

# Measuring Health Insurance Literacy: A Call to Action

*A Report from the Health Insurance Literacy  
Expert Roundtable*

*Sponsored by:*

**Consumers Union**

*in partnership with*

**University of Maryland College Park**

*and*

**American Institutes for Research (AIR)**

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## Executive Summary

On November 14, 2011, a 1-day roundtable was held at the Kaiser Family Foundation in Washington, DC, to discuss a widely recognized, if poorly documented, problem: consumers' struggles to understand and use health insurance. A diverse group of experts from academia, advocacy, health plans, and private research firms brought their perspectives and experience to the meeting.

Consumer testing conducted by Consumers Union, a literature review conducted by American Institutes for Research<sup>®</sup> (AIR<sup>®</sup>), and the experiences of the participants confirmed two critical facts:

1. Consumers have serious difficulties understanding and using health insurance.
2. There is a dearth of usable information on the precise barriers facing consumers.

These health insurance difficulties take a toll on consumers' health and financial well-being, and they have cost implications for health plans and the nation.

Although we have a general impression that consumers struggle to understand health insurance, we lack a precise language for describing what is difficult for consumers about this product. As with many things, developing a "common language"—in the form of a widely accepted *health insurance literacy* measure—brings to the discussion precision as well as an ability to develop a sophisticated understanding of the barriers facing consumers.

A key proposition debated and agreed to by the panel was:

*A widely accepted measure of consumer health insurance literacy is fundamental to shaping effective consumer education, policy development, and research around health insurance "behaviors"; i.e., selection and use of health insurance.*

The expert panel endorsed the launch of a multi-stakeholder project to create a health insurance literacy measure. To provide the foundation for the project, the participants:

1. Explored and confirmed the need for such a measure,
2. Developed a preliminary concept of what a health insurance literate person would be able to do,
3. Crafted a working definition of health insurance literacy,
4. Discussed a preliminary conceptual model, and
5. Engaged in a robust discussion of how the measure would be used.

Roundtable participants arrived at the following working definition of health insurance literacy:

*Health insurance literacy measures the degree to which individuals have the knowledge, ability, and confidence to find and evaluate information about health plans, select the best plan for their own (or their family's) financial and health circumstances, and use the plan once enrolled.*

Participants also discussed timing and roles. Roundtable participants agreed that a health insurance literacy measure would be critical for supporting implementation of the reforms called

for by the Affordable Care Act. The Act calls for major reforms to begin on January 1, 2014, with open enrollment beginning in October 2013. Because of this timing, **the ambitious goal of the project team is to complete the formulation and testing of the measure by the end of 2012.** If we are able to adhere to this timetable, the measure—as well as the improved information that will arise from testing process—will be available to states, health plans, consumer advocates, and consumer educators to perform needs assessments, design new materials, and monitor the success of their outreach efforts and other policy decisions.

## **How to Participate**

Most importantly, the group talked about the need to involve a large and diverse group of stakeholders. For the new health insurance literacy measure to have an effect, it will have to be developed rigorously with the input of this diverse group spanning the academic, public, and private sectors, and including policymakers, regulators, health insurance plans, consumer educators, and consumer advocates.

The final section of this report includes detailed instructions about how interested stakeholders can become involved in the project. We welcome participation in these key areas:

- Forward the report to colleagues and follow progress of the project by **subscribing** to our Listserv.
- **Respond** to the proposed building blocks in this report.
- Participate in the **Research Committee** through peer review, formative development, field testing, or creation of the business case.
- Participate in the **Action Committee** so that the new measurement tool(s) is widely disseminated and provides actual benefit to consumers.
- Help us **identify potential funding** sources or contributing resources.
- Become a **spokesperson** for the project.

## Acknowledgments

This roundtable meeting was successful due the efforts of many people.

Consumers Union recognized the need for a measure of consumers' health insurance literacy and sponsored the meeting. Lynn Quincy, senior policy analyst, led the effort and, along with consultant Wendy Child, is the primary author of this report.

Consumers Union is the policy and advocacy arm of *Consumer Reports*. Part of the mission of Consumers Union is to facilitate consumers' ability to function in the marketplace. Consistent with this mission, Consumers Union identified a critical gap in our understanding of consumers' ability to function in the health insurance marketplace. To fill this void, Consumers Union conducted three consumer testing studies concerning various features of a new health insurance disclosure form that was being developed by the National Association of Insurance Commissioners (Quincy 2010, Quincy 2011-B, 2011-C). Testing this health insurance disclosure form drove home just how difficult health insurance documents are for people to understand. Variation in consumers' ability to use health plan information was readily apparent, but no standard existed to measure or incorporate this variation into the study findings. The studies also revealed how profoundly difficult health plan comparisons were, leaving most consumers unable to compare their health plan options effectively (Quincy 2012).

Bonnie Braun, a professor at University of Maryland College Park School of Public Health and founding Director of the Horowitz Center for Health Literacy, had the initial vision to suggest that this need should be addressed as part of an ambitious, multistakeholder project.

Kristin Carman, Co-Director, Health Policy and Research at the American Institutes for Research<sup>®</sup> (AIR<sup>®</sup>), and San Keller, Principal Research Scientist at AIR<sup>®</sup>, quickly became core partners in the project, generously providing substantive expertise and the preliminary literature review.

The American Institutes for Research bring extensive experience in developing measures of consumer literacy, consumer and patient experience in health care, studying and developing interventions to support consumer use and adoption of comparative information to choose treatments, health care providers, and insurance; and their mission to conduct and apply the best behavioral and social science research and evaluation towards improving peoples' lives, with a special emphasis on the disadvantaged. AIR's experience can be leveraged to provide critical insight to the project.

The Kaiser Family Foundation provided our meeting space. Consumers Union's Theresa Thomas expertly took care of all the logistical details.

Wendy Child, a qualitative research and communication planning consultant, took notes, recorded our deliberations, and prepared a preliminary draft of this report.

**Most critical to our success, our expert roundtable participants gave generously of their time and expertise. In alphabetical order, the participants were:**

<b>Name</b>	<b>Organization</b>
Nancy D. Berkman, PhD	Senior Health Policy Research Analyst Program on Health Care Quality and Outcomes Division of Health Services and Social Policy Research RTI International
Kate L. Bicego	Consumer Education & Enrollment Manager Health Care For All (Massachusetts)
Bonnie Braun, PhD	Professor, and Health Literacy Faculty Scholar University of Maryland School of Public Health Department of Family Science and Horowitz Center for Health Literacy
Kristin Carman, PhD	Co-Director Health Policy & Research American Institutes for Research
Kathy Coltin, MPH	Director, External Quality Data Initiatives Harvard Pilgrim Health Care
Sandra J. Huston, PhD	Associate Professor Personal Financial Planning Texas Tech University
San Keller, PhD	Principal Research Scientist American Institutes for Research
Lynn Little, MA	Extension Educator and Co-Chair, MoneySmart Impact Team University of Maryland Extension–Washington County
Lynn Quincy, MA	Senior Health Policy Analyst Consumers Union
Steve Rush, MA	Director Health Literacy Innovations Program UnitedHealth Group Alliances
Susan Shockey, PhD	National Program Leader, U.S. Department of Agriculture, National Institute for Agriculture, Division of Family and Consumer Sciences, Washington, DC, and President, American Association of Family and Consumer Sciences

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## I. Background

### ***Why Measure Consumers' Health Insurance Literacy?***

The United States has one of the most complicated systems in the world for financing health care. As our country grapples with reforms designed to improve access to health care, the role of health insurance is changing, as are consumers' responsibilities with respect to finding and selecting health insurance.

Many enacted and proposed reforms envision a competitive health insurance marketplace whereby consumers act as informed shoppers, driving health plan competition based on quality and value. The reality is that private health insurance, as well as Medicare (our nation's health insurance program for seniors and disabled persons) and Medicaid (our national program for low-income people), feature many complex provisions and rules for enrollment. Consumers' ability to understand, shop for, and use their health insurance plans is varied and, for some, extremely limited.

When consumers don't understand health insurance, it undermines not only the well-intentioned efforts of policymakers, but also a health plan's ability to communicate with their enrollees. It causes frustration among consumers and may undermine their coverage selection and their access to health care.

Although we have a general impression that consumers struggle to understand health insurance, we lack a precise language for describing what is difficult for consumers about this product. Unfortunately, efforts to improve consumers' ability to understand and use their health insurance will be undermined in the absence of a methodology for measuring these abilities.

For these reasons, this expert roundtable sought to begin developing a "common language." Our proposal is to develop a widely accepted *health insurance literacy* measure to bring precision to the discussion, as well as to develop a more sophisticated understanding of the barriers facing consumers.

### ***Why Convene An Expert Roundtable?***

Somewhat surprisingly, no widely accepted measure of health insurance literacy currently exists. In fact, until recently, very little information was available about what consumers do and do not understand about selecting and using commercial health insurance. The robust field of *health literacy*<sup>1</sup> research has yielded more than 200 studies—but none of them explored consumers' ability to shop for and use their health insurance (Berkman et al., 2011).

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<sup>1</sup> The two terms are very similar: health literacy and health insurance literacy. Health literacy refers to the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions (Berkman et al. 2011). Health insurance literacy, however, is a newly conceived term intended to describe consumers' ability to understand and use their health insurance plans. In theory, health *insurance* literacy would be a subset of health literacy, but current health literacy tools cannot effectively measure this dimension of consumers' health care behaviors.

In response, Consumers Union, along with our core partners, assembled a diverse group of stakeholder experts to discuss a key proposition and explore related questions. A 1-day roundtable was held on November 14, 2011, at the Kaiser Family Foundation in Washington, DC.

As a critical first step towards the goal of developing a *widely accepted* measure, this expert panel encompassed a diverse group of stakeholders. Participants included measurement experts from the fields of consumers' health literacy and financial literacy, as well as "content" experts from the same fields. This interdisciplinary group included representatives from insurance plans, academia, consumer educators, consumer advocates, and private sector researchers. (See Acknowledgments for a list of panel participants.)

The key proposition placed before the roundtable was this:

*A widely accepted measure of consumer health insurance literacy is fundamental to shaping effective consumer education, policy development, and research around health insurance "behaviors"; i.e., selection and use of health insurance.*

Over the course of the day, roundtable participants discussed and shared knowledge about:

- What is known about consumers' struggle with health insurance?
- What would a definition of health insurance literacy include?
- A conceptual framework or model for measuring health insurance literacy: what to measure and why?
- What can be learned, and possibly borrowed from, other measurement tools?
- The process for developing a measurement tool (content, data collection, field testing).
- The requirements for a widely adopted measure.

This report summarizes the results of the roundtable discussion and concludes with a variety of suggestions as to how other interested stakeholders can get involved in the project.

### **Consumers' Ability to Understand Health Insurance: What We Know**

With an initiative of this type, it is critical to compile and build upon existing knowledge. Before and during the meeting, we shared what was known about consumers' ability to understand and use health insurance. As a literature review revealed and participants confirmed, studies that explore consumers' understanding of private health insurance are particularly rare.

In 2010 and 2011, Consumers Union conducted extensive consumer testing of a new health insurance disclosure form.<sup>2</sup> This exercise illuminated just how difficult health insurance documents are for people to understand. A literature review conducted by American Institutes for Research (AIR), as well as the expert roundtable discussion, confirmed a second, crucial fact: **few studies have explored the nuanced reasons why consumers struggle with health insurance.**

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<sup>2</sup> A complete description of this new form, as well as the full study results, can be found in three reports: Consumers Union 2010, Consumers Union 2011-B, Consumers Union 2011-C. A Summary Brief is also available (Quincy 2012).



The limited literature shows that consumers are confused about health insurance—both how to compare and choose plans, as well as how to use benefits. See Appendix A for a list of Works Consulted.

The literature showed:

- Consumers struggle with cost-sharing terminology, e.g., terms such as coinsurance, allowed amount, annual benefit limit, and out-of-pocket maximum (Quincy, 2010, 2011-B, 2011-C).
- Consumers struggle with some medical services terminology, e.g., the difference between a screening and diagnostic tests (Quincy, 2010, 2011-B).
- Consumers often stay in the same plan year after year, even when better choices are available to them (Gruber, 2009)
- People struggle to use certain types of informational formats, e.g., 88% of U.S. adults cannot calculate an employee's share of health insurance costs, using a table based on income and family size (Kutner et al., 2006).
- Consumers' ability to choose the "optimal" plan declines as the number of choices increase and as the complexity of the choices increases (Shaller 2005; Wood, 2011).
- Problems exist with self-efficacy—consumers dread shopping for health insurance and lack confidence in their ability to accurately assess their choices (Issacs 1996; Quincy, 2010, 2011-B).
- Problems with numeracy affect consumers ability to comprehend health plans (Greene et al., 2008; Wood, 2011)

Researchers also have speculated as to the adverse outcomes associated with poor understanding of health insurance:

- Delays or failure to enroll in any health plan (Dorn, 2011)<sup>3</sup>
- Reduced ability to access needed care effectively (Dorn, 2011)
- Delaying or avoiding care (Dorn, 2011)
- Poor functioning of health care markets (Cebul 2011; Gruber, 2009; Maestas 2009; Quincy, 2012)
- Health insurance difficulties appear to be correlated with poor health status in the Medicare population (McCormack, 2009; Morgan, Teal, Hasche, et al., 2008).

These outcomes have important ramifications for health care costs generally, as well as for the viability and long-term sustainability of the Affordable Care Act (ACA).

Roundtable participants' own experiences corroborated these findings. For example, comments included:

*"The thing that's hardest for people to do on their own is make health insurance choices. Because there's nobody out there who's going to tell them what to do. I mean, once you're in a plan, you have someone you can call [at the plan to get help]."*

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<sup>3</sup> Research shows that people without health insurance are less likely to seek care (Buchmueller, 2005).

*“Consumers have a good understanding of words and concepts like ‘premium’ and ‘co-pay’. But after that, no. And they don’t understand how poor their understanding is.”*

*“‘High deductible,’ ‘low deductible’... Some people don’t understand what these mean. The packets people get are huge—with 100 documents—and you have to do a lot of comparison...and it’s not just one or two [companies] they’re comparing.”*

*“Plans are requiring more numeracy skills as we move into limited and tiered networks...”*

*“[Re problems assessing health and financial risks...] Do they even think about, ‘I have this condition and need drugs—so how [do I evaluate plans based on that?]’?”*

*“We know from studies that consumers will stay with the plan they know—not switch to plans that may be better for them.”*

*“I made a decision about an insurance plan this year. Next year, I have to make another one. I need records, like my out of pocket costs...a basic thing I need to know is how to have those records, so I have them to make... a good decision.”*

### **Measuring Literacy: Existing Tools**

Literacy measures long have been used to quantify not only reading levels but also other types of abilities. Existing tools, particularly in the areas of health literacy and financial literacy, provide a solid starting point.

One key lesson is what *not* to do. Both the health and financial literacy fields face a proliferation of goals, definitions, and measurement tools, making it hard to consolidate findings across studies and inform policy (Huston 2010; Institute of Medicine, 2009)

However, existing measures of health and financial literacy also offer useful concepts, questions, and scoring methods even though they cannot measure health insurance literacy per se. These tools may provide potentially feasible data collection approaches (e.g., computer-assisted interview or survey), ideas for “domains” of measurement (e.g., prose, document, Web-based information seeking, self-perceived ability), or scoring approaches.

AIR provided the roundtable experts with an overview of the literature on 33 measurement tools related to health literacy, financial literacy, and insurance literacy. This survey found:

- Health literacy measures (13 tools), including direct testing of patients’ abilities (7 tools); patients’ self-reported abilities (3 tools); and population-based proxy measures (3 tools);
- Financial literacy measures (17 tools with insurance-related items); and
- Insurance literacy measure (3 tools).

Only three of these tools incorporated specific items related to health insurance. McCormack and colleagues (2009), for example, found that older adults were aware of health insurance terms but not whether older adults understood or utilized the concepts.

The review revealed that health literacy measures were generally designed for rapid screening in health care settings to assess how patients recognize medical terms (Davis, et al., 1991;

Hanson-Divers, 1998; Weiss et al., 2005) or to identify clinically useful questions that might be effective for detecting inadequate or marginal health literacy (Parker et al., 1995).

Financial and insurance literacy measures were used to explain the need for consumer education and variation in outcomes (Huston, 2010) or for government regulation of the markets—to protect consumers from seller manipulation or misrepresentation (Tennyson, 2011).

## II. Roundtable Outcomes

A comprehensive measure is one that consists of items that test a theory, a framework, or a definition. Roundtable participants had a robust discussion on each of these items.

### ***What Does It Mean to Be Health Insurance Literate?***

A fundamental starting point is to agree on a definition of health insurance literacy. The absence of a widely agreed upon, precise definition can undermine future research efforts that might use the measure, as well as undermine confidence in the measure itself (Huston, 2010).

To address this question, roundtable participants discussed: what would a highly health insurance literate consumer be able to do?

The Roundtable experts readily agreed that consumer health insurance literacy encompasses more than just basic knowledge of health insurance. As one participant put it:

*“Just because you know something doesn’t mean you can apply it.”*

The following summary of what a consumer who is highly health insurance literate would be able to do was proposed:

- Compare the key features of several health plans; understand the scope of covered services and the cost-sharing provisions associated with broad categories of services;
- Assess the adequacy and fit of the provider network for his or her (or family’s) health and financial circumstances;
- Assess the quality of each plan in terms of measures that are important to him or her, such as processing claims or customer service;
- Understand an Explanation of Benefits (EOB);
- Understand his or her appeal rights; and
- Know where to turn for more information and help.

Verb usage is important in this type of exercise. For example, panelists debated what it meant to “understand.” There was widespread agreement that consumers must have knowledge about health plan concepts and features, but they must also have other skills and attributes that allow them to *act* on that knowledge. For example, the consumer testing conducted by Consumers Union found that even highly knowledgeable participants lacked confidence in their analysis because they were worried they had overlooked something in the health plan document’s “fine print” (Quincy 2010). Lack of confidence *by itself* can undermine consumers’ ability to function in the health insurance marketplace.

A measurement tool, the group agreed, must assess all three aspects: knowledge, skills, and confidence. Appendix B contains an initial list of the knowledge that a health insurance literate person might have.

### ***Health Insurance Literacy: A Working Definition***

Once we have a sense of what a health insurance literate person would be able to do, we can begin to craft a definition of health insurance literacy.

Roundtable participants arrived at the following working definition:

*Health insurance literacy measures the degree to which individuals have the knowledge, ability, and confidence to find and evaluate information about health plans, select the best plan for their own (or their family's) financial and health circumstances, and use the plan once enrolled.*

Reflecting on what they liked about this definition, the experts said:

*"This [definition] would tell us a lot about what we're measuring...these individual characteristics and skills to accomplish these tasks."*

*"It includes the circumstances that can have an effect on which plan you choose. You may not be able to choose the Cadillac because you can't afford it."*

*"It's beginning to get us both a general way of measuring the population, but also more specific ways of learning where an individual is and what you need to do."*

*"The concept of 'degree to which' [means] on some scale—this is where these individuals are."*

*"This implies domains of measurement and specific content."*

Participants agreed that it might be useful to craft an additional, shorter definition that quickly and intuitively explained the concept, but that this longer, more precise definition provides the foundation needed to begin crafting a measure. The group suggested that the following could serve as the shorter definition:

*Health insurance literacy measures how well an individual can understand and (potentially) use health insurance information.*

### **How Would the Health Insurance Literacy Measure Be Used?**

Another exercise—central to the development of a health insurance literacy measure—is to develop an understanding of how the measure would be used and by whom. In other words, what questions would be answered by the measure?

*"You have a measure for a purpose."*

*"...what will we use this for? What happens if people have more of this? What do we get?"*

The experts described the ways they envisioned the data being useful. A key use would be to measure the health insurance literacy levels in a population. For example, a state might want to measure health insurance literacy levels among residents who will be shopping in the new health insurance Exchanges,<sup>4</sup> in order to better target their outreach and health plan comparison

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<sup>4</sup> The 2010 Patient Protection and Affordable Care Act, as well as state-based reform efforts, include the concept of an Exchange—a new health insurance marketplace for consumers who buy on their own and for small firms.

materials. Similarly, a health plan might want to measure health insurance literacy among its enrollees to better target health plan communications or to improve interpretations of results from enrollee surveys like Consumer Assessment of Healthcare Providers and Systems (CAHPS).<sup>5</sup>

Legislators have been known to include statutory requirements requiring that certain health plan documents be “understandable by the average plan enrollee.”<sup>6</sup> A health insurance literacy measure would, for the first time, provide an actionable method of identifying “the average plan enrollee.”

However, most participants emphasized what might be termed the *indirect* uses of a health insurance literacy measure. The very process of developing and field testing a health insurance literacy measure should yield the nuanced information that will tell us *how* to improve communications and design policies and procedures that improve consumers’ ability to shop for and use health insurance. In turn, when these “interventions” are tested with consumers, the presence of the measure could confirm that the new communications work across a range of health insurance literacy levels.

For many participants, a goal was to improve health plan communication.

*“Better health insurance literacy information allows us to improve health plan communications, leading to better consumer understanding and the ability to rigorously compare their options, etc.”*

*It would help me and my staff to advise people better—if I had a quick set of questions, I’d get what this person needs and [then, be able to] go down different pathways.”*

*“One way to use it is as a needs assessment for both prospective and current members—to help them understand the benefits and how to use them. Once you have a needs assessment, you can establish thresholds, e.g., 85% of members understand. Another use is as a risk adjustor. Health plans are measured on how well they provide materials, whether people understand what they bought, etc. I could look great on those measures if I have a population [has high health insurance literacy], but not [if they don’t]...the measure could be the adjustor. How well is the plan doing given who it serves?”*

*“After listening to thousands of overwhelmed, fearful consumers unable to have a happy life over this, this is exciting that it could help people I serve.”*

Another goal, shared by many participants, was to improve consumer education programs about health insurance and, by doing so, improve consumer welfare.

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Choices in the Exchange would be structured to promote competition based on price and quality. For more, see: <http://healthreform.kff.org/Faq/What-is-a-health-insurance-exchange.aspx>

<sup>5</sup> The CAHPS surveys ask consumers and patients to report on and evaluate their experiences with health care.

<sup>6</sup> The 2010 Affordable Care Act includes this provision with respect to the new *Summary of Benefits and Coverage* disclosure form. The Employee Retirement Income Security Act of 1974 (ERISA) includes a similar requirement with respect to the *Summary Plan Description* provided by larger employers to their employees.

*“I could see a needs assessment being useful in teaching adults about this...people who score in some range need this kind of help.”*

*“If someone could tell me the five things I really should think about, I would have a guide...a mental model of things to know and understand.”*

*“[It would lead to] better financial security...they will understand how much insurance they need.”*

Participants speculated that policymakers would benefit from data substantiating the scope of consumer difficulty with health insurance information.

*“A clear use for this: population-based measurement to make a much stronger policy argument of the need for vast improvement in insurance coverage information and education—so, K–12 education, better materials: that’s a policy goal.”*

### **Requirements for a Widely Accepted Measurement Tool**

Closely related to the issue of *how* the measure will be used is the project goal of developing a measure that is widely accepted. This goal does not reflect a desire to profit personally from the measure but the desire to avoid a proliferation of health insurance literacy measures. When research has a common measurement standard at its foundation, then results can be compared across studies, increasing the utility of the findings. A proliferation of standards and/or definitions yields an inconsistent picture of consumers’ literacy levels and undermines efforts to conduct evidenced-based policymaking (Huston, 2010).

The group agreed that widespread consensus around the measure would facilitate the successful interventions envisioned above. To that end, the *project* must:

- Involve a broad, diverse group of stakeholders at each key decision point.
- Achieve broad consensus on the *definition* of health insurance literacy.

The *measure* itself must:

- Be grounded in sophisticated measurement science, including rigorous cognitive and field testing to assure its validity
- Be in the public domain
- Produce data that will be valuable to multiple end users: insurance plans, consumer educators and advocates, regulators, and policymakers
- Be reliable and valid when used with the same people over and over across time (suitable for longitudinal analyses)
- Be easy for end users to administer

We believe that the goal of crafting a *widely -accepted* measure can be consistent with an approach that envisions *variations* in the measure. For example, the measurement tool that might be incorporated into population surveys may not be appropriate as a “quick” assessment tool that



enrollment counselors can use with individual consumers.<sup>7</sup> However, if these two tools are grounded in the same conceptual model and scoring approach, and the predictive power of both has been rigorously vetted, our overall project goals will still be readily realized.

### ***A Conceptual Model for Measuring Health Insurance Literacy***

Armed with a working definition and an understanding of how the measure would be used, the formative process of building a measure can begin. This process starts with a conceptual model of consumers' health insurance literacy.

A conceptual model provides critical context. It illustrates how the consumer characteristics to be measured (such as knowledge, skills, and confidence) interact with external forces (e.g., the number and type of plan choices) to produce outcomes (such as the informed selection of a health plan).

A model also provides an appropriately broad foundation for the proposed measure. If the conceptual model is too narrowly defined, the resulting measure may not be comprehensive enough to accomplish the overall goals for the project.

Work presented by Professor Sandra Huston, describing a process used to hone a model of consumers' financial literacy, provided our starting point.

Exhibit 1 shows the relationship between knowledge, skills, and confidence and subsequent health insurance behaviors or “outcomes”—selecting and using a health plan.<sup>8</sup>

A person's health insurance literacy level is a function of their innate skills (like reading ability) and knowledge, skills, and confidence that are specific to health insurance selection and use.

As the model shows, health insurance education, in theory, can improve a person's health insurance literacy level, and lead to choosing and using a health plan in ways that best fit one's personal or family health and financial circumstances.

However, outcomes are influenced by more than just a consumer's health insurance literacy level. The model recognized and incorporated the contribution of external forces to health insurance outcomes. For example, the type of health insurance options available to the person in the community would influence health plan selection. The panelists agreed that health insurance literacy in the real world was the product of individuals' capabilities and the health insurance system in which they operate. In this model, the health care sector shares responsibility for making sure that individuals can use health insurance information effectively.

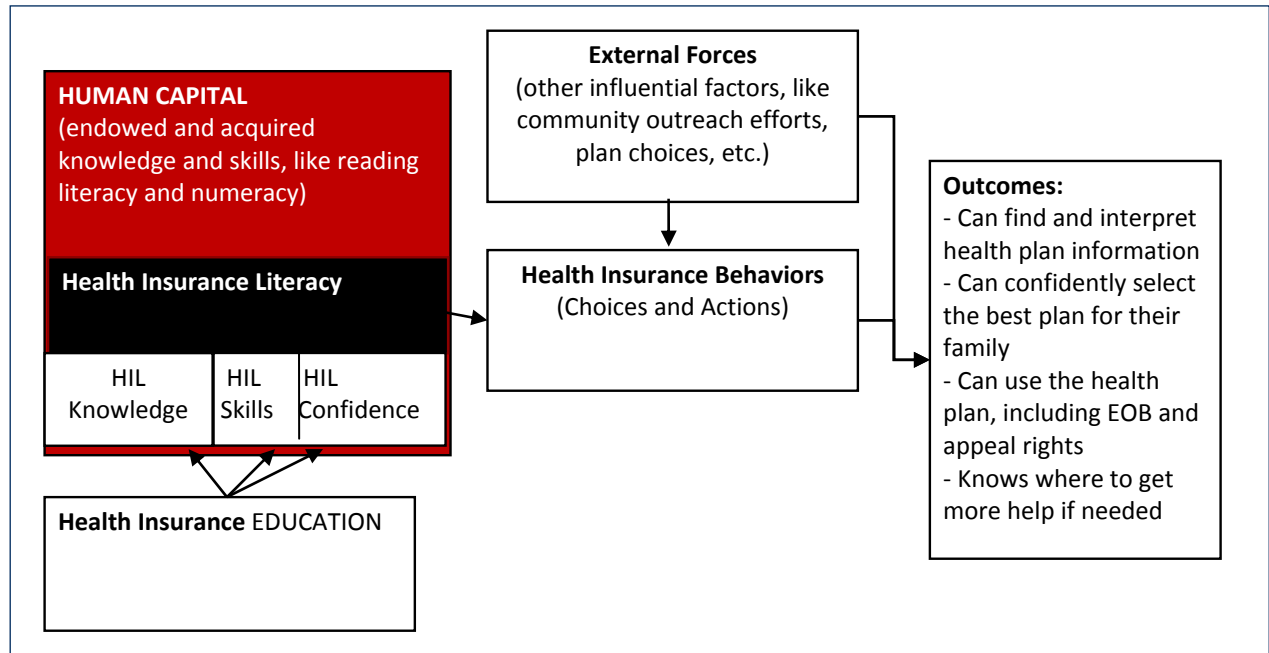
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<sup>7</sup>There is a fundamental difference between screening and measurement. The goal of screening is to divide people into categories (have/have not). Measurement, on the other hand, is an attempt to explore in depth the structure and function of objects of interest. In fact, a true measure should establish the basis for a reliable screening tool. For more discussion, see Pleasant in Institutes of Medicine 2009.

<sup>8</sup>This graphic representation, as well as the modeling exercise itself, was guided and influenced by the model used by the “Financial Literacy Assessment Project” at Texas Tech University, as presented by Dr. Sandra Huston (adapted from: Huston, S. J. (2010). Measuring financial literacy, *Journal of Consumer Affairs*, 44(2), 296–316.)



**Exhibit 1. How Health Insurance Literacy Leads to Personal Health Insurance Outcomes**



Note: Adapted from Huston, S. J. (2010). Measuring financial literacy, *Journal of Consumer Affairs*, 44(2), 296–316.

A key area of focus going forward will be to better define the *knowledge, skills, and confidence* that allow individuals to make informed decisions. As a starting point, we provide the discussion below and the additional detail included in Appendix B.

**KNOWLEDGE:** Someone who is health insurance literate would *know* things such as:

- **Basic knowledge: health insurance is meant to protect people from the financial effects of expenses associated with many health problems and catastrophic illness or injuries.** These expenses may exceed what someone is able to pay from other financial resources such as earned or investment income and savings. Many forms of insurance also provide coverage for predictable expenses, such as preventive care.
- **Where and how to choose health insurance.** For example, a person would know health insurance can be purchased or acquired in several ways. A policy might be obtained through an employer’s sponsored health plan, or it could be issued to members of an association. Or, a person might purchase an individual or family insurance policy. In addition, a person would know that choosing among available options requires knowing not only the cost (premiums) but also the relationship between cost and amount of coverage that will be provided (or not) for various foreseeable and unforeseeable conditions and for different “tier” options within the same company—especially as tiered options expand. For example:

*“This concept of tiers is completely befuddling to consumers...anything that’s tiered, they struggle with.”*

*“I’ll give you my example. We have three tiers where I work. I’m in the premium plan. My employer is increasing the cost 10%. I know I should look at 3 years of expenses and*

*recalculate [this]. But there is no way! Talk about health insurance literacy...I know what I need to do. Whether I do it or not...*"

- **How to use health insurance.** One example of what consumers have to understand about using their selected insurance is the concept of “preferred providers”—physicians and other—health care providers, hospitals, labs, and so forth with health plan contracts that limit what they can charge. This usually means lower costs for patients. However, consumers are generally responsible for determining whether or not a physician they wish to see, or even one to whom they may be referred, is an “in-network” provider or not. The same applies to labs, hospitals, or other services. Consumers may have to pay higher costs if they go to providers outside the network. But many people do not realize this or know how to assess and compare different plans’ preferred providers. Another example of information necessary for using health insurance might be how to appeal a claim rejection.

**SKILLS:** Skills and abilities include finding, understanding, evaluating, communicating, using, and navigating prose, documents, quantitative information, and speech.<sup>9</sup> Someone who is health insurance literate would need to have basic skills as well as skills specific to health insurance. For example:

- Basic reading proficiency and numeracy skills, such as understanding percentages—and more often than ever, basic Web navigation skills. In the words of Roundtable experts:

*“Plans are requiring more numeracy as we move into limited and tiered networks.”*

*“There’s a math component to this...understanding the concept of percentages applies sometimes to premiums; for example, you pay 20% and your employer pays 80%.”*

*“You need to be able to anticipate foreseeable services [to choose]—like if you know you want to get pregnant or are diabetic and taking medications. Your copay, coinsurance, deductible...and then there’s the unforeseeable...getting hit by a bus...what would I pay if that catastrophe occurs?”*

*“Can I afford the insurance? [A factor is] the kind of skills I need to make that affordability determination.”*

- Skills specific to health insurance, such as the ability to calculate how much coverage a plan offers.

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<sup>9</sup> Ways skills and abilities differ: **Skill** statements refer to the proficient manual, verbal, or mental manipulation of data or things. Skills can be readily measured by a performance test where quantity and quality of performance are tested, usually within an established time limit. Examples of proficient manipulation of things are skill in typing or skill in operating a vehicle. Examples of proficient manipulation of data are skill in computation using decimals; skill in editing for transposed numbers, etc.

**Ability** statements refer to the power to perform an observable activity at the present time. This means that abilities are evidenced through activities or behaviors similar to those required on the job, e.g., ability to plan and organize work. Abilities are different from aptitudes. Aptitudes are only the potential for performing the activity. See <http://www.cdc.gov/hrmo/ksahowto.htm>.

**CONFIDENCE:** Consumer testing has demonstrated that knowledge and skills are insufficient (Quincy 2010 and 2011b). Health insurance literate persons must also have the confidence to apply the knowledge and skills to take actions that will benefit themselves and their families. As one Roundtable participant put it:

*“We had an interviewee who sat with her hands on her head. She said, ‘I have materials from so many different companies. I can’t make a decision. I’m afraid I’m going to make the wrong decision.’”*

### III. Next Steps: Developing and Testing the Measurement Tool

#### ***From Conceptual Model to Measurement Tool: The Process***

This roundtable meeting made significant progress in the foundation for a measure of consumers' health insurance literacy. We explored and confirmed the need for such a measure and developed a preliminary concept of what a health insurance literate person would be able to do, a definition of health insurance literacy, and a preliminary conceptual model. We also engaged in a robust discussion of how the measure would be used.

Achieving the final goal of a rigorous, widely accepted measurement tool will require more—specifically a multistep process of designing and testing a measurement tool.

The experts agreed that the critical components of this process include:

- Engaging a broad range of stakeholders to collaborate throughout the process and communicate with constituents and colleagues to ensure that this measure has widespread value.
- Expanding the literature review beyond the basic overview completed for the Roundtable, and assessing whether others are doing relevant research or instrument-development work.
- Further refining and developing of a broad consensus on:
  - The construct of what a health insurance literate person can do (Appendix B),
  - The definition of health insurance literacy (pages 6–7),
  - The conceptual framework or model, and
  - How the measure will be used with content, and a scoring rubric that supports these uses.<sup>10</sup>
- Developing and testing the measurement tool:
  - Evaluating what can be borrowed from other measures;
  - Where needed, developing new questions to assess consumers' knowledge, skills, and confidence for choosing and using health insurance plans;
  - Making decisions about how the data will be collected, processed, scored, and reported;
  - Conducting cognitive testing of questions, responses, and reporting formats; and
  - Conducting field testing and analysis.
- Developing user support/training materials for the final measure.
- Promoting broad dissemination and use.

#### ***Timetable: Getting Ready for Health Care Reform***

*“We really have to move!”*

*“I would like to suggest that we have the tool completed by the end of 2012...”*

The benefits of a health insurance literacy measure extend far beyond helping consumers with the changes envisioned by the 2010 Patient Protection and ACA. However, the significant reforms

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<sup>10</sup> A rating/scoring method, either a threshold or ranking system, is imperative to ensure common interpretation of the results. This scoring system should be sophisticated enough to provide targeted information for policymakers/regulators and others (Huston, 2010).

envisioned by this Act—timed for January 1, 2014 implementation—present a *unique* opportunity to have a significant impact, *if* the work on the measure can be completed by the end of 2012.

In anticipation of the new rules that begin on January 1, 2014,<sup>11</sup> a significant amount of consumer outreach will be conducted by states, health plans, consumer advocates, and consumer educators during the second half of 2013. In turn, consumers will be particularly receptive to new information as they actively look for information to understand their new roles and responsibilities under the reforms.

**The ambitious goal of the project team is to complete the formulation and testing of the measure by the end of 2013.** If successful, the measure—as well as the improved information that will arise from testing process—will be available to states, health plans, consumer advocates, and consumer educators to perform needs assessments, design new materials, and monitor the success of their outreach efforts and other policy decisions. Exhibit 2 describes a timetable that would achieve this goal.

**Exhibit 2. Tentative Timeframe for Measure Development**

Task	Target Timeframe
1. Identify stakeholders	Feb 2012
2. Identify environmental scan search strategy	Feb 2012
3. Develop stakeholder interview protocol	Feb 2012
4. Conduct stakeholder interviews, analyze data	Feb–Mar 2012
5. Augment preliminary literature review, synthesize	Feb–Mar 2012
6. Refine conceptual model, vet with review panel	Mar–Apr 2012
7. Design field test	Apr 2012
8. Conduct concept elicitation focus groups	May–Jun 2012
9. Contact vendors for enrollment/data collection	Jun 2012
10. Draft instrument, vet with review panel	Jun–Jul 2012
11. Cognitively test instrument	Jul–Aug 2012
12. Revise instrument field	Jul–Aug 2012
13. Construct data files/analyze data	Sep–Nov 2012
14. Revise instrument, develop briefing slides	Nov–Dec 2012
15. Draft user’s manual, papers, manuscript	Jan/Feb 2013

<sup>11</sup> The 2010 Patient Protection and Affordable Care Act (ACA) includes numerous reforms, many of which have been implemented already. The most far-reaching reforms, however, begin January 1, 2014. On that date, consumers are required to have health insurance, unless no affordable options are available to them. Health plans may not turn down applicants or charge more due to pre-existing medical conditions. Tax credit subsidies will be available to lower income families and small businesses that offer coverage. The health insurance choices available to individuals and small firms will be more structured. For more information on the enacted and planned changes, see <http://www.healthcare.gov/law/timeline/index.html>.

## **Stakeholders: The Call to Action**

*“Building and maintaining a community of interested parties is a critical priority.”*

Multiple stakeholders have an interest in health insurance literacy and need to be at the table during and beyond the development of a measure.

Key stakeholders include policymakers, regulators, health insurance plans, consumer educators, consumer advocates, and persons working in the academic, public, and private sectors. Anyone working in the financial or health literacy arenas may be interested in following this work. Accrediting organizations may also be interested.

One can participate in a number of ways, including:

- Follow the progress of the project by subscribing to our Listserv (see next page for details).
- Respond to the proposed building blocks included in this report, such as:
  - The construct of what a health insurance literate person can do (Appendix B)
  - The definition of health insurance literacy (pages 6–7)
  - The conceptual framework
  - The list of works consulted: are important studies missing? (Appendix A)
- Forward this report and project description to colleagues who might have an interest in this work.
- Participate in our **research committee**. Provide peer review or actively participate in the formative development and field testing of the measure and the scoring rubric. Another activity for this group is to develop a research agenda that uses the measure. One particular area panelists discussed is the need to investigate and document the business case for the measure.
- Participate in our **action committee**. The panelists agreed that we would need to develop an action plan to ensure that the new measurement tool(s) actually benefit consumers, rather than merely become debated among academics.
- Help us identify potential funding sources or contributing resources for tasks such as formative development of the measure, field testing the measure, curriculum development, and professional training in use of the instrument.
- Become a spokesperson for the project. Promote the work at conferences, symposia, or other forums related to health insurance literacy, financial literacy, consumer outreach or education efforts around health reform.
- Host and maintain a Web site documenting the progress of the project.

## How to Participate

E-mail your areas of interest to Consumers Union ([HIL\\_project@cu.consumer.org](mailto:HIL_project@cu.consumer.org)) or fax to 202–265–9548.

YES, I am interested in participating in the <b>Health Insurance Literacy Project</b> in the following ways:	Check all that interest you
<b>Follow our progress</b> of the project by subscribing to our Listserv: Key announcements only	
Active discussion group (all topics)	
<b>Share</b> this report and project description with colleagues who might have an interest in this work	
<b>Provide feedback on key content areas</b> (due to Lynn Quincy by <b>February 28, 2012</b> ):	
The construct of what a health insurance literate person can do (Appendix B)	
The definition of health insurance literacy (pages 6-7)	
The conceptual framework	
The list of works consulted	
Participate in our <b>research committee</b> . Provide peer review or actively participate in the formative development and field testing of the measure and the scoring rubric; develop a research agenda that uses the measure. <i>Task lead: AIR researchers, San Keller and Kristin Carman</i>	
Participate in our <b>action committee</b> . This committee will develop an action plan to ensure that the new measurement tool(s) actually benefit consumers, rather than merely become debated among academics. <i>Task lead: Bonnie Braun, University of Maryland</i>	
Help us <b>identify potential funding sources</b> or contributing resources for tasks such as formative development of the measure, field testing the measure, curriculum development, and professional training in use of the instrument. <i>Task lead: Lynn Quincy, Consumers Union</i>	
<b>Become a spokesperson</b> for the project. Promote the work at conferences, symposia, or other forums related to health insurance literacy, financial literacy, consumer outreach or education efforts around health reform.	

Your contact information:

Name: \_\_\_\_\_ Organization: \_\_\_\_\_

Phone: \_\_\_\_\_ E-mail: \_\_\_\_\_

**May we share your contact information with others in the stakeholder group? Y/N**

## IV. Appendices

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## **Appendix B: Health Insurance Knowledge, Skills, and Confidence—A Draft List**

To develop a clearer picture of the knowledge and skills that health insurance literate consumers would possess, we drafted this preliminary list.

### **Fundamental Health Insurance Principles**

- Many health problems and catastrophic illnesses are very expensive to treat.
- Health insurance helps protect people from the financial effects of unexpected health problems or catastrophic illness for which costs that may be higher than what they are able to pay from savings and income.
- Not everyone has an expensive health problem every year.
- Most people pay a “premium” to purchase this coverage.
- The combined premiums from policyholders enable health plans to help pay medical expenses of those with unexpectedly high costs. Some years, they may pay more in premiums than they receive in covered medical care. Other years, the cost of medical care paid by their plan may exceed what they paid in premiums.
- People cannot predict what their medical bills will be. So, most people need health insurance.
- Health insurance also pays some or all of the costs for care that is not catastrophic or unexpected—such as preventive care.
- Not all health plans are alike. What is covered and how it is covered differ from policy to policy.
- Various health plan features like “deductible,” “co-insurance,” “co-pay,” “benefit maximum,” and patient’s “out-of-pocket limit” determine how the costs of care are allocated between the enrollee and the insurance company.
- People should not wait until they or a family member become seriously ill to try to purchase health insurance. [Prior to 2014,] they might be turned down.
- [Starting in 2014] by federal law, everyone will be required to have health insurance, unless there is no affordable option available to you.

### **How to Purchase/Acquire Health Insurance**

- Health insurance can be purchased or acquired in a number of settings. You can purchase an individual insurance policy on your own for yourself and your family; or through an employer-sponsored health plan; or through a policy issued to members of an association group.
- Depending on where you get your health coverage, you may not have to pay the full premium for the coverage. For example, many employers pay a majority of the premium for their workers. Lower income families may be eligible for subsidized coverage, in which a portion of the cost is born by taxpayers. Many people who buy their own health plan, however, pay the full premium.
- When purchasing a policy, it is very important to know not only the premium, but also things like:
  - What services are covered by the plan, and how much will you have to pay out-of-pocket? The least expensive policy may not provide the best overall value for your health and financial circumstances. How much “coverage” the plan provides depends on things

like the type and scope of covered medical services; e.g., is maternity care covered? Does it cover the medications you require?

- Who are the preferred providers? Do they include your current physicians, or will you have to pay more to see them? Most health plans use a network of preferred providers (doctors and hospitals). These providers have signed contracts that limit what they can charge—which usually means lower costs for the patient. Which providers your policy covers can make a big difference in your costs and the quality of care you get if you become ill. If staying with your current doctor or hospital is important to you, check to see if they are included in the plans you are considering.
- What is the company’s quality rating and history of consumer complaints? While robust information about these may not yet be available, this information is expected to expand. [Note to stakeholders: currently this information is hard to find and not always robust. However, this may improve over time, suggesting a role for this type of information.]
- If you don’t have access to coverage through your employer or spouse’s employer, you can find out about other insurance options through [www.healthcare.gov](http://www.healthcare.gov).
- Rules for renewing health insurance coverage vary by health plan. Contact your employer or health plan directly regarding renewal options and time periods.

### How to Use Health Insurance

- Most health plans use a network of preferred providers (doctors, hospitals, labs). These providers have signed contracts that limit what they can charge—which usually means lower cost for the patient. Most health plans limit the doctors and hospitals you can use. This is called a “preferred provider network.” You should contact your health insurance company to find out what doctors and hospitals are in-network for your plan. Enrollees are generally responsible for seeing whether or not the doctor, lab, or hospital is an “in-network” provider, where their costs are usually lower. Enrollees can ask the doctor or hospital to learn whether that provider is in their health plan’s network or not.
- Out-of-network providers can be far more costly, as they are not subject to the insurer’s provider contracts. If an enrollee uses an out-of-network provider, a different method is used to figure consumers’ costs. If the plan is a health maintenance organization (HMO) plan, out-of-network care might not be reimbursed at all. If the plan is a Preferred Provider Organization (PPO) or Point of Service (POS), insurance companies use “fee schedules” to determine the average cost of a procedure. This is often called the “usual and customary” or “reasonable and customary” charge. This cost may differ from the actual charge made by the consumers’ health care provider, and the consumer may be responsible for the any extra costs.
- Depending on the *type of policy you buy*, you may need a *referral* from their primary care doctor to get care from a specialist.
- Consumers must understand the key terms that govern how much they will pay: deductible, coinsurance, copay, benefit maximum, and patient’s out-of-pocket limit.
- Most managed care plans have a list of drugs that they cover, called a “formulary.” The patient’s copay for prescription drugs probably will depend on whether they are getting a generic drug, a brand name formulary drug, or a brand name drug not on the plan’s formulary. For example, the copay might be \$10 for a generic drug, \$25 for a formulary drug, and \$40 for a brand name nonformulary drug.

- A person may receive a bill from the provider (doctor, hospital, and/or lab) and/or an “Explanation of Benefits” from his or her insurer. Each person should check these carefully for errors and call the customer service number on the bill if one has any questions.
- A person may think that a health insurance company has made an error regarding coverage. If so, that person has grievance and appeal rights. The person should contact the Consumer Assistance Program in his or her state for assistance filling a grievance or appeal. A list can be found here: <http://www.healthcare.gov/using-insurance/managing/consumer-help/index.html>.
- [Note to stakeholders: research demonstrates that purchasers of high deductible health plans obtain care, including needed care, less frequently. What is the corresponding knowledge item for consumers? ]
- Where to get help:
  - Number on the back of your insurance card
  - State insurance department or Consumer Assistance Program (for individual and small group plans)
  - Your employer’s human resources department (if an employer plan)

