, D. Schillinger, D. Nickleach, and E. J. Perez-Stable. 2012a. Language barriers and understanding of hospital discharge instructions. *Medical Care* 50(4):283-289.
- Karliner, L. S., L. Ma, M. Hofmann, and K. Kerlikowske. 2012b. Language barriers, location of care, and delays in follow-up of abnormal mammograms. *Medical Care* 50(2):171-178.
- LaVeist, T. A., D. Gaskin, and P. Richard. 2011. Estimating the economic burden of racial health inequalities in the United States. *International Journal of Health Services* 41(2):231-238.
- Masland, M. C., S. H. Kang, and Y. Ma. 2011. Association between limited English proficiency and understanding prescription labels among five ethnic groups in California. *Ethnicity & Health* 16(2):125-144.
- NCQA (National Committee for Quality Assurance). CLAS & Disparities Environmental Scan. Report submitted to the Centers for Medicaid & Medicare Services. NCQA: Washington, DC, April 15, 2015. Contract # HHSM-500-2014-00442G.
- Penchaszadeh, V. B. 2001. Genetic counseling issues in Latinos. *Genetic Testing* 5(3):193-200.
- Rivadeneira, R., V. Elderkin-Thompson, R. C. Silver, and H. Waitzkin. 2000. Patient centeredness in medical encounters requiring an interpreter. *American Journal of Medicine* 108(6):470-474.
- Schenker, Y., A. J. Karter, D. Schillinger, E. M. Warton, N. E. Adler, H. H. Moffet, A. T. Ahmed, and A. Fernandez. 2010. The impact of limited English proficiency and physician language concordance on reports of clinical interactions among patients with diabetes: The DISTANCE study. *Patient Education and Counseling* 81(2):222-228.
- Schenker, Y., A. Fernandez, K. Kerr, D. O'Riordan, and S. Z. Pantilat. 2012. Interpretation for discussions about end-of-life issues: Results from a national survey of health care interpreters. *Journal of Palliative Medicine* 15(9):1019-1026.
- Sequist, T. D., G. M. Fitzmaurice, R. Marshall, S. Shaykevich, A. Marston, D. G. Safran, and J. Z. Ayanian. 2010. Cultural competency training and performance reports to improve diabetes care for black patients: A cluster randomized, controlled trial. *Annals of Internal Medicine* 152(1):40-46.
- Smith, W. R., J. R. Betancourt, M. K. Wynia, J. Bussey-Jones, V. E. Stone, C. O. Phillips, A. Fernandez, E. Jacobs, and J. Bowles. 2007. Recommendations for teaching about racial and ethnic disparities in health and health care. *Annals of Internal Medicine* 147(9):654-665.
- Vela, M. B., K. E. Kim, H. Tang, and M. H. Chin. 2008. Innovative health care disparities curriculum for incoming medical students. *Journal of General Internal Medicine* 23(7):1028-1032.
- Weissman, J. S., and R. Hasnain-Wynia. 2011. Advancing health care equity through improved data collection. *New England Journal of Medicine* 364(24):2276-2277.
- Wilson, E., A. H. Chen, K. Grumbach, F. Wang, and A. Fernandez. 2005. Effects of limited English proficiency and physician language on health care comprehension. *Journal of General Internal Medicine* 20(9):800-806.

Appendix A

Workshop Agenda

Integrating Health Literacy, Cultural Competency, and Language Access Services: A Workshop

October 19, 2015
Beckman Center
Irvine, California

- 8:30–8:45 Welcome and Introduction of Workshop Agenda
Bernard Rosof, M.D., M.A.C.P., Chair, Roundtable on Health Literacy
- 8:45–9:05 Health System Transformation: How the Affordable Care Act and Other Incentives May Support Integration
Dennis Andrulis, Ph.D., M.P.H., Texas Health Institute
- 9:05–10:10 Panel: For each of the areas (health literacy, cultural competency, and language access services), each presenter will address two questions:
- What are the key concepts in that area?
 - What three things have changed over time that facilitate integration?
- 9:05–9:10 Introduction of Panelists
- 9:10–9:20 Health Literacy
Michael Wolf, Ph.D., Feinberg School of Medicine
- 9:20–9:30 Cultural Competency
Guadalupe Pacheco, M.S.W., Pacheco Consulting Group

- 9:30–9:40 Language Access Services
Wilma Alvarado-Little, M.A., M.S.W., Alvarado-Little Consulting
- 9:40–10:10 Discussion
- 10:10–10:30 BREAK
- 10:30–12:00 Issues and Challenges
- 10:30–10:35 Introduction of Speakers
Moderator: Winston Wong, M.D., Kaiser Permanente
- 10:35–10:55 An Overview of Issues and Challenges.
Alicia Fernandez, M.D., University of California, San Francisco
- 10:55–11:30 A moderated discussion. For this session we have the people who presented in the first panel in each of the three areas plus a moderator. The moderator explores three scenarios to which the three panelists respond.
- 11:30–12:00 Discussion
- 12:00–12:45 LUNCH
- 12:45–2:15 Addressing the Challenges: Action Panel
- 12:45–12:50 Introduction of Panelists
Moderator: Ignatius Bau, J.D., Health Policy Consultation Services
- 12:50–1:05 Integrating Health Literacy, Cultural Competency, and Language Access into Quality Improvement Standards and Activities
Jessica Briefer French, M.H.S.A., National Committee for Quality Assurance
- 1:05–1:20 State Legislative Approaches to Integration: How Language Access Can Be Codified in State Legislation
Sarah de Guia, J.D., California Pan-Ethnic Health Network

- 1:20–1:35 How Cultural Competency, Language Access, and Health Literacy Are Integrated into Programs and Interventions Aimed at Reducing Disparities
Marshall Chin, M.D., M.P.H., University of Chicago Medicine
- 1:35–1:50 Effective Communication in Health Care: The North Shore–Long Island Jewish Health System Approach to Realignment of Efforts in Health Literacy, Cultural Competency, and Language Access
Stacey Rosen, M.D., North Shore–Long Island Jewish Health System
- 1:50–2:15 Discussion
- 2:15–3:15 Small Group Discussion
- Each group will address a different area related to integration of health literacy, cultural competency, and language access services.
 - Each group will have a facilitator from the planning committee to keep discussion on task.
 - Each group should appoint a recorder and someone who will report on the group’s discussion and suggestions.
 - Groups
 - Research—Newport Room. Facilitator: Janet Ohene-Frempong
 - Policy—Balboa Room. Facilitator: Gem Daus
 - Services and Care—Board Room. Facilitator: Andrew Pleasant
- 3:15–3:30 BREAK and RECONVENE
- 3:30–4:30 Group Reports
Moderator: Bernard Rosof, M.D., M.A.C.P., Chair, Roundtable on Health Literacy
- 3:30–3:40 Research
- 3:40–3:50 Policy
- 3:50–4:00 Services and Care
- 4:00–4:30 General Discussion

- 4:30–5:00 Reflections of the Day
*Moderator: Bernard Rosof, M.D., M.A.C.P., Chair,
Roundtable on Health Literacy*
- 5:00 ADJOURN

Appendix B

Biographical Sketches of Workshop Speakers and Moderators

Wilma Alvarado-Little, M.A., M.S.W., has, for more than 25 years, been a strong voice advocating for linguistically and culturally appropriate health services. In addition to her interests in public policy, research, and health disparities prevention, she is a health care interpreter and trainer who has been instrumental in the development and implementation of hospital- and clinic-based programs. She has also been involved with media initiatives on the importance of identifying linguistic and cultural barriers in the provision of quality health care services. She works tirelessly to educate health care institutions on provision of quality language access services and has participated in efforts led by The Joint Commission, the American Medical Association, and the HHS Office of Minority Health. She is the former Cochair of the Board of the National Council on Interpreting in Health Care, and is a member of the National Project Advisory Committee for the Review of the CLAS Standards, the HHS Office of Minority Health, and the New York State Office of Mental Health Multicultural Advisory Committee. In addition, she serves on boards at the state and local levels that address multicultural issues. Prior to becoming an independent consultant, she received a grant from the NIH in May 2009 as part of an award to the Center for Elimination of Minority Health Disparities, University at Albany, SUNY, to support research to identify access and barriers to health care for populations in smaller cities and served as the principal investigator (PI)/Director of Community Engagement/Outreach. She has a master of arts degree in Spanish Literature, a master's in Social Welfare, and bachelor degrees in Spanish and Psychology.

Dennis P. Andrulis, Ph.D., M.P.H., is a senior research scientist at the Texas Health Institute, a health care policy research organization in Austin, Texas. He is also an associate professor at the University of Texas School of Public Health. In his positions, Dr. Andrulis leads the development of initiatives on health care for vulnerable populations, racial and ethnic disparities, and cultural competence, working at community, state, and national levels. Previously, Dr. Andrulis was the associate dean for research of Drexel University's School of Public Health in Philadelphia and directed its Center for Health Equality. His current and recent work has focused on the ACA and its implications for racially and ethnically diverse populations, with a subsequent set of reports being issued in 2013, titled the Affordable Care Act and Race, Ethnicity, and Equity Series, addressing the exchanges, workforce, safety net, public health, and prevention, as well as data, research, and quality. In so doing, and as a member of the CLAS National Advisory Group, he has worked to identify and highlight how CLAS has been integrated into health system transformation in the ACA era. Dr. Andrulis is also leading the development of a Marketplace Health Equity Assessment Tool. With support from the W.K. Kellogg Foundation, The California Endowment, and the Connecticut Health Foundation, this first-of-its kind protocol offers a comprehensive review and evaluation of progress in ensuring diverse populations and in improving access to care. He is also co-investigator on a project supported by the Robert Wood Johnson Foundation to develop a National Health Equity Index as part of their Culture of Health Initiative. He is principal investigator on a Sierra Health Foundation initiative to create a community survey on social determinant-related access to care challenges for racially, ethnically, and linguistically diverse populations in South Sacramento. Previous work has included the creation of an Organizational Cultural Competence Assessment Protocol, which offers hospitals, community health centers, health plans, and health departments a tool to inventory and assess progress in meeting the needs of diverse patients and communities—a tool that was approved by CMS for health plans in meeting Quality Assurance/Performance Improvement requirements in 2003. Work supported by HHS/Office of Minority Health included creation of a National Consensus Statement on Diversity and Preparedness. Dr. Andrulis has a Ph.D. in Educational Psychology from the University of Texas at Austin and a masters of Public Health from the University of North Carolina at Chapel Hill.

Ignatius Bau, J.D., is an independent health care policy consultant, focusing on issues of patient-centeredness and health equity through the implementation of health care reform. His organizational clients have included state health departments, health plans, hospital systems, physician organizations, community health centers, consumer organizations, community-based orga-

nizations, and foundations. Mr. Bau has been interim executive director at CPEHN, program officer at The California Endowment, policy director at the Asian & Pacific Islander American Health Forum, and immigration attorney at the Lawyers Committee for Civil Rights of the San Francisco Bay Area. He has been a member of the IOM Committee on Future Directions of the National Healthcare Quality and Disparities Reports, Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement, Forum on the Science of Health Care Quality Improvement and Implementation, and chaired planning committees for IOM workshops on Integrating Health Literacy, Disparities Reduction, and Quality Improvement, and Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records. Mr. Bau also has served on expert advisory panels for the National Quality Forum, The Joint Commission, the federal Office of Minority Health, the Office of National Coordinator for Health Information Technology, the Centers for Disease Control and Prevention (CDC), and the California Department of Health Services.

Marshall H. Chin, M.D., M.P.H., FACP, is the Richard Parrillo Family Professor of Healthcare Ethics in the Department of Medicine at the University of Chicago, and he is a general internist with extensive experience improving the care of vulnerable patients with chronic disease. He is director of the Robert Wood Johnson Foundation (RWJF) Reducing Health Care Disparities Through Payment and Delivery System Reform Program Office; director of the Chicago Center for Diabetes Translation Research; associate chief and director of research in the Section of General Internal Medicine; co-director of the John A. Hartford Foundation Center of Excellence in Geriatrics; and associate director of the MacLean Center for Clinical Medical Ethics at the University of Chicago. Dr. Chin is improving diabetes care and outcomes on the South Side of Chicago through health care system and community interventions. He is also leading the evaluation of a Commonwealth Fund project that is implementing the patient-centered medical home in 65 safety net clinics across five states. He is also investigating how to improve shared decision making between clinicians and lesbian, gay, bisexual, transgender, and queer racial/ethnic minority patients. Dr. Chin serves on the CDC Community Preventive Services Task Force, the National Quality Forum Measure Applications Partnership Coordinating Committee, and the editorial board of *Health Services Research*. He is the president of the Society of General Internal Medicine (SGIM), and has won mentoring awards from SGIM and the University of Chicago. Dr. Chin is a graduate of the University of California, San Francisco (UCSF), School of Medicine and completed residency and fellowship training in general internal medicine at Brigham and Women's Hospital, Harvard Medical School.

Sarah de Guia, J.D., is the executive director of CPEHN, a multicultural health advocacy organization dedicated to improving the health of communities of color in California. Ms. de Guia has more than a decade of experience advocating for access to culturally and linguistically appropriate health care, advancing women's reproductive justice, and promoting immigrants' rights. Previously, Ms. de Guia held the position of CPEHN's Director of Government Affairs, where she spearheaded the organization's legislative work and successfully achieved passage of eight legislative proposals on issues ranging from improving language access to "health in all policies" in state planning. Previously Ms. de Guia worked as the Health Program Manager with Latino Issues Forum and as Legislative Analyst with the Mexican American Legal Defense and Educational Fund. From 2012 to 2014 Ms. de Guia served as a mentor with the Women's Policy Institute, a legislative training program for women leaders, and she is a 2014 graduate of CompassPoint's Next Generation Leaders of Color program. Ms. de Guia earned her juris doctor from Santa Clara University School of Law and her bachelor of arts from the University of California, Berkeley, in Ethnic Studies and Public Policy.

Alicia Fernandez, M.D., is a professor of Clinical Medicine at UCSF and an attending physician in the General Medical Clinic and the Medical Wards at San Francisco General Hospital. Her research primarily focuses on health and health care disparities, and she is particularly interested in vulnerable populations, Latino health, immigrant health, and language barriers. In addition to her research and clinical practice at San Francisco General Hospital, she does a great deal of mentoring for students, residents, fellows, and faculty. She has received several honors and awards, including the Arnold P. Gold Professorship for Humanism in Medicine. She has served as an advisor to the RWJF, The California Endowment, the National Quality Forum, the Commonwealth Fund, the American Medical Association, the American Board of Internal Medicine, and other organizations on projects focused on health care disparities, Latino health, and populations with limited English proficiency. She was a standing member of the AHRQ Health Care Quality and Effectiveness study section (2006–2010) and is currently a member of NIH Health Services Organization and Delivery (HSOD) study section.

Jessica Briefer French, M.H.S.A., is a senior research scientist at NCQA, with responsibility for leading large and complex grants and contracts. Ms. French has worked in health care quality for 20 years in both the private sector and on government contracts and private foundation grants. Over the last decade, her work has focused on measurement and evaluation of quality of care for vulnerable populations including racial, ethnic, and linguistic

minorities; people dually eligible for Medicare and Medicaid; children with special health care needs; and human research subjects. Ms. French served on the National CLAS Standards Advisory Committee and the National CLAS Standards Evaluation Project Advisory Group. She is a subject-matter expert on a current contract with the Office of Minority Health at CMS. Ms. French has managed a variety of large and complex projects involving multiple stakeholders. She is currently PI for a research study to identify best practices in person-centered, goal-based integrated care for people with complex health care needs. Ms. French works on projects to develop approaches to measuring integrated care for persons who are dually eligible for Medicare and Medicaid. She leads NCQA's team to provide technical assistance to states in reporting child, adult, and health home core set measures. Other work has included large federal contracts with CMS to collect, process, and analyze performance measures from Medicare managed care plans, various foundations, and state- and grant-funded projects to develop, implement, and support quality measurement and reporting.

Guadalupe Pacheco, Jr., M.S.W., is the founder, president/CEO of the Pacheco Consulting Group (PCG), located in Washington, DC. Drawing on the more than 30 years of senior-level health management policy development and nonprofit experience to the principal, PCG provides services to public- and private-sector clients in the areas of health policy, cultural-centric service delivery, and public engagement. Through innovative, visionary, and goal-oriented approaches of its leaders and consultants, PCG tailors and delivers successful outcomes to its clients based on their needs. Mr. Pacheco previously served as Project Manager for Lockheed Martin Corporation. He was outsourced to HHS Office for Civil Rights to assess and relaunch the office's civil rights medical school curriculum initiative for medical schools across the country. Prior to that position, Mr. Pacheco served as the Training Director for the AIDs Education and Training Center-Multicultural Center (AETC-MC), Howard University College of Medicine. As the training director, he oversaw training development and the execution of curriculum activities related to the AETC-MC. Mr. Pacheco also served as a senior health advisor/project officer to the Director, Office of Minority Health, Office of Assistant Secretary for Minority Health, HHS. As the senior health advisor, he managed the agency's portfolios on cultural competency, emergency preparedness, health literacy, e-learning, and Latino-related initiatives. Additionally, Mr. Pacheco provided oversight and review of major public health policy initiatives, including the implementation of the ACA, to determine their effectiveness in mitigating health disparities of minority populations. Mr. Pacheco serves on various advisory and membership bodies, including the American Diabetes National Capital Area Leadership Board, Excelencia in Education, the Greater Washington

Hispanic Chamber of Commerce, and the advisor to the Certified Medical Interpreters, LLC. Mr. Pacheco received his B.A. and M.S.W. from California State University of Fresno and has completed course work for an M.P.A. from the University of Southern California.

Stacey Rosen, M.D., FACC, FACP, FASE, is the vice president for the Katz Institute for Women's Health (KIWH) and oversees the development and coordination of a comprehensive and integrated approach to women's services at the health system. Dr. Rosen is a practicing cardiologist and echocardiographer and was the associate chairman of the Department of Cardiology at LIJ prior to joining KIWH. She is an associate professor of Medicine at the Hofstra North Shore–LIJ School of Medicine and currently serves as a society master at the School of Medicine. Previously, she served as the director of the Cardiovascular Disease Fellowship Program at North Shore–LIJ. As a former president and current member of the board of directors of the Long Island region and a national spokesperson of the American Heart Association, Dr. Rosen devotes considerable time to raising community awareness about heart disease in women. She also serves as a member of the Scientific Advisory Board for WomenHeart: The national coalition for women living with heart disease. Dr. Rosen is a graduate of the 6-year medical program at Boston University School of Medicine and is board certified in Internal Medicine, Cardiology, and Echocardiography. She is a fellow of the American College of Cardiology, the American College of Physicians, and the American Society of Echocardiography. Dr. Rosen served two terms as an American College of Cardiology councilor, serving Nassau and Suffolk counties. She has received numerous teaching awards including the Ann Gottlieb Award for Excellence in teaching from North Shore–LIJ, awards for volunteer service from the American Heart Association, she and was voted one of Long Island's Top 50 Most Influential Women. She received the Cardiovascular Science Award from the American Heart Association at the 48th annual American Heart Ball for the Long Island region in 2011.

Michael S. Wolf, Ph.D., M.A., M.P.H., is Professor of Medicine, Associate Division Chief (Internal Medicine & Geriatrics), and Director of the Health Literacy & Learning Program (HeLP) within the Feinberg School of Medicine at Northwestern University in Chicago. He also holds appointments in Cognitive Sciences, Communication Studies, Medical Social Sciences, Psychiatry & Behavioral Sciences, and Surgery. As a health services researcher and cognitive-behavioral scientist, Dr. Wolf has extensively studied cognitive, psychosocial, and health system determinants of health, specifically in the area of health literacy and health communications research. His work has primarily focused on understanding health care complexity; Dr. Wolf

has led several large-scale, pragmatic trials to evaluate multifaceted interventions to promote patient engagement in health, targeting chronic disease self-management, medication safety, and adherence.

Winston F. Wong, M.D., M.S., serves as Medical Director, Community Benefit, Kaiser Permanente, and is responsible for the organization's partnerships with communities and institutions in advancing population management and evidence-based medicine, with a particular emphasis on safety net providers and the elimination of health disparities. As a captain of the Commissioned Corp of the U.S. Public Health Service from 1993 to 2003, Dr. Wong was awarded the Outstanding Service Medal. Wong currently has served on a number of national advisory committees, including those sponsored by the National Quality Forum, CMS, and the IOM addressing issues of access and quality for diverse populations, most recently as a member of the IOM Committee on the Integration of Primary Care and Public Health. In 2013, Dr. Wong was appointed to the National Academies of Sciences, Engineering, and Medicine's Board on Population Health and Public Health Practice. He is also a board member of The California Endowment, the Essential Hospitals Institute, and the School-Based Health Alliance. Bilingual in Cantonese and Toisan dialects, and a graduate of the University of California, Berkeley, and the UCSF School of Medicine, Dr. Wong continues a small practice in Family Medicine at Asian Health Services, a federally qualified health center based in Oakland, where he previously served as Medical Director. Dr. Wong was featured as a "Face of Public Health" in the May 2010 issue of the *American Journal of Public Health*.

