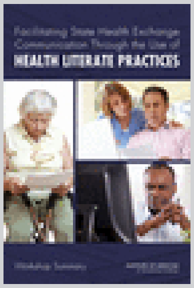

Facilitating State Health Exchange Communication Through the Use of Health Literate Practices: Workshop Summary

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Facilitating State Health Exchange Communication Through the Use of HEALTH LITERATE PRACTICES

Workshop Summary

Maria Hewitt, *Rapporteur*

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

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> *"Knowing is not enough; we must apply.*
> *Willing is not enough; we must do."*
> —Goethe

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

David Coultas, The University of Texas Health Science Center at Tyler
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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the final draft of the report before its release. The review of this report was overseen by **Hugh H. Tilson,** University of North Carolina. Appointed by the Institute of Medicine, he was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the rapporteur and the institution.

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Introduction

Implementation of the Affordable Care Act (ACA) of 2010[1] will result in significant changes to the U.S. health care system. Among its many provisions, the ACA will extend access to health care coverage to millions of Americans who have been previously uninsured. Coverage will be achieved through a variety of mechanisms, including, for example, expansion of Medicaid eligibility and the establishment of state health insurance exchanges (IOM, 2011). The ACA calls for each state to set up an "exchange," or marketplace, where small businesses (those with 100 or fewer employees) and people not covered through their employers could shop for health insurance at competitive rates. Some of those insured through the exchanges would pay for the insurance coverage themselves, while others with relatively low incomes would receive subsidies to help defray the cost of the premiums. As envisioned, the exchanges, which are to be operational by 2014, will offer four levels of plans—platinum, gold, silver, and bronze—that would vary in price. States have flexibility in how the insurance exchanges would operate, and in fact, states can opt out of setting up an exchange. A federally operated exchange would operate in those states that do not set up one themselves.

Health insurance products are complex, making comparison shopping and educated decisions difficult. Plans available through the exchanges

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[1] The Patient Protection and Affordable Care Act (PPACA, Public Law 111-148) was signed into law on March 23, 2010. The PPACA was later amended by the Health Care and Education Reconciliation Act of 2010 (Public Law 111-152), and the final version is referred to as the Affordable Care Act (ACA).

will differ by their associated premium cost, benefit coverage, and out-of-pocket expenses (e.g., deductibles, co-payments). It may be particularly difficult for individuals with poor literacy and numeracy skills to find an insurance plan that meets their needs when faced with many insurance options. Nearly half of all American adults—90 million people—have inadequate health literacy to navigate the health care system (IOM, 2004). Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan and Parker, 2000).

Many of the newly eligible health insurance consumers will be individuals of low health literacy, some speakers of English and others more comfortable using languages other than English. Health insurance terms such as "deductible," "co-insurance," and "out-of-pocket limits" are difficult to communicate even to those with moderate-to-high levels of health literacy and so health exchanges will face challenges as they attempt to communicate to the broader community. In addition to having to convey some of these basic, and yet complex, principles of insurance, state exchanges will be attempting to adapt to the many changes to enrollment and eligibility brought about by ACA. While these challenges may seem daunting, there are important lessons to be learned from a number of existing programs and research endeavors.

The Institute of Medicine (IOM) convened the Roundtable on Health Literacy to address issues raised in its report *Health Literacy: A Prescription to End Confusion* (IOM, 2004). The roundtable brings together leaders from the federal government, foundations, health plans, associations, and private companies to discuss challenges facing health literacy practice and research and to identify approaches to promote health literacy in both the public and private sectors. The roundtable's focus is on building partnerships to move the field of health literacy forward by translating research findings into practical strategies for implementation. The roundtable also serves to educate the public, press, and policy makers regarding issues related to health literacy.

The roundtable sponsors workshops for members and the public to discuss approaches to resolve key challenges. Reports from workshops held by the roundtable include the following:

- *Standardizing Medication Labels: Confusing Patients Less: Workshop Summary (2008)*
- *Health Literacy, eHealth, and Communication: Putting the Consumer First: Workshop Summary (2009)*
- *Toward Health Equity and Patient-Centeredness: Integrating Health Literacy, Disparities Reduction, and Quality Improvement: Workshop Summary (2009)*

- *Measures of Health Literacy: Workshop Summary (2009)*
- *The Safe Use Initiative and Health Literacy: Workshop Summary (2010)*
- *Innovations in Health Literacy Research: Workshop Summary (2011)*
- *Health Literacy Implications for Health Care Reform: Workshop Summary (2011)*
- *Promoting Health Literacy for Prevention and Wellness: Workshop Summary (2011)*
- *Improving Health Literacy Within a State: Workshop Summary (2011)*

The roundtable sponsored a workshop in Washington, DC, on July 19, 2011, that focused on ways in which health literacy can facilitate state health insurance exchange communication with potential enrollees. The roundtable's workshop focused on four topics: (1) lessons learned from existing state insurance exchanges; (2) the impact of state insurance exchanges on consumers; (3) the relevance of health literacy to health insurance exchanges; and (4) current best practices in developing materials and communicating with consumers.

The report that follows summarizes the presentations and discussion that occurred during the workshop. Chapter 2 provides an overview of health insurance exchanges with views on their creation and optimal operation. Chapter 3 presents evidence on the extent to which consumers understand underlying health insurance concepts and some of the unique challenges faced by consumers who speak languages other than English. Chapter 4 describes the relevancy of health literacy to health insurance reform and how health literacy interventions can facilitate the implementation of health insurance reforms. Chapter 5 follows with a review of best practices in developing materials and communicating with consumers. Chapter 6 concludes with reflections on the workshop presentations and discussions by members of the roundtable and its chair. Further information is provided in the appendixes, the workshop agenda (Appendix A), workshop speaker biosketches (Appendix B), and testimony provided by the organization America's Health Insurance Plans (AHIP) (Appendix C).

The workshop was organized by an independent planning committee in accordance with the procedures of the National Academies of Science. The role of the workshop planning committee was limited to planning the workshop. Unlike a consensus committee report, a workshop summary may not contain conclusions and recommendations. Therefore, this summary has been prepared by the workshop rapporteur as a factual summary of what occurred at the workshop. All views presented in the report are those of workshop participants. The report does not contain any findings or recommendations by the planning committee or the roundtable.

REFERENCES

IOM (Institute of Medicine). 2004. *Health literacy: A prescription to end confusion.* Washington, DC: The National Academies Press.

IOM. 2011. *Health literacy implications for health care reform: Workshop summary.* Washington, DC: The National Academies Press.

Ratzan, S. C., and R. M. Parker. 2000. Introduction. In *National Library of Medicine current bibliographies in medicine: Health literacy*, edited by C. R. Selden, M. Zorn, et al. NLM Pub. No. CBM 2000-1. Bethesda, MD: National Institutes of Health.

2

State Health Insurance Exchanges—Overview

STATE HEALTH INSURANCE EXCHANGES: HELPING CONSUMERS NAVIGATE AN ENROLLMENT SUPERHIGHWAY

Alice Weiss, J.D.
National Academy for State Health Policy

Weiss opened by describing the National Academy for State Health Policy (NASHP) as a non-partisan, non-profit organization dedicated to helping states achieve excellence in health policy and practice (www.NASHP.org). NASHP conducts policy analysis and research, convenes forums for states to learn from each other, and assists executive and legislative branch officials, both at the state and federal levels. These activities help state decision makers assess opportunities for advancing effective policies. NASHP is unique as an organization insofar as it works across agencies and branches of government. Other organizations that are focused on state policies work selectively with certain decision makers, such as Medicaid directors, governors, or legislators. NASHP provides opportunities for state health policymakers to meet, learn from one another, and promote best practices.

NASHP has a growing body of work on eligibility and enrollment. Since 2008, NASHP has been the National Program Office for the Robert Wood Johnson Foundation (RWJF) initiative “Maximizing Enrollment.” NASHP is working intensively with eight states and less intensively working with all states on their efforts to enroll more eligible individuals into public coverage and publicly subsidized programs. This initiative has provided a great deal of information that can assist states as they design and implement their state health insurance exchanges.

To disseminate their findings and foster communication, NASHP hosts an interactive venue on health reform topics for states and other policy makers called State Refor(u)m (www.staterefor(u)m.org). It is a website where states can post materials, share information, and engage in conversations about health reform. NASHP also provides technical assistance to the State Health Reform Assistance Network, a RWJF project that supports a number of organizations as they work intensively with 10 states to implement health reform.

ACA Enrollment Reforms

The Affordable Care Act (ACA) created a vision for an "enrollment superhighway." Instead of a system that places the burden to navigate the array of public programs on the consumer, there is a single, unified application that can be used to apply to any program. This seamless, "one-stop" system would provide consumers with assistance and understandable information to guide them through the enrollment process. Individuals would present their enrollment information and then be guided through the eligibility process as states draw down their electronic information and match their information to various program eligibility requirements. This integrated approach to enrollment differs markedly from current systems, where there are different processes for enrollment. The new system is going to be integrated, not only within a state between Medicaid, the Children's Health Insurance Program, private coverage options, and subsidized coverage, but also with federal programs, such as those offered through the Social Security Administration.

ACA Eligibility Reforms

The ACA replaces the existing multiple categories of Medicaid eligibility with a single eligibility category for individuals under 138 percent of the federal poverty level (FPL). There is also a much simpler process for determining eligibility. Instead of having a standard that depends on whether or not an individual fits into a certain category within his or her income, the ACA eligibility standard depends primarily on modified adjusted gross income. The other eligibility categories are set aside unless an individual meets certain criteria, such as being disabled or elderly. For individuals with incomes between 138 and 400 percent of the FPL, the ACA provides subsidies for health insurance coverage. The enrollment process is technology-enabled. In contrast to the usual paper-based application process, there is a movement toward electronic applications and links to allow applications through Internet portals. Privacy and security standards are in place to ensure that the consumer's information is protected.

Consumer Engagement

The enrollment superhighway is predicated on the notion that consumers will be engaged in the process and have the information they need to make decisions about coverage. However, there is a large gap between where states are today and where they need to be to achieve the envisioned enrollment superhighway, Weiss said. One of the key challenges relates to how consumers experience and engage with enrollment systems.[1] Most state systems are very antiquated; their systems are paper-based and not integrated. The burden is on the individual to go from agency to agency in order to enroll in programs for which they are eligible. Many people entering these systems are technology-savvy and are accustomed to technology-enabled environments. They are using their cell phones to order products online and to download music. Individuals of all races, ethnicities, and economic backgrounds are increasingly accessing digital information through smart phones and other means. According to the Pew Research Center's Internet and the American Life Project (www.pewinternet.org), 35 percent of American adults use a smart phone, and a quarter of them primarily use their phones to download information from the Internet. Latinos and black Americans are as likely, and in some cases more likely, to have a cell phone and are more likely to use their smartphones for these types of interactions. While an increasing number of Americans are relying on modern technologies, states have not yet engaged individuals using these tools.

Enrollment Challenges for States

With eligibility expansions under the ACA, states will have to accommodate a high volume of applicants. In addition, the characteristics of the new applicants will differ from those who have traditionally accessed public programs. The expanded pool of applicants will include employed and middle-income populations. These clients will have different expectations for customer service. Additional challenges will arise when addressing the needs of a much more transient population. The increased eligibility levels and the absence of the categorical eligibility requirements will result in greater access to programs on the part of homeless people and

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[1] For more information on challenges to enrollment, see Weiss and Grossman, 2011.

people without a fixed address. These shifts in the size and makeup of the eligible population will contribute to the need for a robust consumer assistance program that includes the "human touch" that people often need to navigate complex systems. Very few states have such personalized support for their eligible populations. The ACA has recognized this challenge and has provided grants to states to augment their consumer assistance programs.

Many states have done fairly well in accommodating individuals with disabilities, Weiss said, but they have not yet adapted programs to meet the needs of individuals in terms of language and literacy. One in 10 Americans does not speak English as a first language. Consequently, states will need to implement translation programs and programs that will support the needs of individuals with limited English proficiency. Families that include individuals with different citizenship statuses will present a challenge to states. Some families may include one parent who is an undocumented immigrant, another parent who is a legal immigrant, and children who are American citizens. It will be difficult for states to communicate to such families how their right to coverage may vary by program. In addition, there will be families with one privately insured parent and other family members without dependent coverage under the policy who will need help accessing public programs.

Helping people understand their eligibility is going to be particularly challenging, Weiss said. Coverage gaps have been well documented (Sommers and Rosenbaum, 2011). Half of low-income individuals under 200 percent of the federal poverty level experience income changes over the course of a year. Of these individuals, half will experience more than one, and as many as two to four changes in a year. Every time an individual's income changes between 138 percent of poverty and above, there will be a potential transition in coverage. It will be challenging for states to manage these transitions, Weiss said. This will be especially difficult when individuals are required to reimburse the federal government at the end of the year for any subsidies they receive, such as when they are found to be ineligible for coverage for some portion of the year.

The ACA requires states to adopt technology that allows individuals to apply for health insurance coverage online, in person, by mail, or by telephone. All states have developed an online application for either Medicaid or the Children's Health Insurance Program (CHIP); however, in many cases the application must be printed, signed, and then faxed or mailed for processing. Some states have a system for electronic submission of the application; however, relatively few states allow the applicant to complete the entire process online. Fewer than 10 states have systems in place that electronically match information submitted by the applicant to administrative records, Weiss said. Such systems eliminate the need for paper documentation. States will need to innovate to progress from the status quo to what is expected of them by 2014.

The degree of variation that exists among states in their adoption of streamlined eligibility and enrollment policies is another key issue for states. For Medicaid and CHIP most states require income documentation at enrollment and at renewal. Relatively few states have adopted presumptive eligibility or 12-month continuous eligibility. More states have eliminated the face-to-face interview at enrollment and have eliminated the asset test for these programs. States will have to improve their compliance to existing best practices for eligibility and enrollment simplification, Weiss said. Furthermore, when eligibility rules and enrollment policies vary by state, consumers who move from one state to another may have to navigate a completely different program and set of rules. States will have to be able to effectively communicate to help people understand their policies regarding consumer rights and responsibilities.

Another key challenge for states will be the dramatic influx of applicants their systems must process. Many states have Medicaid eligibility levels that are quite low, with an average of roughly 32 percent of the FPL. With the elimination of the categorical limits, most adult parents in low-income families will be eligible for Medicaid. In addition to grappling with this dramatic expansion of Medicaid, states will need to provide new tax subsidies for individuals up to 400 percent of the FPL. These aspects of ACA implementation represent a significant change in how states have traditionally operated. States will need to adapt and develop new policies to manage coverage through the state health insurance exchanges, Weiss said.

The existence of different eligibility rules under Medicaid is going to create confusion. Some individuals newly eligible for Medicaid will be deemed eligible based on a new modified adjusted gross income (MAGI) standard.[2] Other individuals will have their eligibility determined according to their "point-in-time" income. Confusion will likely arise, as individuals will have to present their current income in some cases, but not in others. Adding to the complexity is the fact that the MAGI standard does not apply to individuals whose eligibility for Medicaid is based on disability or age. These individuals will have to provide additional documentation and go through a completely separate eligibility and enrollment process. These differences may pose challenges for both states and consumers.

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[2] The MAGI standard calculates income based on taxable income as defined by the Internal Revenue Service, and is the same methodology that will apply to eligibility for tax credits and subsides for the purchase of private health insurance.

The Need for Consumer Assistance

The state health insurance exchanges create a new marketplace for health insurance with new rules. Consumers will need assistance as they attempt to learn what types of health insurance they are eligible for and, when eligible, details regarding their financial responsibility, and how to enroll. Examples of questions that consumers will likely be asking include the following:

- How do tax subsidies work?
- How do I pay for my coverage?
- What is my share of the cost versus the federal government share? What is the reconciliation process at the end of the year and how does it apply to me?
- How do I select a health plan?
- What is an open enrollment period and how does it work?

In some cases the ACA requirements are in conflict with existing federal and state policy, Weiss said. For example, some states fingerprint individuals as they enroll in public programs. Such a requirement will be difficult to enforce if an online application is adopted. There are also rules related to medical child support where the federal government has to go through a process of trying to find the custodial parent and obtain reimbursement for health insurance coverage.

The adoption of assistive technologies is a key strategy to help consumers navigate through the complexities of program enrollment. Certain states have achieved some success. Utah, for example, communicates with beneficiaries through e-notices. Individuals who sign up for this service may receive an e-mail or text message that says, “You are now eligible for benefits,” or “Your benefits have changed,” or “We need your new address.” Utah has also implemented an online chat system, where individuals can ask questions about benefits and receive answers in real time. Mobile applications hold promise. Passengers transiting through the Chicago-O’Hare airport can download an application for a smartphone that can help them navigate through the airport. States will need to consider how to use these technologies in the context of health insurance enrollment.

A number of states have adopted a focus on improving the interface between the customer and the health insurance options. For example, Massachusetts, Utah, and Wisconsin have systems that allow individuals to make a plan selection, check their accounts, check their benefits, and follow transactions. Such systems allow individuals flexibility and a sense of ownership, Weiss said. Some states have experienced promising results with kiosks enabled with a translation function. The kiosks provide opportunities for communication with populations or individuals with low health literacy or limited English proficiency. In Alabama, individuals have access to kiosks that provide audiovisual assistance. The kiosks have improved service at eligibility offices experiencing long lines and wait times, as well as improving communication capacity. However, some individuals using the kiosk need assistance.

The ACA includes substantial funding to support independent consumer assistance/navigator programs. Of the 51 states and jurisdictions that were eligible for consumer assistance programs, 36 states applied for funding. A promising model that states are considering is one that provides community-based organizations some financial support for each complete and successful application that is submitted. Massachusetts has a help line that is run by a community-based organization, Health Care for All. The help line provides a continuous feedback loop on consumer complaints to the state's Medicaid program and its health insurance exchange. This program ensures that consumer voices are heard as the state implements its reforms.

States need to ensure that their programs are accessible to individuals with limited English proficiency, Weiss said. Providing adequate translation services may involve a contract with a translation company that has real-time translation capacity in multiple languages. States also need to ensure readability and audible access for populations with low literacy. States have made improvements by testing materials for readability and creating materials in multiple formats. Creating a national standard for educational materials would be of value and would obviate the need for each state to develop pamphlets and other materials. Training programs are also needed so enrollment workers are both culturally and linguistically appropriate for the populations served.

There are many opportunities to simplify and improve the consumer experience. Streamlining eligibility and enrollment policies will make a significant difference, Weiss said. Many states are attempting to rebrand health insurance coverage options so consumers do not necessarily associate state offerings with subsidized coverage (e.g., Medicaid, CHIP). Instead, the products are designed to be viewed as basic health insurance plans which vary by individual circumstances.

Weiss said that policies will be needed to minimize coverage gaps and facilitate transitions when eligibility changes. Some states have looked at automatic transfers of eligibility.

Promoting agency and worker culture change also is needed to enhance the consumer experience. Louisiana has had great success in this area. With culture change, the focus shifts from a gate-keeping function toward facilitating enrollment.

There are several examples of "roadside assistance" to aid states as they embark on the enrollment "superhighway":

- The California HealthCare Foundation UX 2014 Project is focused on improving the user experience and helping states and the federal government understand what consumers need and want. This project is developing a prototype to create a seamless, simple, and self-directed online experience. The prototype was expected in fall 2011.
- The CHIP Reauthorization Act increased its support for states to implement translation and interpretation services. This should allow states to implement and bolster such programs.
- The U.S. Department of Health and Human Services has a number of grants that are available to states:
    - Exchange planning/implementation grants
    - Early innovator grants
    - Medicaid Management Information Systems 90/10 federal matching assistance percentage (FMAP) for eligibility system upgrades
- Private organizations are working with consumers and stakeholders to help them both understand these new rules and create materials that will help them. For example, Community Voices for Coverage is working with advocacy organizations and helping them partner with states. Enroll America is working with stakeholder organizations to ensure that Americans know about coverage and are able to navigate systems to gain coverage.

Conclusions

Weiss concluded her presentations by pointing out that the ACA presents opportunities for transformative change in health insurance eligibility and enrollment, and the opportunity for consumers to engage in their health insurance coverage differently. She pointed out that state investment and leadership is going to be critical, as will a focus on creating assistance, accessibility, and simplicity. States, if they want to make meaningful progress, can avail themselves of existing and evolving resources.

LESSONS LEARNED FROM CURRENTLY OPERATING HEALTH EXCHANGES

Sabrina Corlette, J.D.
Georgetown University Health Policy Institute

The majority of people who obtain health insurance through their employers often do not have a choice of plan, or if they do have a choice, it is among a standard set of products offered by one company, Corlette said. For many individuals, the human resources (HR) departments of their employers make the decisions relating to health insurance options. HR departments also provide guidance to employees regarding their plan choices. Individuals who buy insurance on their own, or work for small businesses without large HR departments, do not have this kind of support. The state health insurance exchanges will, in some ways, play a role similar to that played by HR departments. That is, the exchanges will give consumers information about the benefits offered and cost sharing assumed under the plan options, and then empower consumers to make informed choices.

Corlette said that the underlying principle of state health insurance exchanges is that consumers, with appropriate information, can make value-oriented choices and coverage decisions that are right for their particular situations. In addition, it is assumed that exchanges will encourage insurance companies to compete on their ability to deliver care that is high-quality and efficient.

The Georgetown University Health Policy Institute recently completed a study looking at existing exchanges in Massachusetts and Utah (Corlette et al., 2011). In each state, the leadership of these systems is constantly striving to improve operations in order to make the exchange more responsive to the consumer. As part of the Georgetown study, these two exchanges were examined from a consumer and employer perspective in terms of:

- Choice and quality of coverage,
- Affordability of the coverage, and
- Ease of enrollment for consumers and employers.

Utah and Massachusetts are often identified as two divergent models that states can emulate as they implement their own exchanges, Corlette said. Utah is considered a free-market model where any health care insurer is allowed to participate, and consumers are afforded a very broad array of choices. The exchange helps consumers choose coverage that fits their particular situation. Conversely, the Massachusetts exchange is characterized by some as representing a regulatory model. It is more proactive in terms of setting minimum benefit levels, standardizing the benefit options, selectively contracting with plans, setting criteria and standards through its contracting process, and being selective about the plans that are allowed to participate.

The Georgetown study found that the features of these two exchanges are actually far more nuanced and complex than the usual stereotypes used to characterize them. For example, the Massachusetts exchange has been very open to including plans in the exchange and has actually tried to recruit plans to participate. Utah has made a number of regulatory changes to try to make its marketplace more hospitable to its exchange. Each state modifies its policies to make its exchange viable. The Georgetown study suggests that there are positive aspects of both models from which states can draw.

Utah and Massachusetts embarked on their exchanges with two very different visions, Corlette said. In Massachusetts, the exchange was created to be a tool to achieve universal, or near-universal, health insurance coverage. In contrast, Utah developed its exchange in response to a problem, that of small employers who were struggling to provide coverage to their employees. The goal of the Utah exchange was to make it easier for small employers to provide health insurance coverage. The Utah exchange wanted to improve the flow of information among plans, employers, brokers, and consumers. It used a defined contribution approach to give small employers more predictability in their cost exposure. In Massachusetts, the Connector Authority of Massachusetts takes a fairly active role in the marketplace. It selectively contracts and sets standards for participating plans. All plans must offer an essential benefit package to meet what is called the Connector Seal of Approval. Any participating plan must also be accredited by the National Committee for Quality Assurance (NCQA).

Massachusetts has made a significant investment in public education as well as one-on-one consumer assistance, Corlette said. Both a top-down and bottom-up approach have been used to publicize the program. Prominent Red Sox baseball players and other public personalities were engaged as part of a public relations education campaign to talk about access to coverage through the exchange and the shared responsibility people would have to purchase insurance under the Massachusetts Health Reform Law. The state also provided about $3.5 million annually for a "boots on the ground"–style campaign. A community-based organization, Health Care For All, responded to telephone calls about health insurance access and enrollment. Outreach workers at community health centers and other clinical access points were marshaled to go door-to-door in communities to provide information and help people enroll. These investments were critical to the huge expansion in coverage in Massachusetts through enrollment in the exchange.

In some states, community-based organizations charged with outreach, education, and enrollment assistance have come into conflict with private insurance brokers and agents. Competition between these groups was not much of an issue in Massachusetts, Corlette said, because in the individual market, which was the focus of the coverage expansion early on, brokers and agents did not play a large role. They were much more involved in the employer small group market.

Massachusetts fairly quickly started to standardize the benefit package and, in addition to setting minimum benefits, it defined certain benefits and cost-sharing arrangements. The state did extensive market research. According to this research, consumers found the level of choice available in the exchange to be overwhelming (Corlette et al., 2011). They wanted an easier, streamlined shopping experience. A benefit of standardizing the benefit choices was that it allowed people to make better "apples-to-apples" comparisons. It was, for example, easier to compare deductibles for hospitalizations and cost sharing for doctor's visits and lab tests. Allowing these apples-to-apples kind of comparisons narrowed the opportunity for health plans to compete based on risk selection or risk segmentation, and encouraged them to compete more on their ability to provide quality care more efficiently, Corlette said.

There are few similarities between the Utah exchange and what is envisioned in the ACA, Corlette said. Table 2-1 summarizes what the Utah health insurance exchange does and does not do. The Utah exchange will be required to change considerably under the ACA. Currently, it covers about 3,500 people, and they are all in the small group market. The Utah exchange does not cover individuals who are purchasing health insurance as individuals. It also does not extend to large groups, although such coverage has been under discussion.

The Utah exchange provides enrollees with a wide range of plan choices. For example, in 2010 it provided 146 different plan options for

TABLE 2-1 The Utah Health Exchange: What It Does and Does Not Do

The Utah Health Exchange Does:	The Utah Health Exchange Does Not:
• Cover approximately 3,500 enrollees • Provide enrollees with over 100 plan choices • Allow small employers to make defined contributions • Vary rates based on group experience and an individual's age, location, and family size	• Subsidize the purchase of coverage • Cover individuals or large groups • Set minimum benefit levels • Standardize benefit offerings

SOURCE: Corlette, 2011.

about 436 enrollees. The exchange enrollment has expanded, but it is not yet near the goal of 25,000 enrollees by the end of 2011.

In the traditional, small group market, employers were required to contribute at least 50 percent of the premium for their employees. The Utah exchange allows employers to set a defined contribution, such as $100 or $200, toward the cost of the insurance plan's premium. Employer contributions vary dramatically, Corlette said. Some employers are contributing very little, some are still contributing 50 percent (as previously required), and one employer is contributing 100 percent to the employees' premiums. The defined contribution can be considered a premium voucher that is given to the employee, who then makes the choice among the various plan offerings.

Utah's health insurance carriers are still allowed to underwrite their policies. Carriers rate the employer group based on its experience, and they also vary rates according to the individual employee's age, location, and family size. The ability to underwrite will be discontinued under the ACA when health plans will no longer be allowed to experience rate their policies.

There are no state subsidies for the Utah exchange. Unlike the ACA health insurance exchanges and the Massachusetts exchange, people are not getting subsidies to participate, Corlette said. While the carriers have to be licensed, the exchange does not set a minimum benefit standard or require accreditation. The Utah exchange uses "Plan Chooser" software to help people organize their choices, but, unlike Massachusetts, there has been no attempt to standardize the offerings from carriers.

One reason that enrollment in the Utah exchange has been fairly low relates to price. In some cases, employers in Utah found that prices were actually higher inside than outside the exchange. It is possible, Corlette said, that such price issues may be because carriers were responding to the uncertainty associated with an "employee choice" kind of approach, that is, an approach where people were able to choose a plan based on their particular circumstances. Some of the regulatory changes that Utah has made have been in response to these price differences.

The Utah exchange requires each individual employee to fill out a detailed questionnaire about his or her health history and the family's health status. This has been unpopular because it is burdensome, time consuming, and there is a fairly short time frame within which people have to enroll.

In a survey conducted by the Utah exchange in 2010 (Corlette et al., 2011), 55 percent of people reported that choosing a plan was not an easy process. Seventy-four percent needed the help of a broker or agent to complete the process. And many enrolled in a default plan that was the most similar to the one they had been in before.

The approach of handing people a check to cover at least some of their health insurance costs and then asking those people to shop for a plan using Plan Chooser software has not met expectations in Utah, Corlette said. People were still very dependent on their insurance brokers to make a decision. They often chose the default plan because it was the easiest choice to make. The ACA addresses many of the challenges observed in Utah by eliminating health status rating, providing subsidies, and requiring the display of coverage tiers, Corlette said.

In terms of policy lessons, Corlette indicated that the experience in Massachusetts suggests that the insurance exchange can be used as a mechanism to encourage more value-oriented purchasing. Plans with a lower cost structure have had a greater market share inside than outside the exchange. Blue Cross-Blue Shield of Massachusetts (BC/BS), a plan with high-quality products, has a higher price structure largely because it has a much broader network and relatively high marketing expenses. BC/BS has a lower market share inside than outside the exchange. In Massachusetts, Corlette said, consumers have the ability to shop with confidence. They know the plans offered on the exchange have NCQA star ratings and the exchange's seal of approval. Consumers are able to make apples-to-apples comparisons knowing that every plan on the exchange, even one without a well-known "brand name," is a quality plan.

Corlette concluded that to have a successful exchange, market research is critical. The exchanges must know what consumers want and what consumers are experiencing. If benefit designs are going to be standardized, exchanges have to offer consumers what they want, particularly in the small group market and for unsubsidized individuals who can vote with their feet. Public education and assistance are also critical, including one-on-one enrollment assistance, she said. Enrollment has to be simple. In Utah, the long, detailed health questionnaire and a fairly complicated enrollment process was a deterrent to a number of employers and employees.

Since the Georgetown study was completed, both the Massachusetts and Utah exchanges have made changes to try to improve the consumer experience. Massachusetts has added a provider search function so when consumers are comparing different plan options they can search and see whether their doctor is in the plan's network. Utah has simplified its questionnaire to make it easier and quicker to complete and then enroll. The Utah exchange has also added some helpful information, particularly for people participating in the nongroup market. These individuals would not be going through the exchange to obtain coverage, but they have access to relevant information about coverage options through the exchange.

DISCUSSION

Workshop moderator and roundtable chair George Isham observed that the health insurance exchanges in both Utah and Massachusetts were learning from their experiences and making changes. He asked Corlette if there are any requirements for the exchanges to focus on the customer experience and to have in place an improvement process that includes a report on their performance. Corlette responded that there is no requirement in the ACA for exchanges to conduct market surveys, focus groups, or to obtain any kind of feedback from consumers. They are, however, required to fund a navigator program. Navigators provide public education and outreach, and consumer assistance. Corlette said that although there is no specific requirement for exchanges to obtain feedback from consumers, she felt that if a state is invested in the success and sustainability of their exchange, it will invest in market research so it can be responsive to consumers. Unfortunately, such research is fairly resource intensive. Weiss added that in her discussion with states on their implementation efforts, exchange representatives stated they want their exchanges to be viable and attract consumers. They want to encourage healthy people, in addition to those who may have immediate health problems, to purchase coverage. There is, therefore, an incentive for states to understand their potential consumers and to conduct market research on an ongoing basis, Weiss said.

Benard Dreyer, roundtable member, raised the issue of the cognitive load that individuals face as they purchase insurance through health exchanges. He asked if there are ways to decrease this load to make it easier for individuals to make appropriate choices. Corlette suggested that states need to make sure their web interface with consumers is designed so individuals receive essential information easily and then are able to proceed through the system to obtain more information as desired. This “friendly” interface can be achieved through navigation panes and a layering of information. Plan-to-plan comparisons need to allow the consumer to easily judge plans on the basis of plan characteristics most relevant to them. Typically, when consumers make health insurance decisions, they are interested primarily in price, and then secondly in whether or not their doctor is in the plan’s network. One goal of the exchanges is to help consumers evaluate plans on the basis of value, and not just on the basis of price.

Will Ross, roundtable member, commented on the advantages of simplifying the process of determining eligibility for programs, and observed that a presumptive eligibility determination for Medicaid and CHIP coverage is likely an efficient mechanism. Given its efficiency, he asked Ms. Weiss why only 10 to 15 states have adopted presumptive eligibility.

Weiss said that presumptive eligibility is indeed efficient and is an option under the ACA. A provider who has been designated as a qualified provider by the state can classify an individual as presumptively eligible. These designated providers can temporarily assume that a patient is eligible for services, and then start the application process with the understanding that that individual will then complete the application process with the state. One of the key challenges facing states is that the qualified providers have an incentive to use presumptive eligibility as a way to get paid for services that would otherwise be unpaid because the individual was not enrolled in Medicaid or CHIP. In addition, providers may not have an incentive or opportunity to follow through on completing the applications.

In some states, Weiss said, presumptive eligibility has become emergency Medicaid. The state and the providers use this mechanism as a way to pay for services. Another issue has been the difficulty of processing an increased volume of incomplete applications. Some applicants are individuals who are transient or who are not able to provide reliable information. These applications pose an administrative burden. Under the ACA, presumptive eligibility may follow a slightly different model, Weiss said. That is, when a person walks in the door, he or she is presumed eligible for some coverage. The issue will be not whether someone is eligible, but rather for what coverage someone is eligible. States will need to streamline the enrollment process to get people into the system, obtain as much information as possible, and then have a default position of gaining access to a program. As the information is completed, the challenge will be to determine the appropriate payment structures, Weiss said. If an individual receives subsidized coverage and it is later determined that he or she is not eligible for the subsidy, the individual will have to pay back that subsidy. This amount can be substantial from the perspective of a low-income individual. The determination of presumptive eligibility is facilitated in a system that supports electronic records and communications.

Cindy Brach, roundtable member, asked Weiss for clarification on how an individual interacts with the state health insurance exchange to obtain health insurance coverage. Weiss said that the processes of eligibility determination and of plan enrollment through an exchange are different but related. The first step is determining eligibility for coverage and the type of coverage that eligibility confers. In many cases, states first screen individuals for their eligibility for Medicaid. After eligibility for either public or private insurance is determined, the second phase of the process is the choice of plan. Typically, if an individual is determined to be eligible for Medicaid, he or she has between 15 days to a month to select a health plan. If a choice is not made, a default plan is chosen for the beneficiary. Ideally, the eligibility and enrollment process could occur consecutively in real time. The Centers for Medicare and Medicaid Services

(CMS) is discussing the feasibility of a 15-minute eligibility determination and enrollment process. Much progress needs to be made to arrive at this ideal streamlined process from the status quo, Weiss said.

Corlette said that the proposed Department of Health and Human Services (HHS) regulation relating to exchanges leaves somewhat open the question of whether a consumer would need to navigate away from the state's exchange website. For example, a consumer who wanted to obtain a particular plan's summary of benefits form may need to navigate from the exchange website to a particular carrier's website.

Brach said that there is a parallel with Medicaid and Medicare Managed Care, because both populations have health literacy levels that are similar to those of the uninsured. These similarities were evident in the National Assessment of Adult Literacy. She asked Weiss if there are lessons learned from the experience of helping Medicaid and Medicare beneficiaries make plan choices that could be applicable to the exchanges. Weiss replied that states have applied different models in providing plan choices to beneficiaries. Some states only have a few choices, a Plan A or Plan B. States that offer more choices sometimes use an independent enrollment broker who serves some of the same functions as the navigators, that is, providing information about plan options and helping clients understand which choice may best suit their circumstances. Some states have had positive experiences with independent enrollment brokers. However, consumers need to be protected from any conflicts of interest and make plan choices freely and without coercion, Weiss said.

Brach pointed out that CMS's 2012 call letter to health plans indicated there will be a greater degree of standardization of the products that are offered to beneficiaries. Such standardization will help consumers make better comparisons and informed choices. There may have been evidence that plans were using benefit design to try to attract certain kinds of beneficiaries, and the call letter to plans addressed this issue as well. There are some good lessons to be learned from Part D and Part C in the Medicare program.

Ruth Parker, roundtable member, discussed a challenge that the roundtable has tried to address in the last 5 or 6 years: to transition from discussing the definitions of low health literacy and how many individuals can be enumerated as having low health literacy to focusing on organizations and asking how health literate they are in terms of what they ask people to do. How navigable is the system? How understandable is it? How actionable and how clear are the system requirements? In the recent roundtable meeting, where an overview of the ACA and opportunities within it were reviewed, some of the questions that arose were "How can health literacy be monitored and policed?" and "Where are the enforcement tools?" (IOM, 2011). In this context, the Plain Language Act of 2010 is relevant, Parker said. It has implications for communications from federal agencies, specifically CMS and the role CMS is playing in the states, the state exchanges, and the flow of funds that will come from the federal government to the state. Parker asked if there are any enforcement tools or "teeth" in the Plain Language Act mandate that information be in plain language that is accessible and usable.

Corlette pointed out that the ACA requires plans that participate in the exchanges to use a uniform enrollment form and a standard summary of benefits form. The National Association of Insurance Commissioners has been working with a multistakeholder group to develop consumer-friendly language. A readability expert has reviewed the materials, and further work is under way. HHS will issue a proposed rule relating to these standardized forms. The proposed rule that HHS recently issued on exchanges includes a requirement to use plain language as they develop their web portals.[3] The proposed rule allows considerable state flexibility and discretion; therefore, there may not be firm requirements related to plain language. Firm requirements could be built into the final regulation, Corlette said.

One audience member asked if a mechanism exists for sharing the findings from market research and program development across the states. Lessons learned from states as they develop training programs for navigators and materials for consumers would avoid duplication of effort on the part of states. Weiss replied that the National Academy for State Health Policy has developed a tool to help states share resources. States will be able to share both their experience with a vendor and the product of that experience so states can learn from one another. Other opportunities for sharing and peer learning are available through the early innovator grants. HHS has created these grants to provide seed money for states to implement exchange work. States with grants that achieve accelerated exchange implementation can serve as models for other states. The grant stipulates that grantees share products, materials, and tools. A website will be developed to facilitate the sharing of resources. HHS is also supporting a learning collaborative to address these types of issues. There should be several opportunities for learning and sharing among states, Weiss said. There are also opportunities for sharing best practices in the private sector. Enroll America (www.familiesusa.org) is a service for stakeholders that are participating with states to share materials and make them more broadly available. The resources needed to implement a successful exchange are intensive, and so it is imperative that states do not "reinvent the wheel."

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[3] HHS released the proposed rule on August 17. As this report is being prepared the comment period is still open so no final rule has been issued.

Dreyer asked Weiss what progress states were making in implementing the enrollment superhighway and whether there are any estimates of the cost of doing so. Weiss replied that the states are very actively engaged in implementation. She mentioned there is a great deal of political discussion and action at the state level with regards to the legitimacy and constitutionality of the reforms. However, states understand that until the federal law is successfully challenged, they must adhere to the law. Many states see the ACA as an opportunity to make desired changes to their systems. States of all political persuasions are moving forward with implementation. Weiss cautioned that states' capacities to implement reforms successfully are in question. Many states are proceeding as though success is an option and are trying to follow very closely the requirements in federal law. Weiss recounted her experience at a recent Robert Wood Johnson Foundation meeting. The foundation is intensively working on implementation with 10 states. The states are at different stages of development but are all committed to the goals of the ACA.

In terms of the costs associated with implementation, Weiss said they could be minimized by federal encouragement and support of cross-state sharing. The transition will be expensive, she said, especially if it is not completed efficiently and effectively. Some opportunities to minimize expenses may be lost because of the time pressure that states are under. Perhaps the most efficient way to proceed with implementation would be to have the federal government create a model and then allow states to access and adapt it, Weiss suggested. In some cases legacy eligibility systems that have been in place for almost 30 years need to be updated. This will be a costly investment for many states.

Sharon Barrett, roundtable member, asked Corlette about the role of the individuals who will be trying to explain the different insurance options to consumers. She asked about training and certification requirements to ensure that the information shared is correct and that communications with individuals of low literacy are treated with respect, allowing informed choice. Barrett raised concerns regarding the reliance on computers as aids to consumers. She pointed out that individuals with low health literacy are often not computer literate.

Corlette said the law requires states to set up navigator programs, funded through grants or contracts. The health insurance exchange would be able to provide outreach and consumer assistance and help people sign up for qualified plans. The law enumerates the duties of the navigators, but it does not specify the kind of training the navigator must have. The law says that the navigator has to show he or she has contacts with particular communities, such as people who are historically underserved. One model for a navigator program is in Massachusetts, where the community groups that were getting grants from the exchange were required to attend quarterly training sessions. States are also looking at licensing navigators as insurance brokers or agents, which would require them paying a fee and, in some cases, a more rigorous level of training. Insurance agents and brokers can also be navigators. However, if such a navigator were to be compensated by health insurance companies, concerns arise regarding potential conflicts of interest, Corlette said. A conflict would exist if there was a financial incentive for the navigator to steer an applicant to a certain plan instead of a plan that was best suited to the consumer.

Every state is looking at different ways to train navigators and ensure their neutrality, Corlette said. Navigators need to be trained in the various private insurance options as well as the federally supported programs such as Medicaid and CHIP. For the public programs, states have reached out to community organizations that serve as intermediaries on application assistance. States have provided such organizations with either up-front grants or reimbursement on a pay-as-you-go basis. In many cases states use a standard training protocol to train and certify an initial cohort. They then provide train-the-trainer opportunities. Corlette said there will be a steep learning curve for some who will be providing counseling regarding health insurance options. Medicaid eligibility workers need to be trained in private health insurance coverage because with the expansion of insurance options, they will need to know about the full range of products that are available. A standard training protocol is needed that goes through all of the insurance options so navigators are well versed and understand both public and private insurance options. In addition, performance standards training will have to be developed to specify how often navigators will have to be certified and what sort of oversight is needed to ensure they are following protocols and operating in a fair and reasonable manner. This is an area where a basic set of standards could be developed and adapted by states.

Brach asked Corlette and Weiss to discuss opportunities, within the navigator programs and elsewhere, to incorporate consideration of health literacy into the state health insurance exchanges. Brach said that states are overwhelmed with the task of launching these exchanges, especially with recruiting the plans and moving forward with exchange implementation. She expressed concerns that health literacy may not be a priority, and yet it is fundamental to getting people to enroll and choose suitable plans.

In terms of opportunities within the navigator programs, Corlette said that the National Association of Insurance Commissioners (NAIC) is discussing the feasibility of developing a model training certification program for navigators. This association represents the nation's state insurance commissioners who typically have the responsibility to license insurance agents and brokers. The NAIC could be approached regarding the need for training in health literacy. Another opportunity to ensure that health literacy is considered as the state exchanges are launched is in the area of rule-making at HHS. HHS is responsible for the traditional rules and regulations and, in addition, has what is called subregulatory guidance as well as one-on-one training opportunities with the states. The staff at the Center for Consumer Information and Insurance Oversight (CCIIO) could be approached about the need to incorporate health literacy and plain language considerations into the rules and regulations, the subregulatory guidance, and the one-on-one training with states.

Weiss said that under the ACA there is one section (section 1561) that deals with health information technology (HIT) eligibility and enrollment standards. A workgroup at the Office of the National Coordinator promulgated standards that have become the foundation for the HIT guidance from CMS and the CCIIO. These standards govern how states manage their HIT under ACA reforms. There is a provision that addresses accessibility and communication and includes specific information about populations with limited English proficiency. Weiss suggested that discussions be held with CMS and others about the need to consider the digital divide and issues around low literacy. States need to have standards and plans in place to accommodate individuals with low literacy skills.

Melissa Houston, an alternate to the roundtable, asked Corlette and Weiss about the development of performance standards and how the public will know if the exchanges have accomplished their goals. Corlette said that some accountability has been built into the law. HHS Secretary Sibelius must determine by January 1, 2013, whether a state exchange is ready to operate and is in compliance with federal standards. The HHS proposed rule suggests there will be flexibility in this requirement so states may be able to operate with a conditional compliance certification.

States are developing their exchanges with planning grants, Corlette said. Additional resources are available through 1-year establishment grants. To be eligible for establishment grants, states must meet certain requirements. So in some sense, the grant process provides a degree of accountability. The establishment grants will no longer be available after 2014. By 2015, the exchanges are to be self-sustaining. Corlette said there is little in terms of accountability once the grant program ends, except to the extent that if an exchange fails to meet the basic ACA requirements, the federal government can step in and run the state's exchange. It is unclear what capacity exists at the federal level to operate a state exchange.

Weiss added that the grant-making process, both for the early innovator grants and the exchange planning grants, has standardized processes in place to ensure that states meet certain obligations to receive additional support. There are gate reviews that must be successfully completed before the grantee can proceed to the next phase of a project. These grant review processes provide some degree of oversight and accountability in the short term. On an ongoing basis, there are standards that are written into the law. At issue is who within the administration will enforce these standards, and how enforcement will be operationalized, Weiss said. States will have a fair amount of oversight, just as they do under the Medicaid program.

Laura Shone, an audience member from the University of Rochester, asked if the state health insurance exchanges would help newly enrolled consumers understand how to use their benefits. Many people entering the insurance systems will lack experience accessing care and understanding their coverage. Corlette said that state exchanges have some discretion in how they set up their consumer assistance function. The exchanges are supposed to have a mechanism for handling consumer complaints and referring people to appropriate state agencies or services when problems are found. The exchanges will not be duplicative of health plan consumer call centers. The ACA requires health plans to have an internal and external appeals process to handle complaints. Corlette said that while these mechanisms exist, it is unclear at this stage how much of this consumer assistance function will be done within the exchange, by a state department of insurance, or other state agency. Some issues could be handled by an external appeals process, such as through an insurance company or employer-based plan.

Shone asked if consumers would be assisted in navigating the health care system. This could involve helping people understand the role of a primary care doctor and how to optimize interactions with providers. She said "People don't know what they don't know," and a helpline has limited utility in helping people make their way through a complex health care system. Studies of the Medicaid and CHIP programs indicate that the major reason families do not reenroll in CHIP is that the reenrollment process is confusing, Shone said. This is counterintuitive insofar as the program should be a familiar one. Shone expressed concern that there is an underestimation of how difficult and intimidating engaging in health care can be.

Corlette agreed with Shone's observation and said that in Massachusetts, reenrollment was much more difficult for consumers when they went through the exchange, in part because their initial enrollment was through a health clinic or hospital. Aside from the navigator program, Corlette said that there is no particular requirement in the ACA that exchanges provide ongoing, hands-on assistance, once enrolled.

Rima Rudd from the Harvard School of Public Health discussed the importance of reports that document the progress of states in meeting their ACA obligations. It is especially important for evaluative studies to include well-specified criteria, she said. Criteria that are used to gauge progress in a study may be adopted as benchmarks that are internalized within organizations or plans. These criteria could relate to aspects of navigation, to reenrollment, or to ease of reading and literacy-related issues.

Isham concluded the session by highlighting some of the points made during the discussion period, including

- The need to acknowledge the cognitive load facing consumers as they make complex choices through health insurance exchanges;
- The applicability of the Plain Language Act to the operations of the exchanges;
- The importance of meeting the needs of the diverse populations seeking assistance through the exchanges;
- The importance of transparency and ensuring accountability of the exchanges in terms of their customer performance; and
- The necessity of learning from government programs that have experience and have succeeded in helping customers, such as Medicare beneficiaries learning of their insurance options.

REFERENCES

Corlette, S. 2011. *Lessons learned from currently operating health exchanges*. PowerPoint presentation at the Institute of Medicine Workshop on Facilitating State Health Exchange Communication Through the Use of Health Literate Practices. Washington, DC.

Corlette, S., J. Alker, J. Touschner, and J. Volk. 2011. *The Massachusetts and Utah health insurance exchanges: Lessons learned*. Washington, DC. http://ihcrp.georgetown.edu/pdfs/Mass%20Utah%20Exchanges%20Lessons%20Learned.pdf.

IOM (Institute of Medicine). 2011. *Health literacy implications for health care reform: Workshop summary*. Washington, DC: The National Academies Press.

Sommers, B. D., and S. Rosenbaum. 2011. Issues in health reform: How changes in eligibility may move millions back and forth between Medicaid and insurance exchanges. *Health Affairs* 30(2):1-9.

Weiss, A. M., and L. Grossman. 2011. *Paving an enrollment superhighway: Bridging state gaps between 2014 and today*. Washington, DC: National Academy for State Health Policy.

3

State Insurance Exchanges' Impact on Consumers

HOW CONSUMERS SHOP FOR HEALTH INSURANCE: LESSONS FOR EXCHANGE DESIGNERS

Lynn Quincy, Senior Health Policy Analyst
Consumers Union

State health insurance exchanges carry out several tasks: they certify health plans, provide outreach to consumers, conduct eligibility determinations, describe health plan choices to consumers, and enroll and disenroll beneficiaries. Quincy said that exchange designers must start with a nuanced understanding of how consumers shop for health insurance to successfully attract consumers, manage their expectations, and allow them to make a meaningful choice among health plan options.

According to three studies conducted by Consumers Union, the image of a careful shopper who is capable of weighing the myriad costs and benefits associated with their health insurance options must be abandoned (Consumers Union and People Talk Research, 2010; Kleimann Group and Consumers Union, 2011a,b). Table 3-1 provides an overview of these studies. The first two studies examined different components of a health insurance disclosure form developed by the National Association of Insurance Commissioners (NAIC). As required by the Affordable Care Act (ACA), the form must be used by the exchanges and all plans (e.g., grandfathered plans, nongrandfathered plans, individually purchased plans, group plans). A third study was conducted, independently of the NAIC work, to assess how consumers respond to actuarial value concepts.

TABLE 3-1 Three Consumer's Union Studies of Consumer Health Insurance Shopping Behavior

Study examined	Study date	States where study was conducted (midsized cities)
Pages 1–4 of new health insurance disclosure form	Sept.–Oct. 2010	Iowa, New Hampshire, California, Ohio
"Coverage facts" label (pages 5–6)	May 2011	Missouri, New York
Actuarial value concepts	May 2011	Colorado, Maryland

SOURCE: Quincy, 2011.

Participants of the three studies were evenly divided between men and women, as well as individuals who were uninsured and insured (with nongroup coverage). Participants represented a variety of education levels, ages (26 to 64), race and ethnic backgrounds, and familiarity with health insurance. The testing sessions were held in 2010 and 2011.

According to the studies, consumers dread shopping for health insurance. This became clear as the researchers engaged consumers in simulated shopping exercises. Quincy reported that one participant became so anxious that he almost left upon learning that the focus group session related to health insurance. One focus group participated stated "I think medical insurance is probably one of the hardest things for me that I shop for. And I think it's one of the hardest things to figure out what's covered" (Consumers Union and People Talk Research, 2010).

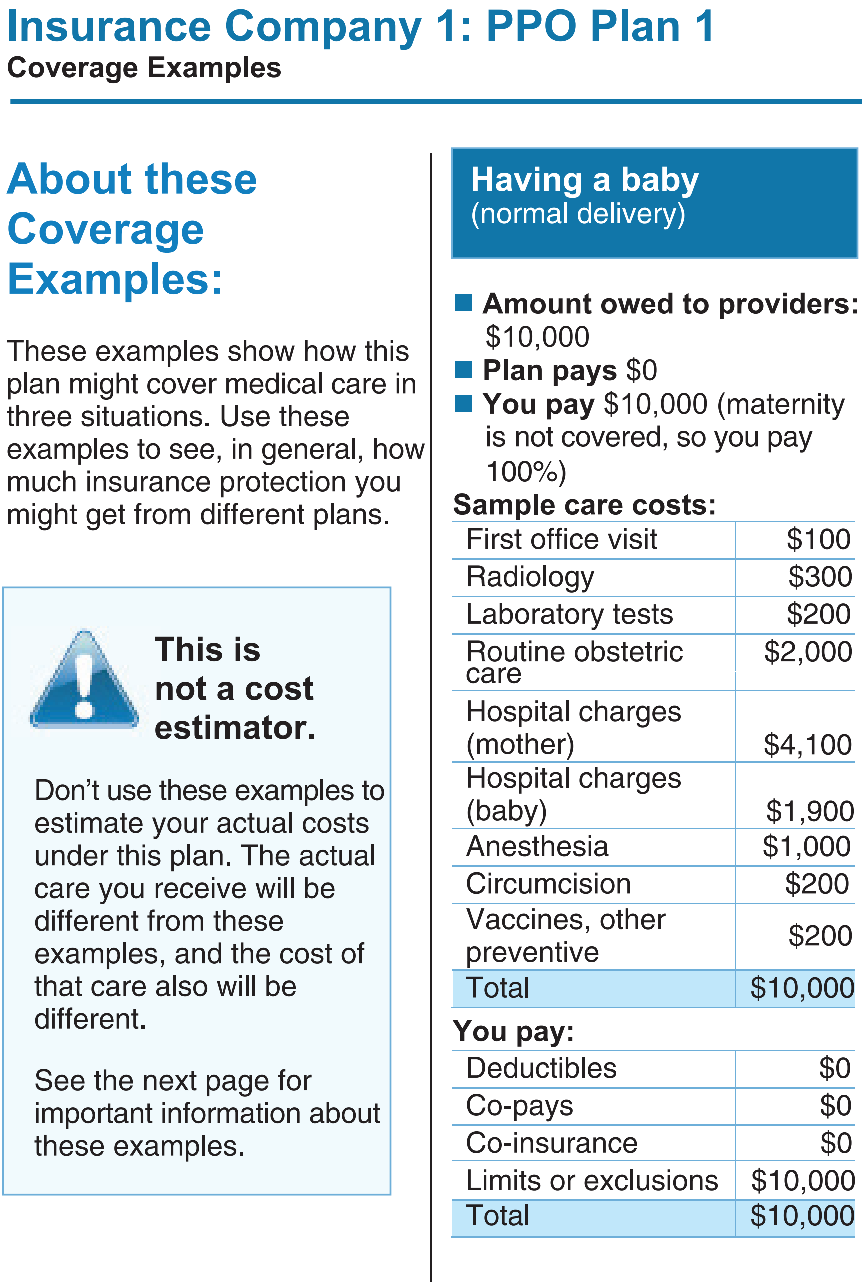
The implications for exchange designers is they have to increase the appeal of shopping for health insurance through the exchange and they have to minimize the aspects of the experience that cause dread, Quincy said.

Another finding from the research is that many consumers doubt the value, or question the purpose, of health insurance. Many view health insurance as prepaid health care rather than health insurance. If the anticipated annual out-of-pocket expenses for health care are less than the cost of insurance premiums and the plan deductible, consumers often feel that insurance is not a good value. The critical concept that is missing is that insurance protects individuals and families from *unexpected* health crises. Many consumers do not understand this basic principle of insurance, Quincy said. This finding suggests that the exchanges will need to provide health insurance education. Consumers will not be in a position to choose a plan if they do not understand the basic value and purpose of health insurance. Health insurance education will have to be provided in a compelling, multilayered, just-in-time approach. To reduce cognitive burden, the information can be parceled out in manageable bites. A valuable teaching tool evident in the research is showing consumers how much a health plan would pay for a very serious illness. This allowed consumers to appreciate the value of health insurance.

Page 5 of the Health Insurance Disclosure Form is shown in Figure 3-1. This page conveys information on costs for some medical scenarios. This page shows how much of the claim is paid by the insurer and how much is paid by the consumer. Consumers found these scenarios very informative, Quincy said. Many study subjects had no idea how much medical care costs. Individuals could identify with the scenarios (e.g., "I might get breast cancer"), and the plan payment amounts allowed consumers to judge the extent of coverage and compare the value of the plans. The research demonstrated that consumers care very much about value. Consumers' notion of value is sophisticated, Quincy said. It encompasses the scope of services covered, the share of the cost paid by the plan, and the quality of the providers that are available within the plan. Consumers do not want the lowest-cost plan; they want the best-value plan they can afford. However, figuring out the "value" of any given health plan is a challenge for consumers. One barrier to understanding value is confusion over cost-sharing terms. Consumers may have heard the term *deductible*, but many do not know what it means. Other terms that are unfamiliar or misunderstood include *co-insurance*, *benefit maximum*, *allowed amount*, and *out-of-pocket maximum*. This difficulty is not surprising. The underlying concepts are complex, and they must be used together to estimate patient costs for services (e.g., do co-payments count toward the deductible? the out-of-pocket maximum?).

Quincy highlighted the challenges associated with health insurance jargon and the need to make the underlying concepts understandable. She acknowledged that plain language considerations are important but insufficient. For example, a consumer may need to understand not only what a co-payment is but also whether it counts toward the deductible. This is a different exercise than simply understanding the meaning of *co-payment* and *deductible*. There is much work to be done to provide consumers with language substitutes for the common health insurance terms that are in use, Quincy said.

The computations that consumers must undertake to assess a plan's value are enormously complicated. Many consumers do not have the skills, health insurance familiarity, and confidence needed to calculate their share of costs. Medical terms are also confusing, Quincy said. According to the consumer research, individuals do not fully understand the difference between primary and preventive care. Other unfamiliar terms include specialty drugs and deciphering the difference between



Insurance Company 1: PPO Plan 1

Coverage Examples

About these Coverage Examples:

These examples show how this plan might cover medical care in three situations. Use these examples to see, in general, how much insurance protection you might get from different plans.

This is not a cost estimator.

Don’t use these examples to estimate your actual costs under this plan. The actual care you receive will be different from these examples, and the cost of that care also will be different.

See the next page for important information about these examples.

Having a baby
(normal delivery)

- **Amount owed to providers:** $10,000
- **Plan pays** $0
- **You pay** $10,000 (maternity is not covered, so you pay 100%)

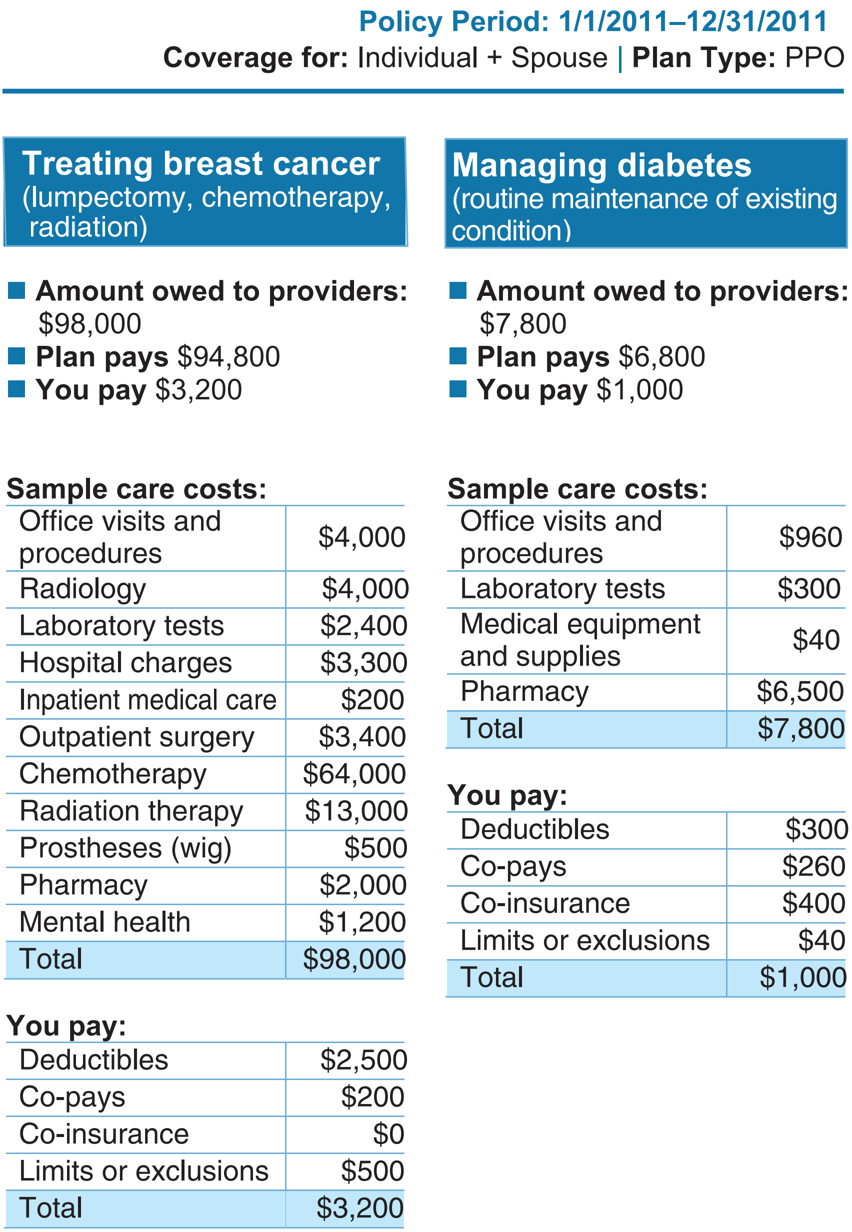
Sample care costs:

First office visit	$100
Radiology	$300
Laboratory tests	$200
Routine obstetric care	$2,000
Hospital charges (mother)	$4,100
Hospital charges (baby)	$1,900
Anesthesia	$1,000
Circumcision	$200
Vaccines, other preventive	$200
Total	$10,000

You pay:

Deductibles	$0
Co-pays	$0
Co-insurance	$0
Limits or exclusions	$10,000
Total	$10,000

FIGURE 3-1 Coverage examples.
SOURCE: http://www.naic.org/documents/committees_b_consumer_information_hhs_dol_submission_1107_soc_populated.pdf.



Policy Period: 1/1/2011–12/31/2011

Coverage for: Individual + Spouse | **Plan Type:** PPO

Treating breast cancer
(lumpectomy, chemotherapy, radiation)

- **Amount owed to providers:** $98,000
- **Plan pays** $94,800
- **You pay** $3,200

Sample care costs:

Office visits and procedures	$4,000
Radiology	$4,000
Laboratory tests	$2,400
Hospital charges	$3,300
Inpatient medical care	$200
Outpatient surgery	$3,400
Chemotherapy	$64,000
Radiation therapy	$13,000
Prostheses (wig)	$500
Pharmacy	$2,000
Mental health	$1,200
Total	$98,000

You pay:

Deductibles	$2,500
Co-pays	$200
Co-insurance	$0
Limits or exclusions	$500
Total	$3,200

Managing diabetes
(routine maintenance of existing condition)

- **Amount owed to providers:** $7,800
- **Plan pays** $6,800
- **You pay** $1,000

Sample care costs:

Office visits and procedures	$960
Laboratory tests	$300
Medical equipment and supplies	$40
Pharmacy	$6,500
Total	$7,800

You pay:

Deductibles	$300
Co-pays	$260
Co-insurance	$400
Limits or exclusions	$40
Total	$1,000

diagnostic tests and screening tests. When such tests are reimbursed differently, it is important to understand this distinction.

In terms of the implications for exchange designers, it is clear that the cognitive load will be considerable for many consumers. When the cognitive load is too great, individuals will use *cognitive shortcuts* to get through the task of shopping for coverage. Exchange designers need to understand and take charge of these shortcuts, Quincy said. The consumer's shortcuts might take the form of, "Well, Blue Cross/Blue Shield—I've heard of them. I'm going to select that plan." Or, "I'm not going to make a choice, it's too hard. I'm just going to let them reenroll me in the plan I was in last year." Or, "I'm going to ask my neighbor what she is in, and I'll enroll in that plan."

State insurance exchanges could instead provide cognitive shortcuts to consumers that are vetted and provide meaningful help with their health insurance shopping. One mechanism contemplated by the ACA is the provision of actuarial value tiers. These preset tiers (platinum, gold, bronze, and silver) allow consumers to see the relative value of their health plan choices. Another shortcut would be an understandable measure of network adequacy. The Coverage Facts Label shown in Figure 3-1 is an example of a shortcut. It allows consumers to quickly compare plans and see what they would pay for a standardized medical scenario.

Quincy said that consumers need a mental map to navigate a complex topic like health insurance. If this map or framework is missing, decision aids such as glossaries or well-designed disclosure forms can do little to help consumers—there is nothing to which they can attach the information. Consumers without a framework need to be provided with one. Without an accurate "map" of how insurance works and what its purpose is, consumers may make incorrect assumptions. Many individuals use their prior experience with health insurance as a framework. For example, an individual might say, "Well, in my last plan, co-payments counted toward the deductible so I assume it works this way." Or, someone who previously had employer coverage, which almost always covers maternity, purchased a plan on her own without realizing that maternity wasn't included . . . and then became pregnant.

If individuals do not have prior experience with health insurance, they may use the experience they have with other types of insurance, Quincy said. For example, with automobile insurance, individuals pay a deductible every time the car is repaired. Some testing participants assumed that health insurance deductibles worked the same way, meaning it had to be paid every time you become ill, not once a year.

Quincy said that information that is provided about health insurance must be from a trusted source. If consumers do not trust information, they will not use it. Trust levels are very low for health insurers. Even when consumers have a good grasp of the information in front of them, they often do not trust their analyses. They worry about the "fine print" because health insurers are "tricky."

State health insurance exchanges need to cultivate an image as a trusted source of information, Quincy said. It is very important for exchanges to manage consumer expectations and to not oversell what they can do for consumers. If there are unmet expectations, it will take many years to overcome the negative perception. Exchanges might want to partner with a trusted entity, preferably a local organization, to build trust in the health plan information provided. More importantly, the exchanges and the health plans operating inside of them have to merit consumer trust. To do so, they will have to vet health plans well, strive for stability in offerings, invest in good communications, test communications with consumers, and engage in these activities over the long run.

There is substantial consumer decision-making research to support the notion that consumers need a manageable number of choices, Quincy said. Given the cognitive difficulty of evaluating their choices, consumers do not want an unlimited number of health insurance choices. Quincy said that if an exchange did everything right—if the products were clearly described, assistance were provided, consumers had a mental map, the products were trusted—and it gave consumers 100 choices, the process would be a failure because consumers cannot manage that many choices. A better strategy is to offer consumers a manageable number of "good" (vetted) choices. Consumer testing in Massachusetts led that exchange to reduce the number of choices from 27 to 9.

To ease the cognitive burden, it is advisable to reduce the number of features that can vary between plans to make them easier to compare. The ACA standardizes some aspects of benefit design, but exchanges should consider additional standardization as they gain experience with consumers use of the exchange.

Based on these consumer testing results, as well as the enrollment experience of many coverage programs, it is clear that some consumers will also need one-on-one assistance choosing a health plan and understanding the implications of their choice, Quincy said. Navigators can facilitate consumer understanding, but exchanges should arm the navigators with consumer-tested tools and decision aids.

Quincy concluded her presentation with a number of recommendations for consideration:

- Craft a widely accepted definition of health insurance literacy and develop a tool for measuring health insurance literacy in consumers.

- Develop standards for products that go beyond plain language standards and address all aspects of health insurance literacy.
- Rigorously test all products that interface with the consumer, and engage in continuous monitoring of consumer reactions to their exchange experience.
- Establish strong marketing rules for insurers inside and outside the exchange, so consumer confusion is not exploited.

THE CHALLENGE OF HEALTH INSURANCE LANGUAGE OR COMMUNICATION WITH VULNERABLE POPULATIONS

Yolanda Partida, M.S.W., D.P.A.
Hablamos Juntos

Understanding how language works is important to effective communication about health insurance options, Partida said. Language is a system of arbitrary signals. Thoughts and feelings are communicated through voice sounds, gestures, or writing symbols. Individuals interpret information in some context and draw upon signals that are part of discourse (the environment, setting, and nonverbal gestures) to infer meaning. A language of a nation, people, or other distinct community is a unique and shared system of rules for combining its components such as words and gestures. A dialect is a language shared by members of a group, jargon specific to a domain (e.g., the dialect of science), an occupation, or region (American Heritage, 2009).

Partida said that it is generally accepted that language is acquired and learned over time through social interactions, experiences, and formal and informal education. In a sense, language is a window on how the human mind works. Mental and social constructs are embedded in language to describe thoughts, interpret meaning, and interact with others (Gasser, 2006). Some suggest that the acquisition of language is instinctual and that the evolution of the human brain has resulted in an innate ability to organize and recall words and concepts (Pinker, 1994). Other scholars posit that the units of language (elements of form, words, grammatical patterns, conventions of usage) are in some sense also units of cognition. Linguists and cognitive scientists contend that language influences how people think and view the world around them. Moreover, language is constantly changing to reflect new and evolving social and cultural realities. New words and terms such as *Googling* and *wiki-like* and *health insurance exchanges* become incorporated into the lexicon.

Language reflects our lived experience and environment, Partida said. Where a person lives gives form to a defined culture and view of the world that serves as platform for interpersonal interactions that is drawn upon to create order and understanding. Entering a new setting or environment can be disorienting or can test the limits of our ability to infer meaning. Partida recalled her first day on the job as a medical social worker walking into a neonatal intensive care unit. Though this environment was familiar and routine to the staff who worked there, it presented a cultural shock to Partida. She pointed out that we become acclimated to environments in which we live and work. Our daily experiences inform how we see and understand these environments and more broadly, the world around us. Soon, our language, the words we use, and how we interpret or make sense of events, is shaped by what we have come to know and what we have experienced. Moreover, it is natural to assume that others see the world as we do.

Immigration, leaving our birth country to live in a new country, can dramatically change our lived experience, Partida said. It is not hard to imagine how geographic relocation can lead to vastly different lived experiences. The children of immigrants come to know about the old country through their parents and communities of immigrants from the same country. New foods, clothing items, and other goods and products become part of these newly changed environments. Local conditions and community response to changing demographics influence how local health care delivery systems and insurance products are viewed by newcomers—either as helpful resources or difficult challenges to be avoided.

Overcoming language differences is critical to integration and economic success for both new arrivals and their new chosen communities, Partida said. How language is learned influences competencies. Many U.S. immigrants are *heritage speakers*. These are primarily second-generation immigrants, primarily children who learn the language of their parents at home and then learn English as they go to school. This way of acquiring a new language is different than learning a foreign language through formal study, where an individual chooses to study the language. With formal language training, a teacher is available to explain the new language's structure and rules. Heritage speakers have to learn these aspects of the language on their own. With the lack of formal training, heritage speakers can exhibit wide variations in their level of language comprehension. More important, independent language learning can result in poor English mastery, language adaptations, and language mixing. Using English and Spanish within the same sentence and blending of English and Spanish to create new words is characteristic of heritage speakers. So much so that blended words such as *lonche* (lunch), *dompe* (dump), and *yonke* (junk) are commonly used and have become incorporated in the lexicon of bilingual and bicultural communities in the United States.

Another form of language acquisition is second language learning, which takes place when an individual is in a different country where another language is spoken. Second language learning is usually informal, resulting in variable levels of proficiency and little or no written skills, Partida said. Vocabulary and speech may be adapted to include everyday language or specialized language, such as language related to medical care or health insurance.

Nearly 70 percent of Spanish speakers in the United States speak Mexican Spanish. Spanish is the primary language of 22 countries; however, the Spanish spoken in Spain differs from that spoken in the Caribbean, Mexico, and Central and South America. Spanish may also be distinct for heritage speakers who learn Spanish in an English-speaking context. The way Spanish is spoken by heritage speakers who learn Spanish in an English-speaking context is also distinct. Some contend that the grandchildren of today's new immigrants will hardly speak the language of their ancestors.

Each language is different, with unique features that require special consideration, Partida said. The lessons learned from translating Spanish to English may not be at all applicable when translating another language into English. For Spanish, because of a high risk for poor first language mastery and rate of attrition, language development history is an important consideration in soliciting opinions about translated materials. For Chinese, there are five regional languages that are spoken (Cantonese and Mandarin are the most well known) and there are two writing systems, simplified and traditional. Simplified Chinese is based mostly on cursive (*caoshu*) forms embodying graphic or phonetic simplifications of the traditional forms. This simplified form is popular and has been promoted to improve literacy. It is officially used in the People's Republic of China (Mainland China), Singapore, Malaysia, and at the United Nations. The graphic traditional writing form used in printed text for over a thousand years are used in the Republic of China (Taiwan), Hong Kong, and Macau. Overseas Chinese communities typically use the traditional characters, but simplified characters are gradually gaining popularity among mainland Chinese emigrants. When translating or designing written materials, the language and communication practices of the target population need to be understood. For Chinese populations, regions of origin can help determine the best writing style to use, Partida said.

Partida pointed out that health communication often contains vocabulary associated with specialized domains of knowledge, such as medicine, biology, physics, and insurance products and practices. Even when there is a shared language and culture between providers and the population they serve, domain knowledge and associated language may interfere with effective communication. The lexicon of medical professionals includes vocabulary and concepts associated with anatomy, physiology, and other science-based fields. Those seeking health care are more likely to draw upon informal or experience-based knowledge of the human body and to use general language to describe symptoms such as pain. They may not know the names of internal organs and what they do, nor really understand how the human body works, nor have meaningful or shared vocabulary to differentiate one kind of pain from another.

Differences in domain knowledge can be as significant as cultural and language differences, Partida said. Insurance and medical language include common vocabulary to represent activities or responsibilities tightly fitted into business practices (e.g., single limit, endorsement, deductible, coverage maximums) that are often poorly understood as intended by those outside these fields. Key concepts and specialized meaning assigned to industry terms (e.g., *enroll, coverage, single limit*) may need to be taught to new members and understanding may need to be verified, perhaps using techniques such as the teach-back method.

Health organizations face several challenges in acquiring health materials in languages other than English. On the whole, the industry relies on translation of materials developed for English audiences. Translation quality research suggests that novice and/or untrained translators often adopt a literal, linguistic, micro-approach to the translation task, and become a source of poor-quality translations. Moreover, the underlying communicative objective of written materials (text) may not be overtly visible. The overall design and layout of written materials influence how a text conveys meaning. But without explicit guidance about the communicative objective (the purpose to be served by a text and how it is to be used), the objective may not be apparent to even highly trained translators (Colina, 1997, 1999). Understanding the art and practice of translation is essential for quality translations. For example, specialized terms (product or program names, destinations within a facility) may be literally translated if the intended use and meaning are not made clear.

Translators, the language professionals who take these jobs, vary in their language skills, Partida said. The highly specialized nature of health insurance language, often framed in contractual terms, represents significant challenges, even for translators with advanced training. Without guidance, translations of highly specialized content are likely to produce severely more opaque or misleading materials. The reason is basic: language and culture are intertwined. Health insurance language is part of a larger system of health practice, health policy, and payment structures. Translating words independent of the larger system is like writing without context. Even translation professionals with advanced training are likely to produce translations with high variability in how industry terms are translated. Useful translations will require reinterpretation of content in the cultural context, language, and value set of the new intended reader. This should not be done by translators in a vacuum.

Experienced and well-trained language professionals, translators, and interpreters also pay attention to language patterns common to first languages spoken within an English context. Over time, the language use of immigrants is likely to reflect living and working in English-dominate society. Much formal language used in health encounters and health insurance materials reflect the nation's practices and policies.

Many translated materials tend to retain English language structure, and easily available machine translation programs such as Google's translation software render literal translations. The range of translation software has expanded in recent years, and many show vast improvements, but none replace the need for a critically thinking language professional with advanced knowledge in the pair language (e.g., English–Spanish, English–Simplified Chinese), Partida said. Another barrier to translation quality is a steady decline in understanding the differences in language structure.

Language is constantly evolving and adapting to broader sociocultural changes in the environment. The Spanish spoken in the United States reflects socioeconomic conditions and health care practices, Partida said. Translators, particularly those living and working in other countries, may not understand the context in which translated materials will be used and the business practices associated with a market-driven health care system. Dictionaries may be useful for some health system language, but some practices have no equivalent in the Spanish lexicon. The quality of a translation may be difficult to judge, and translation of industry vocabulary may be highly variable from one translator to another, and even from one document to another provided by the same health care provider. Variability in how industry terms and practices are translated increases the comprehension challenge for users of translated materials and can be avoided with industry adoption of translation standards.

Partida discussed a Spanish glossary developed through Hablamos Juntos. The project produced an Excel database with recommended standards for translating 237 difficult-to-translate health plan industry terms for the Los Angeles (L.A.) Care Health Plan, a plan serving residents of Los Angeles County. L.A. Care Health Plan and partner health plans expressed long-standing concerns over translation quality and with inconsistencies in translations among the translation vendors they contracted with. California Health and Safety Code (section 1367.04) requires health plans to assess the linguistic needs of their members and to provide for translation and interpretation for populations meeting specified thresholds. For L.A. Care Health Plan this meant translating health plan materials into 10 languages.[1] At the time, there was an expected change advocated by health plans with the potential to reduce this to five languages. Hablamos Juntos produced three glossaries of terms—one in Spanish, one in simplified Chinese, and another in traditional Chinese—that are the property of L.A. Care Health Plan. The glossary consists of the 237 health plan terms, their definitions, parts of speech, and a recommended translation standard. Additional notes and comments were provided on factors influencing the use of the recommended translation and dealing with unique populations, for example, by providing low literacy options for terms.

To develop the glossaries, the team first collected seven samples of translations from translation agencies contracted by the health plan. The data collection tool provided a definition and part of speech for each term. Terms for which there were inconsistent translations were categorized. Focus groups were held with academic linguists and translators with advanced Spanish language education and extensive experience translating Spanish materials. The objective of the focus groups was to test recommendations for translation conventions to promote consistent or uniform translations of English terms common in health coverage and eligibility materials. The focus group discussions examined several categories of problematic terms and ways these could be handled in translations. Among these were acronyms (not commonly used in the Spanish language) and translation of titles and program names. At the conclusion of the focus groups, participants were asked to submit recommendations for the best way to translate terms with inconsistent translations collected from L.A. Care Health Plan translators. The results of the focus group discussions and an examination of the frequency of use of various terms helped the team discern patterns in the use of terms.

Variation in the translation of professional titles and program or agency names, such as *Federally Qualified Health Center (FQHC)* and *health maintenance organization (HMO),* and frequent use of acronyms in translations are sources of confusion for consumers. The recommendations proposed translating the words represented by the acronym early in the document and where possible including a description of what the acronym represented.

The team also identified a considerable amount of inconsistency in the use of certain health insurance terms. For example, the following terms

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[1] CAL. HSC. CODE § 1367.04 subparagraph (A) of paragraph (1):(i) A health care service plan with an enrollment of 1,000,000 or more shall translate vital documents into the top two languages other than English as determined by the needs assessment as required by this subdivision and any additional languages when 0.75 percent or 15,000 of the enrollee population, whichever number is less.

were used inconsistently to describe the disclosure form used by health plans:

- *Combined Evidence of Coverage/Disclosure Form*
- *Evidence of Coverage (EOC) and Disclosure Information Form*
- *Evidence of Coverage and Disclosure Form (EOC)*

The team recommended that terms be used consistently in English source documents and that the database be used to track language changes as they occur to prompt discussion and standards for how historical terminology should be handled in future translations and renewed printings of translations.

Translation problems also arise with naming conventions that are produced through legislation and policy changes. The team found inconsistent use of program names (Box 3-1) and recommended standard terms.

Many terms used as part of the Medicare program are difficult to understand in English (Box 3-2). Their translation into another language does not inform consumers. The presentation of Medicare products needs to go beyond translation.

Terms used to describe processes, such as completing an advanced directive, disenrollment, and disputed health care services, also need to be described and then translated, Partida said. This also applies to other terms that need to be put into easy to understand language, such as preferred provider organization (PPO) plan, primary care physician (PCP),

BOX 3-1
Examples of Inconsistently Used Program Names in Health Plan Materials

- State Department of Health Services (SDHS)/California Department of Health Care Services (CDHCS)
- California Department of Managed Health Care (DMHC)
- California Children's Services (CCS)/California Children Services Program (CCS)
- Medicare Advantage (MA) Plan, also referred to as Medicare Part C or simply Part C
- Healthy Families/Healthy Families Program
- Healthy Kids (State Children's Health Insurance Program [SCHIP])

SOURCE: Partida, 2011.

BOX 3-2
Difficult-to-Understand Medicare Program Components (English)

- Part A covers inpatient care in skilled nursing facilities, critical access hospitals, hospitals, hospice, and home health care (hospital insurance, rarely referenced as Part A, also known as "original" or "traditional" Medicare). The payment method is also sometimes seen in the title "Fee-for-Service" Medicare.
- Part B is medical insurance to pay for medically necessary services and supplies provided by Medicare. Most require a premium. Covers outpatient care, doctor's services, physical therapy or occupational therapy, and additional home health care.
- Part C is the combination of Part A and Part B. The main difference is that it is provided through private insurance companies approved by Medicare.
- Part D is stand-alone prescription drug coverage insurance. Most people do have to pay a premium for this coverage. Plans vary and cover different drugs, but all medically necessary drugs are covered.

SOURCE: Partida, 2011.

and primary care provider (PCP doctor). When a term is selected for use by a health plan, it is essential that the term be used consistently.

Other terms raise broader questions. For example, is it necessary to adopt and translate legislatively negotiated descriptions and terms for educational materials, such as *creditable prescription drug coverage* or *appropriately qualified health care professional*? This may not be advisable if they do not help the intended audience make health care decisions, Partida concluded.

Effective cross-cultural translations require understanding the context and intended meaning of the source language and the implications for production of an equivalent message in another language. Also relevant is the assumed health literacy of the source and target language audiences. Health literacy is the ability to read, understand, and use health care information to make decisions and follow instructions. It involves comprehension of both the context or setting and the skills that people bring to a health care exchange or as readers of health text. Translation conventions that can be understood by target language audiences are needed for industry language (e.g., member), forms of transacting (e.g., consenting process), health education and promotion, and other important activities related to health encounters. Standards for uniquely American health vocabulary and practices can help promote uniformity of translations and better enable target readers to associate translations with relevant experiences.

According to Edward Sapir, the distinguished linguist, language is not only a vehicle for the expression of thoughts, perceptions, sentiments, and values characteristic of a community, it also represents a fundamental expression of social identity, "a potent symbol of the social solidarity of those who speak the language." Shared language helps to promote shared understanding and meaning. In essence, language is more than the sum of its parts; words are entangled with a defined socioeconomic and cultural context. The implications are significant for the translation of health materials developed in English, based on Western concepts of health and shaped by micro- and macroforces that influence health transactions. Developing standards for translation of terms and concepts specific to the American health system can help (1) identify health content with significant differences between English, the source language, and target language and culture; (2) offer guidance on how to achieve shared understanding and meaning across languages; and (3) promote translation consistency.

Information written in clear, easy-to-understand language is essential to access health system benefits and services and quality healthcare. This industry ideal is often difficult to achieve with populations speaking widely diverse languages and associated culturally influenced health beliefs and practices. This diversity of language is likely to grow as globalization of markets, information and communication technology, and international migration trends fuel growth of multicultural and linguistically diverse societies. For California health providers, providing health information in languages other than English is an essential business practice today. This is a practical reality made necessary in a linguistically diverse nation that remains committed to monolingualism. In contrast, plurilingualism in education is a constituent characteristic of the national identity of our European counterparts.

Finally, the field of language translation reflects these two paths to language policy, Partida said. Translation of literature and art emphasize shared understanding and meaning and result in recreated, newly authored products. While health translation practices typically aim to produce linguistic equivalent products that are bound by content in the English original, content that may reflect American health systems values, practices, and vocabulary may have no direct equivalent in the target language. Further, modern medicine and a dynamic health insuring system generate words, concepts, and practices that pose challenges for readers of health materials. Health texts often reflect or include vocabulary referencing; health funding policies or practices determined at the national, state, or organization level; local health practice and conventions; and advances in the biological sciences and medicine. Except for text devoid of sociocultural context, the translation produced in a target language may not necessarily result in shared understanding and meaning. The language translation task requires identifying representative words or expressions in target languages that may not exist. Use of target language terms with no sociocultural bounding as substitutes or equivalents serves only to confuse. Moreover, opportunities to advance learning of new concepts or health system practices are lost with wide variation or inconsistent translation of English terms, Partida said.

DISCUSSION

Arthur Culbert, roundtable member, asked Quincy if those who are planning or implementing the state health insurance exchanges are aware of the Consumers Union findings. The findings would be invaluable for planners and policy makers. Quincy said the final reports were going to be issued in the next few weeks. The results have been shared with the National Association of Insurance Commissioners. The first two studies were designed to help them with their work. Quincy plans to actively disseminate the findings in the fall of 2011.

Cindy Brach, roundtable member, asked if Consumers Union would consider rating health plans in terms of how intelligible their materials are, such as the coverage benefits information and membership materials. Brach suggested that Consumers Union involvement could serve a public education function, raise the awareness of health plans, and play a role in accountability that could help spur improvement. Quincy replied that she could not speak for her organization, but that such a task would be consistent with the mission of Consumers Union. Funding such an effort may be an issue because it is expensive to develop measures that are both meaningful to consumers and that can be trusted because they are backed up by credible data. Partida added that her work with L.A. Care Health Plan illustrated the need to examine both terms used by the state in their public programs (e.g., Medicaid, Children's Health Insurance Program [CHIP]) and the vocabulary unique to the health plans.

Ruth Parker, roundtable member, asked Quincy whether issues related to consumer trust of health insurers arose in Consumers Unions research, and if so, whether there were insights into what can be done to repair broken trust. Quincy said that some of the issues that have contributed to distrust will be alleviated with the full implementation of health reform; for example, coverage rescissions are prohibited and medical underwriting will no longer be allowed in 2014. Trust will likely be enhanced when plans are simplified and plan terms are easier to understand. Exchanges should vet health plans with trust considerations in mind. There can be no hidden traps for consumers; if such loopholes persist, the relationship between the plan and the consumer is damaged and difficult to mend. It would be helpful to understand how consumers react to mechanisms such as the seal of approval for plans used in Massachusetts. The results of consumer testing could be very informative, Quincy said.

Andrew Pleasant, roundtable member, concluded from Quincy's presentation that people use a mental map of health insurance that centers on providing financial reimbursement for sick care. He wondered if the model could be reframed to focus on reimbursement mechanisms for prevention. He wondered if consumers would place a higher value on health insurance if it emphasized the receipt of benefits when the individual is well. Quincy suggested that this perspective changes the equation into "What can purchasing this health plan do for me?" as opposed to "What do I have to pay if I buy this product?" Health insurance information is currently presented with a focus on the consumers need to pay a premium, a deductible, co-payments, and coinsurance. Consumers then have to decide whether the benefits outweigh the plan's cost. If consumers were approached with the notion that if they paid the premium, they would receive well care, in addition to coverage for unexpected, catastrophic illness, they may feel more positively about the plan.

Margaret Loveland, roundtable member, noted that people tend to dread what they do not understand, and what they do not understand, they do not trust. She observed that consumers now have many choices of health care coverage. She asked how consumers (and health insurance plans) feel about simplifying health plans and perhaps reducing the number of choices. Susan Pisano of America's Health Insurance Plans (AHIP) indicated that health plans viewed the prospect of simplification very positively. However, considerable work is needed to simplify health insurance language so consumers can understand the plan's terms, she said. Health plans are actively addressing health literacy concerns. When beneficiaries trust their insurer and understand their benefits, they are more satisfied, make better use of their benefits, and are healthier.

Moderator and roundtable chair George Isham added that in the current insurance market, health plans create products for different groups, such as unions or large employers. In an environment where there are different purchasers, the benefits, services, and price are tailored to suit the needs of the purchaser. This partially explains today's variety in plan benefits and structure. State insurance exchanges, which will offer individual and small group products, are debating how much variation to allow in the products offered. It is likely that different products and approaches may suit the unique markets that exist across the country. Quincy added that purchasers such as unions or large employers do tailor their health plan designs for their employees or members. However, the employees or members generally end up being offered one or a few plan options, making it fairly easy to choose among them. Isham noted that while states will follow the guidance available from the federal government, they may come to different decisions about plan offerings.

Brach asked Partida if federal legislation exists, or is emerging, to regulate language threshold requirements for translation and interpretation services. Many state Medicaid programs must provide language assistance for speakers of languages other than English if the population of speakers of that language exceeds a certain threshold within a community or market area. Brach asked if there are lessons from Medicaid, CHIP, or other programs that would inform the health insurance exchanges. Partida was not aware of any federal legislation that included such requirements, but mentioned that California had required translation services for 10 languages, but that the requirement has been reduced to five languages, in part, because of the difficulty of assuring the effectiveness of translation. There are issues related to both the quality of translation and the literacy of the target population. Providing written materials in the native language of immigrant populations that are illiterate, or marginally literate, is not helpful. There are many Spanish speakers who have no formal knowledge of their Spanish and speak English very marginally. The quality of translations is also an issue given the diversity found within any particular language, Partida said.

Roundtable member Will Ross asked Quincy whether the nation will be able to fulfill its objective of having 30 million more people insured by 2014, given the constraints on Medicaid funding and the cognitive difficulties that consumers have making health insurance choices. Quincy stated that experience with programs such as Medicare Part D, the prescription drug benefit for seniors, suggests that people who are uninsured will gain insurance. What is less certain is whether individuals' choice of an insurance plan will be an informed choice. The ability of consumers to make informed choices will depend on whether they are provided with an appropriate set of tools and assistance they need. One of the benefits of having exchanges implemented in a tailored fashion across 50 states is the ability to compare and contrast the experiences of those exchanges and to observe which programs are succeeding. Isham questioned whether any differences between exchanges would inform change. There are differences in state Medicaid programs, but these differences do not generally contribute to reform. He added that states lacking a robust Medicaid program have difficulty making improvements. Quincy suggested that states have learned from each others Medicaid programs, with "best practices" becoming more prevalent—such as moves toward administrative simplicity, reducing stigma, and improved outreach programs.

Isham asked the panel if mechanisms needed to be developed to ensure that improvements are made. Quincy stated that goals should be established for exchanges, and progress toward those goals should be measured over time.

Linda Harris, roundtable member, asked Quincy what role Consumers Union might play in helping consumers purchase health insurance through the state health insurance exchanges. Quincy stated that the primary and traditional role of Consumers Union is to be a trusted source of information. The ability to provide comprehensive information depends on the availability of financial support. There is considerable interest in improving consumers' choices, and Consumers Union is actively exploring the possibility of partnering with other entities to provide information that can be trusted.

Pleasant asked Partida if the glossary of health insurance related terms she described in her presentation is publicly available. Partida replied that the L.A. Care Health Plan will be making the glossary publicly available.

An audience member, Zadkiel Elder, an economist from the Department of Labor, asked the panel whether health plans could be incentivized to simplify health insurance options. Quincy stated that based on the experience of the Massachusetts exchange, it is possible to simplify plans. That exchange placed the insurance products into three actuarial value tiers. Health plans then provided within a tier all the plans offered that provided a similar level of financial protection. However, consumers had difficulties comparing plans because, although they had similar levels of financial protection, they still had very different underlying provisions. The Massachusetts exchange decided to move away from the actuarial value tiers and develop more standardized plan designs. In this case, consumer testing was instrumental in the move toward standardization, Quincy said.

One study, published concurrently with the Massachusetts move to simplify choices, examined how plans that were in the same actuarial value tier dealt with claims for a hypothetical case of breast cancer (Pollitz et al., 2009). The plans within the tier had similar deductibles and out-of-pocket maximums, but because of exceptions associated with these cost-sharing provisions, the patient's out-of-pocket costs for the hypothetical disease varied by tens of thousands of dollars.

Audience member Angele White, a health educator, described how in her work with clients who are uninsured or underinsured, there is often confusion about health plan coverage. An individual may select a plan only to learn later that the plan does not cover their condition or fit their circumstance. Once covered, it is often difficult to switch plans to one that is more suitable. A client who is pregnant and learns that her plan does not cover the full spectrum of neonatal care may not be able to switch in time to get the coverage she needs. White asked Quincy if some of the lessons learned from research conducted concerning private insurance plans was applicable to public insurance plan enrollment. Quincy said that the same general rules apply. However, it is helpful to tailor communications to clients according to their level of health insurance literacy. Quincy advocates for a measure of health insurance literacy and better health insurance education.

White asked Partida about incorporating cultural and ethnic norms into translations. White found that her clients from different African communities vary in their interpretation of information. Partida described how her team attempted to find common vocabulary across the different Spanish-language countries studied while working on the glossary of health insurance terms. They found that cultural differences in interpretation diminished with time spent in the United States. Immigrants often live in proximity to people from other Spanish-language countries, and they are also being influenced by the English language spoken around them. Partida discussed the difficulty of developing materials within a language that addresses cultural differences. Attempts have to be made to organize and simplify information to reach a broad audience. If insurance terms are explained clearly, simply, and are consistently used, people can begin to learn them.

REFERENCES

American Heritage Dictionary of the English Language. 2009. 4th ed. Houghton Mifflin Company. http://www.thefreedictionary.com/ (accessed September 21, 2011).

Colina, S. 1997. Contrastive rhetoric and text-typological conventions in translation teaching. *Target* 9:353-371.

Colina, S. 1999. Transfer and unwarranted transcoding in the acquisition of translational competence: An empirical investigation, In *Translation and the (re)location of meaning*, edited by J. Vandaele. Selected Papers of the CERA Research Seminars in Translation Studies. Leuven. Pp. 375-391.

Consumers Union and People Talk Research. 2010. *Early consumer testing of new health insurance disclosure forms*. http://prescriptionforchange.org/pdf/CU_Consumer_Testing_Report_Dec_2010.pdf (accessed September 2011).

Gasser, M. 2006. *How language works: The cognitive science of linguistics*. http://www.indiana.edu/~hlw/ (accessed September 21, 2011).

Kleimann Group and Consumers Union. 2011a. *Early consumer testing of the coverage facts label: A new way of comparing health insurance*. http://prescriptionforchange.org/wordpress/wp-content/uploads/2011/08/A_New_Way_of_Comparing_Health_Insurance.pdf (accessed August 2011).

Kleimann Group and Consumers Union. 2011b. *Early consumer testing of actuarial value concepts.* http://prescriptionforchange.org/document/report-early-consumer-testing-of-actuarial-value-concepts (accessed September 2011).

Partida, Y. 2011. *The challenge of health insurance language or communication with vulnerable populations*. PowerPoint presentation at the Institute of Medicine workshop on Facilitating State Health Exchange Communication Through the Use of Health Literate Practices, Washington, DC.

Pinker, S. 1994. *The language instinct: How the mind creates language*. New York: HarperCollins.

Pollitz, K., E. Bangit, J. Libster, S. Lewis, and N. Johnston. 2009. *Coverage when it counts: How much protection does health insurance offer and how can consumers know?* Washington, DC: Center for American Progress.

Quincy, L. 2011. *How consumers shop for health insurance: Lessons for exchange designers*. PowerPoint presentation at the Institute of Medicine workshop on Facilitating State Health Exchange Communication Through the Use of Health Literate Practices, Washington, DC.

4

Health Literacy Relevance to Health Insurance Exchanges

THE IMPORTANCE OF HEALTH LITERACY IN HEALTH INSURANCE REFORM

Frank Funderburk
Centers for Medicare and Medicaid Services

The Centers for Medicare and Medicaid Services (CMS) is actively engaged in activities to promote health literacy, Funderburk said. CMS participated in the development of the Action Plan for Health Literacy (HHS, 2010) and has developed and disseminated a toolkit that provides a comprehensive set of tools to help organizations make written material in printed formats easier for people to read, understand, and use.[1] CMS also supports research-based social marketing efforts that focus on achieving health literacy goals and the objectives of the Affordable Care Act (ACA).

Funderburk pointed out that while health reform expands access to coverage and creates new health insurance options, understanding of these options is relatively low among key target audiences, including both the consumers who will be eligible for individual coverage and the qualified small businesses and their employees that will be eligible for coverage through the exchanges. To derive the intended benefits of the exchanges, consumers will need to become familiar with the enrollment requirements and processes as well as plan benefits, and integrate this detailed and often complex information in a way that allows them

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[1] The toolkit can be found at http://www.cms.hhs.gov/WrittenMaterialsToolkit.

to make sound decisions about which plans will best meet their needs. Clearly, attention to health literacy in general and health insurance literacy in particular will be a key consideration in developing an effective health insurance communication strategy for the exchanges.

Funderburk noted that the usual health literacy framework that aims to match an individual's skills and abilities with the demands and complexity of the material would be useful in this context. He suggested, however, that the utility of the framework would be enhanced if motivational and attitudinal components of the communication were considered. These features will influence the behavioral actions (e.g., consumer engagement in reviewing, comparing, and choosing appropriate coverage) that must occur if the benefits of the program are to be realized. For example, improved access to health insurance and the associated benefits of improved population health and improved quality of life will only occur if consumers use the information to make informed choices that are tailored to their needs and aspirations. Research suggests that motivational and attitudinal issues can be as detrimental to making appropriate health choices as low health literacy (Funderburk, 2011; Kotler and Lee, 2008; Sutton et al., 1995).

Addressing health literacy is essential to the operation of the exchanges, Funderburk said. Attention to health literacy issues is a first step in support of informed consumer decision-making. Using simple, plain language rather than jargon; designing consumer-friendly decision-support tools; presenting comparative information using standardized insurance plan formats; personalizing outreach to diverse, low-literacy consumers; and facilitating communication between consumers and health system navigators can all be marshaled to help consumers understand eligibility rules and the operation of both public and private health coverage. One might think of implementing these diverse communication activities, when combined with a sound understanding of the point of view of the exchange consumers, as part of a broader social marketing campaign. Social marketing involves understanding the mental models that consumers use as they approach their decision-making situations, Funderburk noted. Factors such as health literacy, culture, language, attitudes, perceptions, and life circumstances that might prevent an individual from taking advantage of health benefits for which they are eligible are taken into account, and then strategies to overcome these barriers are developed. Social marketing supports health literacy and health insurance exchange goals. Materials and messages use plain language and are consumer centered. These messages are then tested and refined using real consumers. The process of testing is iterative and ongoing to improve communication and the ability of consumers to make choices. Ongoing testing identifies barriers and improves understanding of market segmentation and the development of materials to meet the needs of subpopulations within the larger market.

Attention to health literacy is part of a consumer focus that can help build an accountable health care system, support better consumer interactions and decision making, help reduce avoidable costs, produce better outcomes, and improve quality of life, Funderburk said. A recent project provides an example that illustrates how these principles were put into practice to help consumers gain a better understanding of their health insurance options. Much of what was learned in this project has implications for the development of the exchanges.

Section 1103 of the ACA calls for CMS to establish an insurance web portal where consumers, including small businesses, can obtain consumer-friendly information about both public and private health insurance plans available to them. The portal was mandated to be operational in July 2010. CMS staff conferred with representatives of existing state health insurance exchanges, conducted an environmental scan, and began to test website formats with people who were uninsured or who were afraid of losing their coverage. CMS staff also explored basic perceptions of people most likely to use this resource in an effort to gain a basic understanding of "consumer reality" about health insurance products. Key questions included the following:

- Perceptions—What are target group perceptions about health insurance in general and options available for their group in particular? What experiences have participants had with public or private insurance?
- Participation—What are factors that influence participants' decision making regarding enrollment, renewal, information seeking, and plan comparison? What barriers are identified?
- Outreach—What factors are likely to influence participants as they access and use information available on the portal? What are consumer expectations regarding the portal? What should the portal be called? What key messages will attract individuals to the portal? How can CMS incorporate consumer feedback into the design process to improve outreach effectiveness?

Examples of features from existing insurance websites were also shown to 18 consumer groups comprising a total of approximately 80 individuals. Limited discussions were also conducted among owners of small businesses.

The portal was designed using plain language, and efforts were made to define specialized terms in ways that were more easily understood. The research team worked with study participants as coproducers. Participants were asked, "How would you say that? How could we say that better?" CMS staff learned, for example, that although the law uses the term *exchange*, the term *insurance marketplace* conveyed the concept more simply and was more easily understood.

As part of the consumer testing, discussion group participants were asked about their feelings of being uninsured. Among those who were uninsured, there was fear and worry related to an unanticipated illness or accident. Among individuals who had health insurance coverage, there was the fear of losing coverage. Employers were worried about being unable to afford coverage and having difficulty attracting and retaining employees if they did not offer adequate insurance options. In general, the value of health coverage was its ability to confer peace of mind and security. Interest in affordable coverage was high among study participants.

When the discussion group participants heard about the opportunities for coverage under the ACA they were hopeful, yet they remained skeptical as illustrated by some of the comments:

- "Who defines affordability? The Rockefellers? Or me?"
- "How are you going to do that?"
- "What's it really going to cover?"
- "How am I going to understand what I'm getting? Because I read this stuff, and it doesn't make sense to me."

The consumer research made it clear that reasonable expectations must be set. For example, not all of the reforms will take place at once. According to the study groups, government could be viewed as a credible source of information. Individuals were willing to trust a government stamp of approval on an insurance plan, especially when a plan was complex and difficult to understand. When study subjects were shown mock-ups of the HealthCare.gov website they were impressed and thought that the government has an appropriate role in providing this service.

Although government websites were generally viewed as trustworthy, respondents reported that such websites are often not easy to understand. Social networks and community sources were described as providing support to allay fears about biased or inaccurate information. The CMS research staff concluded that opportunities exist to exceed consumer expectations. Furthermore, the HealthCare.gov website had the potential to help consumers have more confidence in their decisions. Consumers expressed a desire for content that is personally relevant and timely. They want to know "What's in it for me?" They wanted to be assured that the website was not promoting a political agenda—for example, a push for government-run insurance. The ability to examine public and private insurance plans in a clearinghouse type of environment was viewed positively.

The consumer testing suggested that the term *coverage* is more appealing than *insurance*. Consumer-friendly words included *affordable*, *peace of mind*, *security*, *options*, *choices*, *your needs*, and *insurance marketplace*. Terms to be avoided included jargon (such as *high-risk pools*), income requirements expressed as a multiple of the federal poverty level, use of the term exchanges, and slick marketing language. Consumers had a strong sense of what they looked for in a good web experience, saying, "It meets my needs. It's intuitive, easy to navigate, simple, easy to search, flexible, credible, up to date, and accurate." Consumers have clear expectations for web experiences and will leave a site that does not measure up, Funderburk said.

The ACA provides for penalties for those who do not opt to have health insurance coverage. This worries consumers, suggesting that clear explanations are needed about why there are penalties. Some evidence from Massachusetts suggests that the penalties encourage people to sign up and become engaged.

The health insurance portal at HealthCare.gov continues to evolve. Comparative pricing information for health plans in the individual private market was added in October 2010 using displays that were informed by consumer testing. Plan costs and coverage are provided in standardized language giving consumers an opportunity to compare available plans. The plans are listed according to residence, age, and other demographic characteristics. The default listing of plans is by maximum out-of-pocket exposure, because research suggests that people tend to pay too much attention to premium cost rather than what they are purchasing for that premium. Consumers have options on how they want to review plan options.

Funderburk concluded by saying that CMS is examining methods to improve consumer understanding, such as by building in context-sensitive tutorials. If a website user has difficulties navigating the site, then he or she could access instruction through the site. Additional work is ongoing, and results will be shared with interested parties.

HEALTH INSURANCE EXCHANGES: FACILITATING CHOICE THROUGH HEALTH LITERACY INTERVENTIONS

Rima Rudd, Sc.D.
Harvard School of Public Health

In 2006, policy makers in Massachusetts enacted a far-reaching health reform plan, creating what is known as the Massachusetts health insurance "Connector," along with other reforms, Rudd said. Since then, the ACA has been enacted. As part of its expansion of health insurance coverage, the ACA relies on state health insurance exchanges to inform and enroll clients into suitable public and private plans. The objective of the state health insurance exchanges is to increase access, and its purpose is to help people make decisions to address their health care concerns and to mitigate their health care costs. How these exchanges are being designed is instrumental to their success (Box 4-1).

Several guidelines have been designed to assist states as they develop their exchanges. For example, Rudd made note of *Designing an Exchange: A Toolkit for State Policymakers*[2] as well as *Preparing for Health Reform.*[3] She noted that available guides address the major issues states need to consider in order to provide a mechanism for helping their citizens make important decisions. *Designing an Exchange*, for example, includes very good information on what needs to be communicated and what people need to know. Rudd notes, however, that it is missing a key component: how to best communicate this essential information. States need guidelines about rigorous processes (how to conduct formative research and evaluation studies), about design (what supports and what inhibits reading ease), and about web navigations (what key design elements make it hard or easy for people to use a web-based exchange). These are the critical elements that a health literacy perspective brings to the table.

Rudd provided an example related to work in Massachusetts. In 2007, a student attending Rudd's health literacy class at the Harvard School of Public Health completed a health literacy assessment of the Massachusetts exchange website. Findings related to navigation and text barriers were shared with the state and a health policy committee so improvements could be made. Rudd revisited the site in early July 2011 and found that the site had undergone many changes (though she does not attribute them to the work mentioned). She noted the client interface is welcoming, the site features pictures of a diverse set of people and places, and testimoni-

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[2] Available at http://www.nasi.org/research/2011/designing-exchange-toolkit-state-policymakers.

[3] Available at http://www.rwjf.org/files/research/57093.pdf.

BOX 4-1
The Design of State Health Insurance Exchanges

There will be a host of state-specific policy and administrative decisions that will need to be made in order to effectively and efficiently implement an exchange. These decisions will influence whether the exchange can help meet the objective of increasing access to affordable health insurance for individuals and small businesses.

SOURCE: Carey, 2010.

als are provided from individuals and employers to give the new users a sense of options and issues relevant to people like themselves. Rudd found the website design to be well structured to permit the user to compare plans. There were some clear difficulties as well. For example, some charts were so complex and contained so many items that reading online was nearly impossible. One could still find jargon, complex vocabulary, unexplained concepts, and navigation barriers. These and other health literacy–related findings indicate some of the value of using a "literacy" perspective and some of the concerns state exchanges need to address.

A health literacy perspective can provide guidance currently missing from a variety of how-to postings. First, formative research—those activities undertaken to develop and then test important components of any program before it is launched—is a foundation stone for health literacy improvement (Doak et al., 1996). Some elements of formative research for the development of state health exchanges have been undertaken and have yielded important insights. For example, other panel members had previously noted that the information (content) wanted and needed by consumers is now well known as a result of surveys and marketing work. Furthermore, recent studies have identified the information that is most important to consumers.

Less well known, however, is how best to present key information to consumers so they can use the information with ease. Awareness of the state of literacy among adults combined with well-tested communication strategies can help states provide information in ways that support comprehension, that help with the often complex challenges of web navigation, and that set the stage for informed decision making. Interviewing members of the intended audience at the draft stage can help developers test out various approaches. Giving members of the intended audience the opportunity to examine and comment on the content, the display, and the organization, as well as the words and concepts of materials in draft form, is critical. Such a review provides essential information on access, usability and relevance, clarity, and logic, as well as ordering and sequence.

A second element missing in the guide's table of contents is attention to literacy directly, Rudd said. There is a general lack of recognition that close to a majority of adults in the United States have what could be labeled *limited literacy skills*—difficulty using print materials to accomplish everyday tasks with accuracy and consistency (Rudd, 2007). Rudd made note of the limitations in the early work of health literacy research with its focused attention on the skills or deficits of individuals without due attention to the demands, assumptions, and skills of those in the health sector. Indeed, some of the difficulties people face in using health materials can be traced to the poor quality of the materials themselves. Information, including health education information or package labels, is often not clearly presented in usable and well-organized form. Over 1,000 published peer-reviewed studies indicate that health materials are written at levels that exceed the average reading skills of adults (Rudd and Keller, 2009).

Rudd offered a reminder about the Institute of Medicine's (IOM's) health literacy report indicating that health literacy represents an interaction between the skills of individuals and the demands of the health sector (IOM, 2004). The demands and expectations of the health care system must be balanced with the skills of the intended audience. The importance of improving literacy skills of adults has long been known, but modifications of the demand side have been slow.

Appreciation for the very sophisticated skills needed to engage in health-related tasks is of critical importance. Rudd recounted her experience developing materials for teachers in adult education that would enable them to integrate health literacy into their curriculum. She focused on three areas related to health disparities: (1) health system navigation; (2) chronic disease management; and (3) disease prevention, screening, and early detection. At the start of this work in 1996, she assembled scholars from public health, medicine, nursing, and adult learning and literacy to analyze and deconstruct a variety of health activities within each of these areas. The purpose was to explicate the various tasks involved in critical health activities, the various tools needed to accomplish those tasks, and the literacy skills needed to use the tools and accomplish the tasks. Teachers would then be able to appreciate the value of their expertise and understand the relationship between literacy and health.

A uniform process was undertaken for a wide variety of health activities in each of these three areas. First, the study team identified common clusters of activities. For example, in the case of chronic disease management, one common activity is taking medicine as prescribed. This activity might include as many as 20 different tasks, from reading the label, differentiating between medicine A and medicine B, examining the dosage, to figuring out the timing. For each task, the team identified the tools that people need to complete the task. In the case of taking medicine, one considers the label on the bottle, the materials or package inserts, the directions offered orally, a clock, a calendar, or a phone. The study team then identified the literacy skills needed to accomplish these tasks and to use the associated tools (Rudd et al., 2006). A set of three fully articulated curricula was developed, piloted, implemented, and evaluated. The books have been and are currently being used in the adult continuing education programs of many states to instruct adult education teachers how to integrate health literacy into their classes.

A similar process can be used to understand the activities people need to engage in as they use information from state health insurance exchanges to make decisions central to their lives. An understanding of activities, tasks, and tools can inform the design of booklets and websites. Table 4-1 provides a deconstruction example of two activities related to obtaining health insurance.

A deconstruction analysis can help those responsible for crafting the materials consumers will use and, most importantly, provide insight for those in the state responsible for hiring individuals or agencies to design the appropriate tools. A designer must first understand the literacy skills needed to use tools and then shape the tools to meet the needs of the user. Evaluators can look at the health insurance booklet and ask about the reading level, or whether the writer avoids jargon, or whether the charts are easy to use. Responsible oversight can include demands and proof that evaluators engaged in piloting and revision. Such processes make

TABLE 4-1 Access and Navigation

Activities	Tasks	Tools	Literacy Skills
Examine options	• Read for relevant information • Calculate and compare costs	• Health insurance booklets • Rights and responsibilities lists • Benefit charts	• Read • Have a medical and/or economic vocabulary • Use charts • Calculate
Apply for insurance	• Read form for needed information • Keep/check records • Fill in forms	• Application forms • Financial disclosure forms • Medical history • Family history	• Write responses • Use medical vocabulary

SOURCE: Rudd, 2011.

materials more easily accessible and usable. When states hire contractors to develop their websites and print materials, they could require that these processes be put in place. A checklist could be developed for those engaged in this developmental work and used as standard for submissions. Rigor is required for such important work, Rudd said.

Next, Rudd spoke about the notion of choice. The state health exchanges are being established to help people make informed health plan choices. Rudd provided four overlapping definitions of *choose*: (1) to select from a number of possibilities; (2) to pick by preference; (3) to prefer or decide; and (4) to want or desire. Choice, however defined, involves accessing information. To access information an individual has to locate it, be able to read it, comprehend it, and then use it. Therefore, key information must be locatable—found amid all the options and distractions and the multiple elements of a website. It must also be readable, with words that are commonly used and concepts that are well explained. Most importantly, if people are expected to come to a decision, they must be provided with an opportunity to compare and contrast key items. Thus, designers need to identify important parameters and key items and make them easy to locate so users can examine like items for comparative purposes.

Making health plan comparisons online is much more complicated than buying a commodity online, Rudd cautioned. Health plans involve complex concepts and processes while commercial sites appeal to style, image, and look. They can post pictures of the product with zoom options. Furthermore, products bought online or in person often include a return policy. Health-related decisions are far more complex and have consequences that cannot be resolved at a return desk. Health activities, such as choosing a health plan, must be understood, the tasks involved clearly defined, and then appropriate tools must be designed to support decision-making processes.

Many websites take people through a linear process without leaving room for the kinds of activities that people generally undertake: take several steps, pause to think or to discuss with others, and return to the task at a later time. To help people compare and contrast health plans and then make a decision, the designers need to offer individuals time—an opportunity to weigh and consider, to test out their decision with others, to reconsider, and then finalize it. From Rudd's perspective, this is a design challenge. However, she believes that sophisticated website designers can establish mechanisms that accommodate people's ability to log on and off the website as they obtain information, talk with family and neighbors, and then, after some time, return to the same area of the website visited previously without having to start anew. Decision aids that are respectful of the processes that people use have to be built into systems.

Design protocols, contractor requirements, an emphasis on easy-to-navigate materials and tools, and worker training are all needed to enhance the ability of states to meet consumer needs. Rudd suggested that a successful model to emulate is the easy-to-use telephone call-in process already in place for Social Security applications. In addition, there are classic guides for assessing materials beyond just looking at vocabulary and readability scores (Doak et al., 1996) and advice on web design. Furthermore, this important undertaking can draw lessons from successful programs and practitioners who have engaged in outreach and education programs that have drawn on and work with community partners such as libraries, adult education programs, and social service agencies. Professionals in these settings are well positioned to help people access information, learn new processes, and use available information to make decisions and take action. For example, Rudd identified three community partners who have experience and insights to share:

- Elyse Barbell and Winston Lawrence of the Literacy Assistance Center in New York City (NYC) have successfully partnered with the NYC Health and Hospitals Corporation, the NYC mayor's office, and a variety of other organizations such as human immunodeficiency virus (HIV)/autoimmune deficiency syndrome (AIDS) programs to enhance access to information, services, and care.
- Christine Molnar[4] completed work 10 years ago through the Community Service Society in New York City working with and providing training for community members in order to hold public forums to help people understand their health insurance options.
- Archie Willard of New Readers of Iowa organized a group of people with acknowledged reading problems to improve health services in their state.

Overall, Rudd noted, one must remain aware of existing data about the literacy skills of U.S. adults, consider the activities people are expected to undertake, and be sure to provide them with the best tools possible to enable them to take action.

Rudd emphasized there is knowledge about existing literacy skills of adults in the United States as well as the untoward health consequences of low and limited literacy skills. Rather than continue to focus on, measure, and emphasize the public's deficits, action must be taken. Communication skills must be improved, she said. Messages, materials, and tools must be designed so people can use them with ease.

Improving health literacy involves attention to tasks and tools as well

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[4] Christine Molnar is currently CEO of Safe Space, NYC.

as to words and numbers. It requires rigorous methods in the development and design of materials to ensure access to information. It respects the dignity of people, increasing participation by involving members of the intended audience in development and design.

State health insurance exchanges are projected to be the gateway for approximately 29 million people gaining access to health coverage. The health literacy community is in a position to help states provide information, messages, materials, and programs informed by research and experience, Rudd said.

Rudd mentioned a July 2011 discussion with Jeffrey Sánchez, a Massachusetts state representative who serves as house chairman of the Joint Committee on Public Health, and noted his interest in health literacy and his recognition of its importance for all legislative communication efforts. She is optimistic that others will respond with similar enthusiasm. Rudd concluded her presentation by noting that health literacy is about promoting dignity and providing agency and voice to people so they can make informed choices.

DISCUSSION

Andrew Pleasant, roundtable member, observed that much of the discussion pertaining to health literacy and health insurance exchanges addresses enrollment issues, for example, the navigability of websites and adequacy of information to make plan choices. He said that it is as important for the exchanges to learn about health literacy so newly insured individuals can make informed choices about their health care. In addition to providing access, a central goal of the ACA is to lower cost. Pleasant asked the panel how the exchanges could use health literacy interventions to improve the use of preventive services and help newly insured individuals use the health care system appropriately.

Rudd discussed the important distinction between informed choice and appropriate choice. An informed choice involves presenting information so people can weigh the pros and cons of alternative choices. It is the health professional's job to make sure people make informed choices. Whether or not individuals make an appropriate choice is outside of the professional's purview unless the choice involves an illegal health practice. Health professionals sometimes inadvertently block access to information because of bias or poor communication skills.

Funderburk pointed out that there is no requirement under the ACA to evaluate health system change that occurs as a result of the law. However, it would be informative to document changes in the use of preventive care and other cost-effective services. Learning from the experience of the different models that states adopt and identifying what is working will help states innovate and improve, he said.

Moderator and roundtable chair George Isham pointed out that there is going to be variation across the country that is driven by local geography, local situations, and local cultures. This will add another dimension to the challenge of evaluation. For example, enrollment estimates from New Mexico suggest that a large fraction of the population will remain uninsured under the ACA. When evaluating the relative success of the ACA in improving health behaviors, will measurement be restricted to individuals who are enrolled under the ACA or will it encompass the entire population? When evaluating consumer choices, it may be difficult to judge which are appropriate given differences in values and preferences across cultures. Rudd said that choice can be influenced by how information is provided. Some states may decide to use persuasive communication to influence choice.

Will Ross, roundtable member, noted there is a disconnection between the knowledge, skills, and attitudes of the population, and the skills and the instruments being developed by the health insurers. He asked the panel how health care providers could work to improve the health literacy of patients. Rudd replied using a metaphor, that of making soup. Soup is provided for nutritional value, so key ingredients of the soup are vitamins, mineral, proteins, and other sustaining substances. In addition to these core elements, the soup is enhanced by flavors and spices. One of the things that the health literacy community can do is help legislative bodies identify the core elements of their programs, for example, clarity of communication, and mechanisms to assess the products, such as websites and written materials. It may be advisable to require that states complete a checklist, in the same way that research investigators have to submit paperwork to an institutional review board, Rudd suggested. The checklist could include providing evidence that they have revised materials based on testing with members of the intended audience. There could be regulations about the product and its content, as well as regulations about the process of developing that product. This could be achieved if the key elements of a checklist could be identified and the process to complete it is not too complex or cumbersome.

Ross asked Funderburk if there were incentives that CMS could provide to encourage the kinds of processes described by Rudd. Funderburk replied by describing intensive consumer research that CMS is planning over the next few years that will involve a variety of audiences. The results will be disseminated to states. CMS will help states establish a certification procedure for their websites so there will be assurance that they have taken key findings from the research into account. One evaluation tool that has been informative is the examination of systems for *positive deviance*.[5] This involves looking across the exchanges to identify successful outliers and then reviewing them to understand the elements that contributed to their success. The concept of positive deviance has been applied, often at a community level, to find out, for example, why children in one area are not suffering from malnutrition when they reside in cultural conditions very similar to other neighboring children. Looking into what is going on within the community to foster better nutrition can lead to insights for communities that are faring poorly.

Reviews of the positive experience of selected exchanges will be informative in the context of the state health insurance exchanges given the diversity of programs that will be in place, Funderburk said. For example, if certain plans that include a rich set of prevention or wellness programs are observed to reduce overall health care costs, the plan benefit structure may be adopted more widely. Funderburk pointed out that health literacy does not always have to refer to written materials. It can be applied to one community modeling the behaviors or experience of another community. Information can be provided in a variety of ways, such as using photo novellas within the Hispanic community. Health literacy must be considered in broad terms, he said.

Roundtable member Benard Dreyer asked if there were ways to reduce the numeracy cognitive load on individuals making plan choices. He pointed out that in terms of health literacy, numeracy is much more of a challenge for many people than understanding text. Selecting a health insurance plan requires numeracy skills. Rudd replied that research suggests that information can be provided in such a way that math calculations are already completed (Apter et al., 2008). For example, clinicians are discouraged from saying, "Lose 10 percent of your weight." Instead, providers are instructed to do the math and tell the patient exactly how many pounds it would be advisable to lose. When using a computer to compare health plans, internal programs can make the computations. Mathematicians have written extensively on this topic and have provided strategies to provide numerical data visually to ease its interpretation. Words in common use in medicine, such as *risk*, *probability*, *likelihood*, and *normal range* can be terribly confusing. Clinicians generally do not do a good job of communicating the meaning of these words. Needed are clear coherent explanations of these terms, Rudd said.

Funderburk agreed that it is much easier to compute for individuals the formulations that are needed to determine eligibility. If an individual

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[5] "Positive Deviance is based on the observation that in every community there are certain individuals or groups whose uncommon behaviors and strategies enable them to find better solutions to problems than their peers, while having access to the same resources and facing similar or worse challenges," www.positivedeviance.org (accessed August 25, 2011).

provides his or her income, family size, and other information, a computer can calculate if he or she is eligible for Medicaid, for example, at 1.36 times the federal poverty level for a family of four. It is also instructive to use scenarios with clients. For example, they can be asked, "Do you see yourself as being more like Jane or more like Joan? Joan likes this policy because it provides these benefits." There are strategies to convey information and allow people to make choices that fit their circumstances. Dreyer added that the use of scenarios also helps consumers understand the implications of a plan's out-of-pocket expenses, their potential deductibles, co-insurance, and co-payments.

Ruth Parker, roundtable member, asked Rudd about strategies to reduce consumers' dread of the process of selecting a health insurance plan. Are there ways to lower the cognitive load associated with this process? In addition, she asked about strategies to reduce the distrust that some consumers have toward the insurance industry and government. Rudd indicated that this is a very worthy area of research. She discussed the lessons learned of the value of stories, of the importance and dignity involved in seeing people like themselves reflected in materials, and understanding that people other than themselves also face these difficulties and struggles. A notion of partnership can be conveyed visually and by tone. Such an approach to communication can build trust. Isham added that health literacy is a concept that has to be embedded in a larger notion of customer experience, in a system that is simple and approachable, and encourages trust.

Linda Harris, roundtable member, asked the panel to address the role of the human touch and the importance of relationship-based communication. She pointed out that health literacy is not something that happens naturally and then is sustained over time. Sustaining trust usually depends on having a trusted, ongoing relationship with someone who is helpful. Under the ACA, navigators are important intermediaries. They may be viewed as informed and trustworthy, and could play an important role in sustaining a focus on health literacy. Isham noted that not everyone needs one-on-one assistance, and it is important to provide the appropriate level of assistance to individuals. Some people will be able to navigate the system with the available technology, while others will need help. When in-person assistance is available, it must be readily available. There should not be a lengthy set of automated and recorded telephone prompts at the front end, he said. People should not be placed on hold for long periods of time. A systems approach is needed that steers people to the level of assistance they need.

Dreyer asked the panel whether the information that will be provided through the exchanges is the information individuals want as they consider their options. Many people want to know who their doctor or nurse is going to be, where they are going to get care, and whether care will be accessible. Will this information be available to consumers? Funderburk said information about providers, including provider quality information, will be available. Currently, the commercial plan section of HealthCare.gov allows consumers to see if their provider is part of a plan's network.

Funderburk reiterated the need to reduce cognitive load. He suggested that with a few simple questions, the number of plans to be considered could be reduced considerably. A few additional questions could further refine the selection process. The goal will be to narrow down the focus and to keep people moving through the process, he said. The information needs to be clear and customized to the consumer. IT tools can be used to help people interact with someone online or to connect with a navigator for one-on-one counseling.

Rudd mentioned two oft-cited statements, "Don't let the excellent be the enemy of the good," and "Change inevitably involves suffering." She pointed out that patience is needed as systems progress. The focus immediately is on developing some sound core elements. More core elements will emerge over time as consumers become more sophisticated and desire additional information.

Sharon Barrett, roundtable member, asked the panel how the IOM roundtable could help to further policies that would encourage the use of plain language communication and considerations of health literacy as states establish their health insurance exchanges. Rudd said that raising awareness is key. In her role in academia, she conducts evaluations and publishes and disseminates findings. She and her colleagues also develop tools and policies for consideration. For example, checklists pertaining to health literacy have been proposed for states to use with vendors to ensure that products that are developed meet basic health literacy standards.

Roundtable member Andrew Pleasant asked how states could use incentives to encourage health personnel, health systems, and health insurers to embrace the best practices that health literacy has identified, such as the teach-back method. Rudd described how putting questions about the teach-back method on exams, especially licensing exams, encourages medical schools to teach the method. Arthur Culbert, roundtable member, added that there is a tremendous opportunity for state-based organizations such as Health Literacy Missouri, Health Literacy Maryland, and Iowa's health literacy project to work more closely with their state health insurance exchanges. The considerable expertise within these organizations can be leveraged. Lynn Quincy of the Consumers Union encouraged roundtable attendees to contact the exchange boards that are being established. Isham added that there is also an opportunity to have an effect by creating incentives to improve performance. This first involves knowing how well the exchange is performing. Feedback loops are then needed to gauge both the overall performance of an exchange, as well as the performance of individual participants in the exchange.

REFERENCES

Apter, A. J., M. K. Paasche-Orlow,, J. T. Remillard, I. M. Bennett, E. P. Ben-Joseph, R. M. Batista, J. Hyde, and R. E. Rudd. 2008. Numeracy and communication with patients: They are counting on us. *Journal of General Internal Medicine* 23(12):2117-2125.

Carey, R. 2010. Preparing for health reform: The role of the health insurance exchange. *Academy Health*. http://www.rwjf.org/healthpolicy/product.jsp?id=57093 (accessed September 11, 2011).

Doak, C. C., L. G. Doak, and J. H. Root. 1996. T*eaching patients with low literacy skills*, 2nd ed. Philadelphia, PA: J. B. Lippincott. http://www.hsph.harvard.edu/healthliteracy.

Funderburk, F. 2011. *Communicating about health insurance options: Some evidence-based best practices*. Paper presented at State Health Access Program All Grantee meeting. National Academy of State Health Policy and HRSA. Washington, DC, January 13, 2011. http://www.healthcarecommunities.org/showcontent.aspx?id=10951.

HHS (Department of Health and Human Services). 2010. *National action plan to improve health literacy*. Washington, DC: Office of Disease Prevention and Health Promotion.

IOM (Institute of Medicine). 2004. *Health literacy: A prescription to end confusion*. Washington, DC: The National Academies Press.

Kotler, P., and N. Lee. 2008. *Social marketing: Influencing behaviors for good*. Thousand Oaks, CA: Sage Publications.

Rudd, R. E. 2007. Health literacy skills of U.S. adults. *Journal of Health Behavior* 31(Supp 1):S8-S18.

Rudd, R. E. 2011. *Health insurance exchanges: Facilitating choice through health literacy interventions*. PowerPoint presentation at the Institute of Medicine workshop on Facilitating State Health Exchange Communication Through the Use of Health Literate Practices, Washington, DC.

Rudd, R. E., and D. B. Keller. 2009. Health literacy: New developments and research. *Journal of Communication in Healthcare* 2(3):240-257.

Rudd, R. E., L. Soricone, and M. Santos. 2006. *Health literacy study circles: Skills for health care access and navigation.* Cambridge, MA: National Center for the Study of Adult Learning and Literacy.

Sutton, S. M., G. I. Balch, and R. C. Lefebvre. 1995. Strategic questions for consumer-based health communications. *Public Health Reports* 110:725-733.

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Current Best Practices in Developing Materials and Communicating with Consumers

LESSONS LEARNED FROM THE STATE HEALTH INSURANCE ASSISTANCE PROGRAM (SHIP)

Marilyn Maultsby
Centers for Medicare and Medicaid Services

Congress authorized the State Health Insurance Assistance Program (SHIP) in 1990, Maultsby said. SHIP was originally designed to help consumers navigate the many Medicare supplement insurance choices offered through the Medigap program. There were about 10 different versions of Medigap coverage, and each state had its own rules and regulations pertaining to these plans. Consumers were faced with a great deal of complex information in making plan choices. The Medicare Modernization Act of 2003 added to the complexity, with consumers having to interpret changes to the Medicare program, especially the addition of the Part D benefit for prescription drugs.

The SHIP programs are federally funded by the Centers for Medicare and Medicaid Services (CMS) and are state-based. An increased level of programming has necessitated the increase of funding and support for this CMS program. It has grown to administering $50 million in basic grants in fiscal year 2011, from $10 million in 1991. The state network of SHIP programs now helps consumers understand all of the available Medicare benefits and services and, in addition, assists clients with Medicaid, long-term care insurance, and other programs such as the State Pharmacy Assistance Programs.

SHIP provides one-on-one counseling to beneficiaries, Maultsby said. The interaction with consumers can take a variety of forms, from home-based, one-on-one counseling, to telephone counseling, and communications at public events and fairs.

There are 54 SHIP programs in the 50 states, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands. Maultsby said that the grants to states and territories range from $37,000 (e.g., Guam) to $3 million and more (e.g., Pennsylvania, Florida, and California). During the last fiscal year (April 1, 2010, to March 31, 2011) the SHIP programs had over 2 million one-on-one client contacts. If we combine the number of one-on-one client contacts with people who were provided information and training at public outreach events, including enrollment events, close to 5 million people were served by SHIPs.

There was a 6 percent increase in the number of client contacts in the 2010 grant year compared to the prior grant year, Maultsby said. Of the roughly 15,000 counselors providing assistance, more than half are volunteers (57 percent). Recruiting, training, managing, and retaining volunteers is a very large undertaking. Ensuring that the volunteer coordinators receive sufficient training to manage the large and changing volunteer staff is very challenging to SHIPs. Providing training in volunteer management to SHIPs has been a CMS priority this past year.

Local SHIPs sponsor public and media outreach activities in conjunction with their CMS regional offices. There are 10 regional CMS offices across the country, and a number of partners at both the federal and local levels engaged with SHIPs in approximately 63,000 outreach events this past grant year compared to 55,000 the prior year. These efforts reach beneficiaries from all racial and ethnic groups and urban and rural areas. A penetration rate of SHIP services has been estimated using a formula that takes into consideration the number of beneficiaries served in counties, by zip code. This allows program directors to examine if they are reaching beneficiaries according to income level, such as in targeted geographic areas, Maultsby said.

The goal of the SHIP program is to provide local access to services. Having a 1-800 number at the state level is insufficient. Counselors need to be available at the local level to understand and meet local needs. An approach that works well in an urban area may not work well in a rural area. States have to devise different ways to provide information. In many rural areas, for example, there is no Internet access. The Iowa SHIP has developed a circuit rider program where counselors drive to areas on a regular basis to provide information and one-on-one counseling to beneficiaries.

To ensure that the information that counselors provide is accurate, timely, and appropriate, training is provided on a regular basis, Maultsby said. The state SHIP training programs vary, but there is a core set of information that programs must include that is based on CMS National Medicare Training Program (NMTP). Some states have a 1-week or 3-week face-to-face training period for counselors while other states may rely more heavily on online training tools. The online training is particularly popular for counselors in rural areas with Internet access because of the reduction in travel time and costs of trainers and volunteers. Face-to-face interaction with a trainer supplements the online training and reinforces the information learned online. CMS provides an online counselor certification tool that SHIPs may use to certify their counselors. The tool also helps to identify areas where additional training may be needed.

SHIPs are asked to implement quality assurance activities. In addition to a certification program, some SHIPs have used tools such as the Mystery Shopping Toolkit (developed in collaboration between CMS and SHIPs) to identify shortcomings in information learned and any need to retrain counselors on particular topics. Maultsby said she visits about eight or nine SHIPs a year to familiarize herself with local issues and concerns and identify best practices and opportunities for intervention and for program improvement.

The SHIP network has had a data system in place since 1998 to capture client contact information and information on outreach activities and (human) resources that are being used to counsel and inform beneficiaries and their caregivers. According to program data, beneficiaries generally learn about SHIP programs through other agencies or service providers, such as the Social Security Administration or a senior center, Maultsby said. Other beneficiaries have had previous contact with a SHIP, or learned about the program through the CMS Medicare website, a brochure, mailings, or the 1-800-MEDICARE telephone number. The 1-800-MEDICARE line often refers calls to the SHIP program, so counselors can provide more detailed information. Friends and relatives and state-specific sponsored events represent other opportunities for beneficiaries and their caregivers to learn about SHIP. The SHIP program likes to include caregivers as part of their target audience because beneficiaries, especially elderly beneficiaries, often rely on caregivers for information and support while making decisions.

In terms of how beneficiaries are contacted through SHIP, an estimated one-quarter of the 2 million contacts made are through phone calls, Maultsby said. Face-to-face communications at the 1,300 local counseling sites or an outreach event is the next most common type of contact. The SHIP sites are located in a number of different offices including state area agencies on aging (AAA), senior centers, and Retired Senior Volunteer Program (RSVP) volunteer sites. In order of frequency of use, next are face-to-face client contact at the client's home or facility, and then, providing information by e-mail, fax, and mail. E-mail is becoming a more popular vehicle for communicating with beneficiaries.

Maultsby said that the most frequently discussed topics during SHIP-beneficiary encounters are Medicare Parts, A, B, C, and D. Beneficiaries have questions about their benefits, eligibility, claims and billing, the appeals and grievance process, and issues related to fraud and abuse. There are also issues concerning union plans, Veterans Affairs (VA) benefits, Medigap plans, and long-term care. When indicated, counselors discuss the Children's Health Insurance Program (CHIP) because beneficiaries may have grandchildren or nieces and nephews that are in need of insurance coverage. With the passage of the Patient Protection and Affordable Care Act of 2010 (ACA), SHIPs are in a position to provide information about preexisting conditions, insurance plan coverage, or refer individuals so they can obtain information from the upcoming state exchanges about coverage options available to them.

CMS communicates with SHIPs in several ways, Maultsby said. There is a daily e-mail list on CMS policy and key initiatives. A monthly SHIP Forum Call is held to provide opportunities for training and feedback from SHIPs. These calls also allow for discussions of updates on CMS policies. There is a SHIP Steering Committee composed of SHIP directors that meets with the CMS Division of SHIP Relations on a monthly basis to address funding and policy issues and to discuss support tools for the SHIP network. SHIP counselors rely on the CMS Plan Finder tools at the www.medicare.gov website. This site allows beneficiaries to compare health plans. Information about plans may be mailed to beneficiaries and their caregivers so they can review the information and make an informed decision. SHIP counselors provide enrollment assistance using available tools from CMS and other agencies.

Maultsby said that Medicare beneficiaries tell the SHIP counselors that CMS information is becoming more complex. In response, CMS is examining ways to make systems more user-friendly, such as by using simplified charts, graphs, and diagrams to explain plan information. Print materials are being written using a plain language format that can be understood by consumers.

Maultsby described some of the challenges facing SHIP. First and foremost are state budget shortfalls. The state government in Minnesota, for example, recently shut down, and SHIP services had to be stopped because they were not determined to be a high priority. The SHIP was able to work with other partners so some services could be maintained. Another challenge facing SHIPs is the increasing demand for services, particularly from baby boomers and from returning disabled war veterans. A third challenge is the increasing complexity of Medicare information. This complexity contributes to the need for more time to adequately counsel a beneficiary. The average time spent counseling a beneficiary increased by 15 minutes over the past 4 years, so that it now takes an average of 37 minutes. Baby boomers seeking information from a SHIP are taking up more of a counselor's time because they tend to desire more information and want to discuss (and sometimes challenge) the information that is provided to them. A fourth challenge is the shifting role of SHIPs from that of educator and counselor to case manager and public benefits coordinator. And so, in addition to providing information and referrals pertaining to health care benefits, SHIPs are connecting people with housing, social services, and household needs such as food stamps and utility assistance. SHIPs are increasingly partnering with other federal agencies (e.g., Department of Housing and Urban Development, Department of Agriculture) and state programs to take a more holistic approach to providing services to beneficiaries.

Maultsby concluded by pointing out that SHIPs are addressing some of the same issues that the state health insurance exchanges have to address. SHIP counselors, for example, help beneficiaries understand plan benefits and costs and make decisions that are suitable to their circumstances.

HEALTH PLANS AND HEALTH LITERACY: LAYING THE FOUNDATION AND BEYOND

Susan Pisano, M.A.
America's Health Insurance Plans

Pisano said that America's Health Insurance Plans (AHIP) Health Literacy Task Force represents 50 health plans. The goals of the AHIP task force are to:

- Increase awareness of health literacy (leading to more health literacy programs),
- Identify and develop tools for plans to start up and advance their programs, and
- Share information and best practices.

Health plan representatives who sit on the task force include a diverse membership: medical directors, nurse educators, a pharmacist, and professionals engaged in the quality enterprise, cultural competency, disparities in health, and communications. Health literacy programs within the association's membership emerge from very different places within the plans represented on the task force.

The task force meets monthly, Pisano said. Recent speakers have included Institute of Medicine (IOM) Roundtable on Health Literacy members Arthur Culbert and Cindy Brach, as well as Pamela Peterson, who is the lead author from Kaiser Permanente's recent study on health literacy and outcomes among patients with heart failure (Peterson et al., 2011).

Tools developed by the task force include the following:

- A health plan assessment tool allows plans to judge whether their infrastructure can support good health literacy programs. This tool, developed with Dr. Julie Gazmararian of Emory University under a Robert Wood Johnson Foundation (RWJF) grant, has been pilot-tested in 18 plans and is now in general use.[1]
- A toolkit outlines the five basic steps to start and advance a health literacy program.
- A model policy is available for organizations to adapt and adopt health literacy programs.
- A mentoring program matches professionals from health literacy programs that are more advanced with people in companies that are at the early stages of program development.

Pisano said that progress has been achieved as a result of these efforts. Health plans have contacted the task force to learn more about the available tools. In addition, new members have been recruited to the task force. Health plans with some health literacy activities under way are enhancing their programs. AHIP is writing a book based on interviews with plan representatives to publicize programs and their components.

Some questions about health literacy were added to an existing survey AHIP conducts that focuses on disparities, Pisano said. The disparities survey is supported by the RWJF. Results from this survey have allowed AHIP to track the progress made by member plans. In 2008, 69 percent of AHIP members had some elements of a health literacy program. By 2010, 83 percent of plans had a health literacy program. Roughly half of these health literacy programs were housed within the health plan's disparities or quality improvement initiative. Health literacy activities have also been integrated into programs directed to improve cultural and linguistic services or patient satisfaction. Companies were asked if they had in place certain components of a health literacy program. The following are some responses:

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[1] Some plans have used the organizational assessment as a way to jump-start a program, while others have used the assessment as a planning tool; many use it both ways.

- In 2010, almost all health plans were adopting a targeted reading level for written consumer communication (90 percent) and standardizing member communications in clear, plain language (81 percent).
- Since 2008, health plans improved awareness and training among plan staff on the "principles of clear communication," specifically those who prepare written communication for members or those that interact with members (58 percent to 71 percent in 2010).
- Sixty-seven percent of health plans in 2010 were ensuring that all documents, including those translated from English into other languages, met a targeted reading level.
- About two-thirds of health plans have adopted a company-wide approach to clear communication through the development of policy and procedures.

The AHIP task force asked companies to report if they had completed specific activities related to improving the readability of written documents for their members. By 2010, almost all plans aimed to write materials in clear and plain language and aimed to meet a target reading level. Other methods reported to improve readability include avoidance of jargon and medical terms, and inclusion of materials in languages other than English.

Many plans have brought together teams of professionals from all of the units that touch consumers via the written or spoken word to address health literacy, Pisano said. Some companies have included lawyers and compliance staff. Many have assessed their organization's practices to determine if they have the infrastructure in place to provide clear, easy-to-access and easy-to-use information. Forms and materials from their member services area and nurse call-in area are among those being evaluated with the AHIP assessment tool.

Virtually all plans have adopted a targeted reading level, Pisano said. Many plans have conducted inventories of jargon and acronyms used in the company and have put together tools with words to avoid and words to use as alternatives. These are generally company-specific as companies have tended to develop their own languages.

Pisano said that many plans have checklists (and some use electronic tools) for evaluating written documents. These are composed of the important elements for assuring that the documents conform to principles of clear health communications. Typically, the companies have an extended backup guide to help staff so they have the information they need to do a good job of developing documents. Increasingly, there is a company-wide requirement that new documents and those being revised must conform to principles of clear health communication.

Many plans have provided training to a broad group of employees, first to increase awareness and then to enhance skills. One of AHIP's member companies requires all of its employees to have at least a basic understanding of health literacy and plain language. This company has recognized that providing clear information to patients improves patient satisfaction and loyalty to a health plan, Pisano said. There is some pre-testing, particularly of major documents, but this is expensive. Plans are creative about measurement and feedback. Some may informally test materials with employees within the company who do not have responsibilities for medical or benefits information. Some plans have begun their work focusing on medical information, while others have prioritized benefits information.

Pisano concluded by saying that work on improving written communication tends to be at a more advanced stage than work on verbal communication. However, work in both areas is flourishing.

DISCUSSION

Cindy Brach, roundtable member, asked Maultsby how the model of using volunteer counselors within the SHIP program might be applicable to the state health insurance exchanges. She asked Maultsby to provide further information about how volunteers are recruited and trained, if there are retention problems, and how the quality of the volunteers' work is monitored. Maultsby said that the role of navigators or counselors who can provide one-on-one assistance is essential to the success of any program. The SHIP program follows a case management model to support beneficiaries. About half of the SHIP volunteers are 65 and older.

The SHIPs are looking for new models to recruit volunteers, Maultsby said. For example, 3 years ago the Ohio SHIP developed the Counselor, Recruiter, Educator, Administrator, Marketer (CREAM) Team. To encourage recruitment, volunteers were welcomed to assume any of these roles. This strategy has worked well. Having a sufficient number of trained counselors is essential to SHIP's success. Some counselors specialize in one aspect of Medicare coverage, such as Part D. This is acceptable as long as the counselor can refer a client to others to address questions related to other topics.

Maultsby said that SHIP has sometimes used college students during the annual open enrollment period, and particularly pharmacy students. These students are adept at helping beneficiaries compare Part D plans, taking into account the number and type of medications that the client is taking. Some of the college students return year after year, or intermittently during the course of the year to provide counseling services.

Maultsby described a trend over the last 3 years of a greater degree of turnover among the volunteers. However, the absolute number of volunteers has increased. Turnover with SHIP directors has been problematic, Maultsby said. One-quarter to one-third of the SHIP program directors needs to be replaced each year. These are primarily midlevel state employees, and they tend to advance to other positions within state government or gain employment with health plans.

In terms of quality monitoring, CMS evaluated the SHIP programs using mystery shopping telephone calls or visits and identified access problems in some state programs, Maultsby said. For example, the anonymous shopper would call the programs and there would be no answer, or the call took 3 or 4 days to be returned. When visited, some of the programs were not staffed, or the personnel were out to lunch. Counselor knowledge of key Medicare information in the form of scenarios was tested through calls or visits to the programs. This evaluation technique was too expensive to maintain on an ongoing basis, and so a mystery shopping toolkit was developed under contract to provide states with guidance on how to develop the scenarios, conduct the anonymous calls and visits, protect confidentiality of information, and analyze the data. This technical assistance has helped states conduct evaluations of their SHIPs, Maultsby said. Some states also conduct customer satisfaction surveys.

Yolanda Partida, roundtable member, asked Pisano if the health literacy projects that are going on in the health plans around written communication are being shared across plans. Pisano said that she had been conducting interviews with 30 plans so she could learn of the various ongoing projects and then share that information with other plans. Roundtable chair George Isham added that some of this work has been stimulated by discussions held at the IOM roundtable meetings. Pisano agreed and mentioned that a roundtable member, Carolyn Cocotos, encouraged the AHIP task force to develop a strategic plan. A strategic plan has been developed and is reviewed and updated annually.

Lynn Quincy, Consumers Union, asked Maultsby if there was a mechanism for the SHIP counselors to collect program feedback that is shared with CMS. In reply, Maultsby discussed the Division of SHIP Relations Response Team. This team includes three people who respond to inquiries, suggestions, and comments that come in through the CMS SHIP mailbox. If there are questions that concern CMS policy, there is a list of CMS subject matter experts who are contacted for answers. The answers are shared throughout the program. Counselors have access to a list of frequently-asked questions through the SHIP website.

Quincy asked if, for example, a number of clients had difficulty understanding the term *Part D*, and if the counselors had success explaining Part D using other terms, would there be a mechanism for sharing that type of information with policy makers? Maultsby indicated that the response team would be one way to share such information. Another dissemination vehicle is the Communications Subcommittee of the SHIP Steering Committee. The steering committee includes nine SHIP directors elected from among the SHIP network. This subcommittee reviews the *Medicare and You Handbook* and beneficiary letters. Each year, as the Medicare handbook is updated, the SHIP network serves as a focus group to vet information and content. Information is also shared during the monthly SHIP Forum calls. These calls sometimes include the Aging Network.[2] There can be as many as 300 participants on those calls.

Ruth Parker, roundtable member, asked Pisano about her insights concerning incentives for plans to reduce the cognitive load for consumers, and thereby reduce the dread that consumers feel when having to choose a plan. Parker noted that standardization of content can decrease cognitive load, and this may be part of the answer. Pisano cited some of the results of the consumer testing discussed by Quincy. That research suggests that consumers are extremely happy with a template and a succinct summary of the essential elements of a plan, as long as it is very clear where additional information is available and is easy to access. The option of easily accessing additional information engenders trust. There has been a tendency to tell potential enrollees everything they might want to know, or ever need to know, Pisano said. Refocusing efforts on what consumers want and need to know is a major shift in educational strategy. The research literature also identifies the effect that health literacy has on a plan's bottom line. If patients are engaged, they will have better health outcomes. Successful patient engagement depends on the quality and clarity of the information that is provided.

One audience member commented on the communications within and across SHIPs, saying that these communications provide an opportunity for feedback, interaction, and dissemination of research results to the SHIP counselors so they can integrate these findings into their practice. SHIPs have also been involved in incentive programs. For example, enrollment in the low-income subsidy was a performance requirement. The SHIPs were able to earn bonuses to supplement their general grant if they documented meetings with clients who were eligible for the subsidy. Some of the SHIP activities have relevance to the work of navigators within the exchanges, he said.

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[2] The National Aging Network is a program of the Administration on Aging (AoA). AoA awards funds for nutrition, supportive home and community-based services, disease prevention/health promotion services, elder rights programs, and caregiver support programs to state units on aging, Area Agencies on Aging, tribal organizations, and native Hawaiian organizations. Available at: http://www.aoa.gov/AoARoot/AoA_Programs/OAA/Aging_Network/Index.aspx (accessed August 12, 2011).

Maultsby said that it is important to include providers, especially primary care physicians, in the information exchange. She asked if there is a role for SHIPs to be providing outreach to doctors' offices to move the health literacy agenda forward. Isham discussed the importance of community collaboration to bring all relevant parties together. There are many opportunities to create community conversations around health literacy that involve doctors, hospitals, health plans, and others, he said.

Another audience member suggested that navigation programs could be assessed using a model such as the institutional review boards. Pisano discussed the feasibility of having a checklist of items against which to evaluate an exchange or a navigator program. An important item on that checklist would be local community engagement. Maultsby said that consumer input at some level is necessary so local needs and available services are recognized at regional and state levels. The audience member stated that input from the navigators is also key to program success. Isham agreed and highlighted the need for people working within a system to be integrated into the feedback loop so their knowledge and experience can be harnessed to improve services.

An audience member noted that many of the brochures provided in clinic settings are very technical. Some of these are written and distributed by pharmaceutical companies. She asked the panel if there were incentives that states could put in place that would encourage resource providers to develop materials with health literacy in mind. Roundtable member Margaret Loveland described Merck's health literacy program. At Merck, all patient educational materials are reviewed using a health literacy checklist. One factor that prevents materials from adhering to health literacy practices is the inclusion of information about branded products. If they include such information, the material must mention the fair balance information[3] on the product label. This product information is generally not written to adhere to health literacy best practices. Discussions about the need for improvements in product labeling information are ongoing with the Division of Drug Marketing, Advertising, and Communications of the U.S. Food and Drug Administration. Loveland indicated that Merck's unbranded print materials are improving and that other pharmaceutical companies are also considering health literacy in their communications. Isham discussed the roundtable's work on pharmaceutical labeling (IOM, 2008) and wondered if similar issues might arise for state health insurance exchanges if there are legal requirements regarding disclosure of health plan details. He asked whether any such

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[3] "In direct-to-consumer advertising, fair balance refers to the presentation of accurate and fair assessment of the risks as well as the benefits of the drug." Available at: http://www.pharma-mkting.com/glossary/fairbalance.htm (accessed August 25, 2011).

requirements compromise the exchanges' ability to provide plan information in easy-to-understand terms.

Parker added that pharmaceutical companies are finding that there is a return on investment when they use health literacy principles as part of their marketing practices. Pisano mentioned that AHIP's model policy encourages member plans to only contract for the development of materials with vendors who have staff who are knowledgeable about health literacy. Progress will be made as private companies and government agencies require vendors to state how they are going to ensure their products will comply with principles of clear health communication.

REFERENCES

IOM (Institute of Medicine). 2008. *Standardizing medication labels: Confusing patients less*. Washington, DC: The National Academies Press.

Peterson, P. N., S. M. Shetterly, C. L. Clarke, D. B. Bekelman, P. S. Chan, L. A. Allen, D. D. Matlock, D. J. Magid, and F. A. Masoudi. 2011. Health literacy and outcomes among patients with heart failure. *JAMA* 305(16):1695-1701.

6

Reflections on Lessons Learned

George Isham, roundtable chair and workshop moderator, invited members of the roundtable and members of the workshop planning committee to reflect upon lessons learned during the workshop. Cindy Brach, roundtable member, noted that vastly simplified written materials and easy-to-navigate websites are necessary for individuals facing health insurance choices, but that even with these tools available, some individuals will need personal help. Brach indicated that navigators are going to be critical to achieving the enrollment goals of the Patient Protection and Affordable Care Act (ACA), and, in addition, to ensuring that individuals are able to make appropriate insurance choices. She highlighted the opportunity to incorporate health literacy into the training of patient navigators through the work of the National Association of Insurance Commissioners as they create a training template for the exchange patient navigators. Roundtable member Susan Pisano agreed that an excellent training program for navigators is one of the most important contributions that could be made to assure optimal functioning of the state health insurance exchanges.

Melissa Houston, roundtable alternate member, highlighted the importance of standardizing some of the core elements of the health exchanges. She said that standardization is necessary to prevent duplication of effort and to maximize the efficiency and effectiveness of the exchanges. Standardization could apply to the training of navigators and to the development of consumer-friendly websites and other communication aids.

Roundtable member Yolanda Partida applauded the involvement of health plans in promoting health literacy, and in particular, the focus on developing standards for user-friendly language and improving methods to communicate complex health insurance information. Once this information is available in an understandable format in English, it will be easier to translate information across languages and culture.

Ruth Parker, roundtable member, discussed the potential importance of the Plain Language Act of 2010 to the operation of the exchanges, particularly the enrollment processes. Parker said she was impressed by how large a segment of the population will be engaged with the health insurance exchanges. She suggested that the enrollment process will improve, in part, because of the magnitude of the audience that needs to be reached. It may be that individuals will liken the process of enrolling in a health plan to the national tax system. There is a federal process to file taxes, and there is a state process. People are aware that there are multiple forms and that some of these forms are relevant to some and not to others. When filing taxes, personal assistance is available through accountants. Navigators will be available to assist those needing help in making insurance choices. Exchanges need to be demystified and their functions understood by using clear, standardized language. Isham added that the analogy to the tax system should stop short of the frustrations that many experience. Instead, the model of the tax system is appropriate in the use of easy-to-use forms with customization where necessary.

Martha Gragg, roundtable member, noted that the awareness of health literacy principles has increased in the last few years, especially among health plans. She suggested that employers, as critical determinants of employee insurance options, need to become more aware of issues related to health literacy.

Linda Harris, roundtable member, expressed concern that some states might be overwhelmed in trying to develop a health insurance exchange. Effort will be needed to assure clear communication that incorporates considerations of health literacy, cultural competency, and language diversity. States will need to create mechanisms to inform and enroll hard-to-reach populations that are currently not insured, she said. Community-based organizations will have to be engaged to bring such individuals into the system. Harris said that a repository of the literature and materials on health literacy relevant to the exchanges would be potentially very useful.

Will Ross, roundtable member, noted that enrollment in some of the exchanges has been lower than expected and that it is the responsibility of the exchanges and health plans to improve their relationship with consumers. Market research has shown that consumers are overwhelmed and fearful of making health insurance choices, he said. The onus is on the exchanges to improve the experience of choosing and then enrolling in a health plan. Ross highlighted the importance of standards that apply to health plans. If high-performing health plans were certified in some way, the plans would have an incentive to adhere to the standards, and it would be easier for consumers to identify quality plans.

Arthur Culbert, roundtable member, said he was encouraged by the availability of market research that reveals some of the barriers and opportunities to reaching consumers with information about health insurance options. There are tremendous opportunities to build trust with clients at the state level through the health insurance exchanges. In addition, the growing number of state centers of health literacy can partner with the exchanges to promote best practices in health communication. Culbert added that the development of successful state health insurance exchanges should be considered apolitical and a responsibility of the nation.

Margaret Loveland, roundtable member, was impressed by the complexity of health insurance exchanges. Health literacy considerations, the use of plain language, and recognition of language diversity are key to improving the process of health insurance enrollment for consumers, she said.

Benard Dreyer, roundtable member, found the research that has been conducted on consumer experiences with health insurance very informative. He noted, however, that while the research identifies what consumers want to know, there is less research related to how to communicate health insurance information to consumers. There is a very large cognitive load associated with health insurance information. Health literacy comes into play in any attempt to reduce this cognitive load. Strategies are needed to condense the amount of information that people need to make informed choices among plans, Dreyer said. He discussed the particular challenges faced by people whose primary language is not English and the need to incorporate appropriate accommodation for speakers of other language into the exchanges. Dreyer also cautioned that although the Internet is a powerful tool, it is not a solution to many communication challenges. Many people do not use the Internet, and other popular communication modes such as texting and tweeting are not particularly well suited to complex decision making. In-person assistance through the navigators will be critical to an exchange's success, Dryer said, and he expressed some concern that there would be an inadequate supply of navigators to meet the needs of the many individuals who will be gaining access to health insurance through the state exchanges.

Andrew Pleasant, roundtable member, noted that 75 percent of health care expenditures are spent on treating or managing preventable chronic disease. Health literacy is one of the most powerful tools to prevent these unnecessary expenditures. One of the positive messages of the day's proceedings, he said, is the advancement that health literacy has made in the last decade. There are remarkable opportunities to infuse health literacy into the 50 state health exchanges. These exchanges could help foster a paradigm shift, from thinking of health insurance as a product to assist with acute and chronic care conditions to thinking of it as a product to help reach optimal health. This paradigm shift will occur if health literacy is infused into the health communications enacted by the state exchanges, he said.

Debbie Fritz, roundtable member, stated that some sort of interface is needed for the exchange of information among exchanges so best practices are shared among the states. To effectively communicate with consumers, information will have to be condensed to be useful in decision making. Lessons from quality improvement endeavors may be instructive, she said. Many initiatives have invested in measuring quality within health systems and monitoring consumers' perspectives of quality. There are also lessons on communication from Medicare's Part D program. The Centers for Medicare and Medicaid Services (CMS) has developed a star program so consumers can look at overarching plan information instead of having to read all of the plan details. Consumers may access the plan details, but CMS has assembled the information so consumers are not subject to cognitive overload.

Scott Ratzan, roundtable member, commended Frank Funderburk for incorporating consumer motivation in the roundtable's health literacy framework. That framework included the skills and abilities of consumers, and the demands and complexity of health decision making. Motivation is key to consumer behavior, Ratzan said, whether that behavior involves the renewal of a health plan or engaging in preventive health programs. The lessons from health literacy permit the tailoring of messages through social marketing to increase motivation. Ratzan added that new technologies hold great promise. For example, mobile phones have fully penetrated the United States, with some members of the population having multiple phones or devices. Links between these devices and CMS or health exchanges must incorporate health literacy attributes.

Isham discussed the existence of a policy gap between the design of the health insurance exchanges and their anticipated performance. In his experience as a leader in a large, not-for-profit health care system with a track record of significantly improving patient experience, progress does not occur by chance. Change occurs through thoughtful deliberation and careful design of key elements of large systems. A concern raised during the day's proceedings related to the capacity to meet the need for person-to-person assistance as part of the navigator program. Such support will likely be in demand and is costly to deliver, Isham said. It will be important in program design to use the navigators judiciously and allow individuals with some familiarity with technology to benefit from web-enabled information systems.

Isham indicated that the population served by the state health insurance exchanges would differ from the Medicaid and Medicare population in terms of demographic characteristics, distribution of risk, and level of health literacy. The population served by the exchanges will have its own unique characteristics. Nevertheless, lessons learned from the Medicare and Medicaid programs will be applicable to the exchanges. He noted that there is a great deal of opportunity associated with the ACA. In some sense, this is the current generation's mechanism to address the chronic problem of access to health care in the United States. It is not perfect, but it represents an opportunity.

Isham invited questions from the audience. Ms. Garcia, from the University of Maryland, expressed a concern that complex health insurance information would be oversimplified and "dumbed down" under the guise of health literacy. There may be missed opportunities to educate patients about some of the complexities of health insurance coverage that they may want or need to know. There is a danger to simplification and presenting information at the level of the lowest common denominator. Isham responded that a very clear, simple interface is necessary for those needing basic information, but in addition, any system has to have the flexibility to provide detailed information to those who need it. This represents a complex design challenge. Funderburk added that the intent is not to aim communications to the lowest common denominator, because this level of information does not generally meet anyone's needs. It is important to understand the unique needs of segments of the population and then to provide those audience segments with the information they need. People have different cognitive styles and different experiences in dealing with health care information. Initial interfaces can be designed to be responsive to most people's needs most of the time. Systems can then be designed to alert consumers when further information can be accessed.

Pisano discussed the notion of consumers liking a simple template, but at the same time wanting to know where to get more information. Some of her research with physicians showed a similar pattern. They wanted clinical information to be presented in a simplified manner but to be able to drill down to obtain detailed information. This desire for information needed at the moment, but available in more detail, is likely a universal principle.

Isham concluded the workshop by thanking the roundtable members for their participation and their questions and the presenters for their contributions to a very informative workshop.

A

Workshop Agenda

9:00–9:10 **Welcome and Overview**
George Isham, Chair, IOM Roundtable on Health Literacy

9:10–10:15 **State Health Insurance Exchanges—Overview**

9:10–9:30 ACA: Creating state insurance exchanges
Alice Weiss
Deputy Director for Maximizing Enrollment for Kids
National Academy for State Health Policy

9:30–9:50 Lessons learned from currently operating health exchanges
Sabrina Corlette
Research Professor
Health Policy Institute
Georgetown University

9:50–10:15 Discussion

10:15–10:30 BREAK

10:30–11:45 **State Insurance Exchanges Impact on Consumers**

10:30–10:50 How do consumers understand health insurance concepts, or do they?
Lynn Quincy
Senior Health Policy Analyst
Consumers Union

10:50–11:10 The challenge of health insurance language
Yolanda Partida
Director, National Program Office
Hablamos Juntos

11:10–11:45 Discussion

11:45–1:00 LUNCH

1:00–2:15 **Health Literacy Relevance to Health Insurance Exchanges**

1:00–1:20 Why is health literacy relevant to health insurance reform, generally?
Frank Funderburk
Director, Division of Research
Center for Medicare and Medicaid Services

1:20–1:40 Facilitating correct choices through health literacy interventions
Rima Rudd
Department of Society, Human Development and Health
Harvard School of Public Health

1:40–2:15 Discussion

2:15–2:30 BREAK

2:30–3:30 **Current Best Practices in Developing Materials and Communicating with Consumers**

2:30–2:50 Lessons learned from SHIP on individual counseling
Marilyn Maultsby
Director, Division of SHIP Relations
Center for Medicare and Medicaid Services

2:50–3:10 Health Plans and Health Literacy: Laying the Foundation and Beyond
Susan Pisano
Director of Communications
America's Health Insurance Plans

3:10–3:45 Discussion

3:45–4:15 **Summing Up: Lessons Learned**
Panelists and roundtable members

4:15–5:00 Discussion

5:00 ADJOURN

B

Workshop Speaker Biosketches

Sabrina Corlette, J.D., is a Research Professor at the Health Policy Institute at Georgetown University in Washington, DC. There she directs research on health insurance reform issues as they affect consumers and patients. Her areas of focus include state and federal regulation of private health insurance plans and markets and implementation of new insurance market rules under the Affordable Care Act (ACA). She trains individuals and organizations on federal and state health insurance laws and programs and provides technical support through the development of resource guides, white papers, issue briefs, and fact sheets.

Prior to joining the institute faculty, Ms. Corlette was Director of Health Policy Programs at the National Partnership for Women & Families, where she provided policy expertise and strategic direction for the organization's advocacy on health care reform, with a particular focus on insurance market reform, benefit design, and the quality and affordability of health care.

From 1997 to 2001, Ms. Corlette worked as a professional staff member of the U.S. Senate Health Education, Labor and Pensions (HELP) Committee, where she served as health legislative assistant to Senator Tom Harkin (D-IA). After leaving the Hill, Ms. Corlette served as an attorney at the law firm Hogan Lovells (formerly Hogan & Hartson LLP), where she advised clients on health care law and policy relating to the Health Insurance Portability and Accountability Act (HIPAA), Medicare and Medicaid, and the Food, Drug, and Cosmetic Act.

Ms. Corlette is a member of the DC Bar and received her J.D. with high honors from the University of Texas at Austin and an A.B. from Harvard University.

Frank Funderburk joined the Centers for Medicare and Medicaid Services (CMS) Division of Research in 2007. He is currently responsible for the strategic planning, implementation, and analysis of a variety of health care research efforts that support and enhance CMS communications activities. He is especially interested in developing data-driven communication strategies that can overcome persistent informational, attitudinal, and motivational barriers to better health care, including those related to health and digital literacy. His research has included evaluation of the effectiveness of a variety of outreach and education campaigns as well as a recent experimental study of direct marketing strategies for improving outreach to vulnerable beneficiaries eligible for but not enrolled in the Low Income Subsidy. He has investigated ways in which health care decision-making style can influence beneficiary perception of Medicare programs as well as receptivity to specific outreach and communication activities. His work has helped to inform recent initiatives encouraging adoption of electronic health records and quality initiatives such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) public reporting of consumer's hospital experiences.

Prior to joining CMS, Mr. Funderburk was an analytic scientist at the Delmarva Foundation for Medical Care where he directed external quality review for Medicaid programs in nine states and the District of Columbia. He also worked with states to develop innovative outreach programs to improve the quality of care and the quality of life of people receiving Medicaid.

Mr. Funderburk has over 20 years of health care, health communications, and health policy research experience ranging from basic scientific studies of brain-behavior relationships involved in decision making to large multicenter clinical trials of new pharmaceutical products as well as national surveys of consumer behavior.

Marilyn D. Maultsby is director of the Division of State Health Insurance Assistance Program (SHIP) Relations, in the Office of External Affairs and Beneficiary Services, at the Centers for Medicare and Medicaid Services (CMS), in Baltimore, Maryland. She has held this position since 2006. The Division of SHIP Relations provides management and oversight of CMS-funded grants to SHIPs in the 50 states, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands. The division also provides information, training, and technical support to these programs.

As director of the Division of SHIP Relations, Ms. Maultsby has played a key role in the development and implementation of a performance measurement system for the SHIP network, the provision of SHIPs' access to a designated 1-800-MEDICARE number, the implementation of enhancements to the SHIP National Performance Reporting System, and in training new SHIP directors.

Prior to coming to CMS, Ms. Maultsby was executive director of the Maryland Health Care Foundation, a nonprofit, charitable organization established in 1997 by the Maryland State General Assembly to support efforts to improve access to health care services to uninsured and underinsured persons in the state. The foundation served as an incubator for innovative programs to improve access to health care services for the uninsured and underinsured. Program results provided information for regulatory and legislative decision making.

In addition to her work at the foundation, Ms. Maultsby has over 30 years of experience in the health care industry, including as Vice President of Strategic Planning and Administration for Blue Cross Blue Shield of Maryland, Director of Sales and Marketing for Maryland Fidelity Insurance Company, and Director of Planning for the Maryland State Health Planning and Development Agency.

Ms. Maultsby's community involvement has included serving as president of the Maryland State Board of Education, treasurer of the Northwest Hospital Center Board of Trustees, and as a member of the President's Advisory Council of Villa Julie College (now Stevenson University). She has also chaired the Boards of Directors of Associated Black Charities, Girl Scouts of Central Maryland, and the House of Ruth. In recognition of her mentoring, professional, and community achievements, Ms. Maultsby was inducted into the Circle of Excellence of the Daily Record's Maryland's Top 100 Women Award.

Yolanda Partida, M.S.W., D.P.A., is director of the National Program Office for Hablamos Juntos: Improving Patient-Provider Communication for Latinos, an initiative of the Robert Wood Johnson Foundation (RWJF) to improve access to quality health care for Latinos with limited English proficiency. Hablamos Juntos (We Speak Together) is working with 10 demonstration sites around the country to develop affordable ways health providers can offer language services. Grantees are implementing seven program requirements in three benchmark areas: (1) increasing the availability and quality of interpreter services; (2) developing useful health-related materials in Spanish; and (3) supporting the development of symbols-based signage to help patients find their way around health care facilities.

Dr. Partida has extensive experience in public teaching and private hospital administration, as well as public health administration and public policy. She has consulted on health policy and management, implemented cross-border public health strategies in the most populated U.S.-Mexico border region, and helped launch Healthy San Diego, a multihealth plan managed care program for Medicaid patients. Dr. Partida received her D.P.A. from the University of Southern California, School of Policy, Planning, and Development.

Susan Pisano, M.A., is the vice president of communications for America's Health Insurance Plans (AHIP). She acts as a spokesperson for AHIP and is responsible for outreach to member companies, the news media, and other major audiences. She is the primary staff member for AHIP's Health Literacy Task Force.

Ms. Pisano has worked at AHIP since 1987. Before coming to AHIP, she was the public relations director at Pacific Medical Center in Seattle, Washington, a local institution affiliated with a health maintenance organization (HMO) since 1985. She began her career at Pennsylvania Hospital in Philadelphia, and received her bachelor of arts degree at Chestnut Hill College in 1971 and her master of arts degree in 1975 from Villanova University.

Lynn Quincy is a senior policy analyst with the Consumers Union. She works on a wide variety of health policy issues, with a particular focus on consumer protections, health insurance literacy, and health insurance reform at the federal and state levels. Ms. Quincy serves as a consumer representative with the National Association of Insurance Commissioners (NAIC). Her recent work includes three studies examining consumer reactions to the new health insurance disclosure forms being developed by the NAIC. Prior to joining Consumers Union, Ms. Quincy was a senior researcher with Mathematica Policy Research, Inc., where she performed policy analysis, provided technical assistance, and modeled outcomes in support of state coverage expansion strategies. She also held senior positions with the Institute for Health Policy Solutions and Watson Wyatt Worldwide (now Towers Watson). She holds a master's degree in economics from the University of Maryland.

Rima Rudd, Sc.D., is the Senior Lecturer on Society, Human Development, and Health at the Harvard School of Public Health. Her work centers on health communication and on the design and evaluation of public health community-based programs. She has been teaching courses on innovative strategies in health education, program planning and evaluation, psychosocial and behavioral theory, and health literacy since 1988.

Dr. Rudd is focusing her research inquiries on literacy-related disparities and literacy-related barriers to health programs, services, and care, working closely with the adult education, public health, oral health, and medical sectors. She wrote several reports that have helped shape the agenda in health literacy research and practice. They include the health literacy chapter of the Department of Health and Human Services report *Communicating Health: Priorities and Strategies for Progress* (2003), the Educational Testing Services report *Literacy and Health in America* (2004), and two in-depth literature reviews (*Review of Adult Learning and Literacy*, volume 1 in 2000 and volume 7 in 2007). She served on the Institute of Medicine's Committee on Health Literacy, the National Research Council Committee on Measuring Adult Literacy, the National Institute of Dental and Craniofacial Research Workgroup on Oral Health Literacy, on the Joint Commission Advisory Committee on Health Literacy and Patient Safety, and contributed to the ensuing reports and white papers.

Dr. Rudd currently serves on the National Health Literacy Advisory Board for the American Dental Association and is the Senior Health Literacy Advisor for the Missouri Foundation. She is a visiting professor in the Faculty of Health and Social Care, London Southbank University, and was appointed the visiting Health Literacy Scholar at the Horowitz Center on Health Literacy at the University of Maryland, School of Public Health. She is a coprincipal investigator on several ongoing health literacy research projects. Dr. Rudd is considered a leader in this growing field of research and practice.

Alice M. Weiss, J.D., is the codirector of Maximizing Enrollment, a $15 million Robert Wood Johnson Foundation initiative directed by the National Academy of State Health Policy (NASHP) that helps states increase enrollment of children eligible for public health coverage and prepare systems for enrollment of newly eligible populations. Weiss also contributes to NASHP's health reform implementation work, mostly in projects supporting peer-learning by states in efforts to improve to eligibility and enrollment systems. Weiss previously served as Health Counsel for U.S. Senate Finance Committee Chairman Max Baucus (D-MT), working on Medicaid, the Children's Health Insurance Program (CHIP), and private health insurance legislation. In that capacity, she drafted legislation to reform Medicaid, provided an emergency health coverage response to Hurricane Katrina, improved the Native American health coverage system, and reauthorized the CHIP program. Weiss has also held key policy positions with the U.S. Department of Labor and the National Partnership for Women & Families focused on the Employee Retirement Income Security Act (ERISA), private insurance and Medicaid legislation, rulemaking, and litigation policy. In those positions, Weiss played a central supporting role in the creation of Patients Bill of Rights legislation and ERISA internal claims procedure rules, testified before Congress, led coalition legislative campaigns, and represented consumer interests before the National Association of Insurance Commissioners as a funded consumer representative. Weiss received her bachelor of arts from Haverford College and her Juris Doctorate from Northeastern University Law School.

C

Statement on Health Plan Leadership in Advancing Health Literacy and Clear Health Communication

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Submitted to the
Institute of Medicine
Health Literacy Roundtable Meeting
"Facilitating Health Exchange Communication Through the Use of Health Literate Practices"

July 19, 2011

I. INTRODUCTION

My name is Susan Pisano, Vice President for Communications at America's Health Insurance Plans (AHIP), and I am pleased to be here today to discuss the important topic of health communication and health literacy. AHIP is the national trade association representing the health insurance industry. Our members provide health and supplemental benefits to more than 200 million Americans through employer-sponsored coverage, the individual insurance market, and public programs such as Medicare and Medicaid. AHIP advocates for public policies that expand access to affordable health care coverage to all Americans through a competitive marketplace that fosters choice, quality, and innovation.

We appreciate this opportunity to appear before the Institute of Medicine (IOM) Health Literacy Roundtable today. America's health insurers are committed to improving the health of the individuals and populations they serve and to making health benefits more affordable. My remarks today focus on the following areas:

- The importance of health literacy;
- How health plans are engaged in addressing health literacy; and
- Common approaches that can serve as models to assist other entities in improving health literacy.

II. THE IMPORTANCE OF HEALTH LITERACY

The National Action Plan to Improve Health Literacy released in May 2010 highlights the importance of engaging all stakeholders linked in a multi-sector effort to improve health literacy. The report highlights strategies that particular organizations or professions can take to further the key goals identified to improve health literacy.[1] Promoting change in the health care system through improved health information and communication, informed decision making, and developing and disseminating health information that is accurate, accessible, and actionable can have a demonstrable impact on the health and quality of life of millions of Americans.

Research shows clearly that health and benefits information plays an important role in the health status of individuals, and that those with poor health literacy who cannot easily access, understand, and act upon such information are more likely to experience poor health, less likely to be engaged in their care, have a harder time managing their chronic diseases, and more likely to incur significantly higher than necessary health care costs as a result.

A study recently published in the *Journal of the American Medical Association* by authors from the Kaiser Permanente organization found that patients with congestive heart failure and low health literacy are three times as likely to die in a given year as patients with better health literacy skills.[2] Several other studies and reports, including the recent Department of Health and Human Services (HHS) National Action Plan to Improve

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[1] Office of Disease Prevention and Health Promotion. (May 2010). *National Action Plan to Improve Health Literacy*. Washington, DC: U.S. Department of Health and Human Services.

[2] Peterson, P. N., S. M. Shetterly, C. L. Clarke, D. B. Bekelman, P. S. Chan, L. A. Allen, D. D. Matlock, D. J. Magid, and F. A. Masoudi. 2011. Health Literacy and Outcomes Among Patients With Heart Failure. *JAMA* 305(16):1695-1701. doi:10.1001/jama.2011.512

Health Literacy, document the importance of health literacy as a part of a person-centered process and essential to the delivery of cost-effective, safe, and high-quality health services.[3]

Increasingly, stakeholders across the health care system have recognized the important linkage between health literacy and health status, and are working to provide consumer health and benefits information that promotes "clear communication" and are (1) easy to access, understand, and act upon; (2) promote consumer engagement in their own health; and (3) result in better health outcomes.[4]

Achieving these goals requires a collaborative, system-wide commitment that involves all of the professionals, organizations, and disciplines communicating with consumers, whether directly or indirectly, via the spoken or written word. Because it brings together stakeholders from across the system, today's IOM meeting offers a unique opportunity at an important juncture to identify patient needs and share strategies at a time when tens of millions of previously uninsured Americans soon will have insurance coverage.

Nearly nine out of ten adults have difficulty using health information to make informed decisions about their health, profoundly affecting their health and access to care. Yet, by 2014, millions of newly insured populations will be accessing the system, and will need assistance in seeking appropriate providers and sites of care. Recognizing that consumers all too often are unable to understand medical terms and instructions, a collective effort by key stakeholders is needed to provide information consumers can understand and use to make decisions about their benefits, personal care and care for their families.

III. HOW HEALTH PLANS ARE ENGAGED IN ADDRESSING HEALTH LITERACY

Health plans view health literacy as a key component in engaging patients in self management of their chronic disease, in care during transitions (including transitions from hospital to home), in medication adherence, and in wellness and prevention. Health plan efforts to reduce disparities in care include programs such as cross-cultural training of physicians and other clinicians to improve communication and address health literacy. Written and verbal communication that can be easily understood

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[3] Office of Disease Prevention and Health Promotion. 2010, May. *National Action Plan to Improve Health Literacy*. Washington, DC: U.S. Department of Health and Human Services.

[4] *Health Literacy Universal Precautions Toolkit*. AHRQ Publication No. 10-0046-EF, April 2010. Rockville, MD: Agency for Healthcare Research and Quality. http://www.ahrq.gov/qual/literacy/index.html.

and acted upon can improve a consumers' ability to use their benefits to their fullest and maximize their own health.

A growing number of health plans are actively engaged in working to improve health literacy. Three years ago, with interest from other stakeholders, AHIP convened a Health Literacy Task Force, which includes representatives from about 50 member plans. The Task Force includes medical directors, nurse educators, and a pharmacist, as well as professionals engaged in the quality enterprise, cultural competency, disparities in health, and communications. It is focused on increasing awareness of health literacy and encouraging the development or expansion of health literacy programs. In addition, the task force identifies and develops tools to help health plans start up and advance their programs and share information and best practices.

The set of tools developed includes

- An organizational assessment tool, developed with Dr. Julie Gazmararian of Emory University under a grant from the Robert Wood Johnson Foundation. This tool was pilot-tested in 18 plans and is now widely used by plans to determine if they have the infrastructure in place to promote good written and verbal communications about health and benefits;
- A toolkit outlining the five basic steps to start and advance a health literacy program, including bringing together a team, making the case for moving ahead, assessing the organization, developing policies and procedures, and making an action plan, and training of staff;
- A model policy for organizations to adapt/adopt; and
- A "mentoring" program that matches professionals from programs that are more advanced with companies that are just starting out.

There continues to be significant startup activity in this area, with interested parties seeking information on program development and tools to sustain and advance ongoing health literacy programs. Health plans also have engaged with multiple public and private partners including the Agency for Healthcare Research and Quality to pilot test the health literacy Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey item set for health plans. This new survey item set will help examine consumers' perspectives on how well health information is communicated by health plans and health professionals in a health plan setting. This is a step forward in improving how plans and providers are addressing the health literacy needs of individuals and delivering health information that is understandable to the vast majority of Americans.

One-on-one interviews with our members also are providing insights into how health literacy programs are continuing to evolve. Although some initially focused on medical information and others focus on benefits information, these programs generally are evolving to embrace both.

Work in the area of written communication is generally more advanced. Many plans are now focusing more attention on verbal communication, and there is considerable activity in both areas. In fact, one of our member companies requires all employees to have some understanding of plain language by participating in a basic half-hour seminar. Some plans have begun to be interested in how they can use social media in a health literate way, as they move from a focus on more traditional means of communication to make use of the channels best suited to today's audiences. Finally, we are beginning to see the emergence of health plan-based research from plans that are interested in contributing to the body of evidence about health literacy and its potential.

Our biannual health plan surveys on disparities in health, funded by the Robert Wood Johnson Foundation, reveal increased activity in the foundational elements of health literacy programs, such as assessments and dissemination of low-literate materials, development of organizational policies, and training of staff.

Two years ago, this national survey showed that approximately 69 percent of plans responding had introduced some components of a health literacy program; this grew to 83 percent in 2010. About half of these programs are housed as part of health plans' disparities or quality improvement activities, while others are integrated into plan efforts in culturally and linguistically appropriate services, patient engagement, patient satisfaction, and communications and marketing.

In 2010, almost all health plans were adopting a targeted reading level for written consumer communications (90 percent) and standardizing member communications in clear, plain language (81 percent). Health plans also have improved awareness and training among plan staff, specifically those who prepare written communications for members or who interact directly with members, on the principles of clear health communication (increasing from 58.4 percent in 2008 to 70.6 percent in 2010). Sixty-seven percent of health plans in 2010 ensured that all documents, including those translated from English into other languages, meet a targeted reading level. Although not assessed in these surveys, the reading levels may vary across health plans and among states, with ranges from

4th to 8th grade reading levels.[5,6] About two-thirds of health plans adopt a company-wide approach to clear communication through the development of policy and procedures. Other common approaches to improving clarity and understanding of written communications included avoidance of jargon and medical terms and translation of materials in commonly spoken languages other than English.

IV. COMMON APPROACHES TO IMPROVING HEALTH LITERACY

Through national surveys, outreach, and interviews with our member plans, we have identified eight common approaches that could serve as models to assist other entities in improving health literacy:

- Assess the organization to determine if an infrastructure exists to provide clear, easy to use information.
- Convene teams of professionals from all of the organization's units that touch consumers via the written or spoken word to address health literacy. This allows infusion of health literacy across an organization.
- Use tools such as the organizational assessment as a way to jump start a program, or as a planning and prioritization tool.
- Adopted a targeted reading level.
- Conduct inventories of jargon and acronyms used by the company and create lists of "words to avoid" and "words to use" as alternatives. These are generally company specific as companies tend to develop their "own language."
- Create checklists (or electronic tools) for evaluating written documents to assure that they conform to principles of clear health communications.
- Consider a company-wide policy that new documents and those being revised must conform to principles of clear health communication.
- Provide training to a broad group of employees to increase awareness and enhance skills.

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[5] Gazmararian, J. A. 2009. *America's Health Insurance Plans' response to health literacy*. PowerPoint presentation at the Institute of Medicine workshop on measures of health literacy. Washington, DC, February 26.

[6] Health Literacy Innovations, LLC. 2007. *National survey of Medicaid guidelines for health literacy*. Bethesda, MD. http://www.healthliteracyinnovations.com/information.

Looking forward, the health plan community is intensely focused on improving communications to consumers, recognizing that clear written communications tend to be at a more advanced stage than clear verbal communications. Consumer testing of materials is an important priority for achieving further progress. While the costs associated with such testing and difficulty in getting consumer engagement have been limiting factors, health plans are creative in getting feedback on their materials, including obtaining this information through existing assessment tools or through employees who are engaged in activities unrelated to the materials being tested.

V. CONCLUSION

Thank you again for this opportunity to testify on this critically important issue. It is our hope that today's IOM meeting will advance the ongoing dialogue about how to infuse health literacy into care delivery and also pave the way for mechanisms that allow all entities to share information and tools across the health care system as the federal government, states, consumers, providers, and health plans gain experience in how to provide the structure and resources for consumers to use their health benefits and health information to their best advantage.