Key Points

- Nearly nine out of ten adults have difficulty using health information to make informed decisions about their health, according to America’s Health Insurance Plans.¹
- Only 12 percent of English-speaking American adults had proficient health literacy skills, according to the Department of Education’s National Assessment of Health Literacy, which used 2003 data - the latest comprehensive information on health literacy.²
- The cost of low health literacy to the U.S. economy was estimated by one study at between $106 billion and $238 billion in 2006. This represented between 7 percent and 17 percent of all personal health care expenditures.³
- Adults ages 25 to 39, those who are white and Asian-Pacific, people with higher levels of education, and those with higher incomes are more health literate than adults ages 65 and older, most minority groups, people with less education and people with low incomes.⁴
- About half (51 percent) of Americans do not understand the basic health insurance terms premium, deductible and copay.⁵
- When people need to do math to figure out out-of-pocket costs, the lack of understanding grows. Only 16 percent of respondents in a Nov. 2014 Kaiser Family Foundation survey could calculate the cost of an out-of-network lab test, for example.⁶
- 79 percent of all Americans know that a health insurance premium has to be paid every month, but only 64 percent of uninsured adults know that.⁷

The second open enrollment period, during which eligible individuals may enroll in a Qualified Health Plan for 2015 in a marketplace, runs from November 15, 2014 to February 15, 2015. Some studies show that many do not understand the very terms and concepts necessary to make informed choices.⁹ For many people, it is the first time that they will have coverage. In addition, insurance is becoming more “consumer driven,” and often includes higher deductibles, which shifts financial risk to the patient. That increases the stakes and requires an even more sophisticated understanding of health insurance.

This toolkit addresses the extent and significance of both health literacy and health insurance literacy for Americans buying and using health insurance.

Nearly nine out of ten adults have difficulty using health information to make informed decisions about their health, according to America’s Health Insurance Plans.

Health Literacy
Knowing how to find a doctor, fill a prescription, how to use and pay for that medication, and understanding the medical provider’s explanations are all measures of health literacy.
A landmark Department of Education study identified low levels of health literacy as a problem. Using the Institute of Medicine (IOM) definition of health literacy – the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions - the authors concluded that only 12 percent of adults had proficient health literacy, 53 percent had intermediate, 22 percent had basic and 14 percent had below basic health literacy. The report attributed differences in health literacy to such factors as education, age, race/ethnicity, sources of information and health insurance coverage.  

And, there are economic implications. The cost of low health literacy to the U.S. economy is between $106 billion to $238 billion annually, analysts at George Washington University estimates in 2007. This represents between 7 percent and 17 percent of all personal health care expenditures.  

The Department of Education study found that adults who spoke languages other than English, or spoke multiple languages including English, had below average health literacy, as compared to adults who spoke only English.

Health Insurance Literacy

Health insurance literacy focuses more specifically on insurance coverage, and the ACA brought the subject to the forefront. A health insurance literacy expert roundtable in 2011 defined health insurance literacy as “the capacity to find and evaluate information about health plans, select the best plan given financial and health circumstances, and use the plan once enrolled.”

Upon passage of the ACA, the Obama administration created the HealthCare.gov website in an effort to help consumers compare health coverage options. The ACA also funded navigator and in-person assister programs to help individuals, families and small businesses compare and contrast plans, identify what type of financial assistance may be available and help complete and send application forms for insurance.

Findings from recent surveys vary, but generally show some deficit in people’s understanding of insurance terms, and larger problems in the ability to calculate cost sharing. Three-quarters of Americans ages 22-64 report that they know how to use health insurance, yet only about one-fifth could calculate the cost of a routine doctor visit.

In a Kaiser Family Foundation survey from October 2014, most people (79 percent) knew that a health insurance premium must be paid each month, and 72 percent were able to identify the correct definition of a deductible. However, math was an issue. Only about half of respondents correctly calculated the out-of-pocket cost for a hospital stay involving a deductible and copay, and only 16 percent were successful in determining the cost of an out-of-network lab test with a capped allowable charge.
Another report, from 2013, found that 51 percent of Americans did not understand such basic health insurance terms as premium, deductible and copay.\(^{19}\) Thirty-seven percent of marketplace enrollees did not know their deductible, and 47 percent of those receiving subsidies did not know the amount of federal assistance they were getting.\(^ {20} \)

Health insurance literacy is low among racial and ethnic minority groups, and, in particular, among minority groups with low incomes, and those who are uninsured, surveys have shown. Hispanic adults have the lowest health insurance literacy while white adults have the highest.\(^ {21}\)

Also, the abundance and complexity of insurance choices can overwhelm consumers and impact their understanding of plan features. Studies of Medicare’s prescription drug program (Medicare Part D) have found that enrollment wanes when consumers face too many choices. As part of a study published in *Health Affairs* in 2011, when consumers had fewer than 15 choices, enrollment was lower because they had trouble finding what they wanted. However, enrollment also dropped off when consumers had more than 30 choices. In addition, hyper-variation can make it difficult for consumers to compare the features of plans.\(^ {22}\)

**Public and Private Initiatives**

The federal government has several initiatives in place to improve health and health insurance literacy. In 2010, the federal government announced the **Plain Writing Act**,\(^ {23}\) Healthy People 2020 and the **National Action Plan to Improve Health Literacy**.

The action plan charges health professionals with communicating in clear and simple ways to the patient. It concludes that patients cannot adopt healthy behaviors and comply with recommendations if they do not understand the problem and their part in helping to improve their health status.

Before the first ACA open enrollment period, the federal government launched a marketplace assister program with more than 28,000 full time-equivalent staff and volunteers helping consumers to understand their insurance choices.\(^ {24}\)

Some states also have health and health insurance literacy programs, including Minnesota, Kentucky, Pennsylvania and New York.\(^ {25} 26 27 28\)

Moreover, some commercial health insurance plans have initiated programs. For example, WellPoint in 2010 launched the **Plain Language Initiative** to ensure that its documents are understandable.\(^ {29}\)

On October 14, 2014, the Pharmaceutical Research and Manufacturers of America (PhRMA) launched the **AccessBetterCoverage.org** website, which is an educational resource to help consumers gain information about how health insurance works, what to expect from health coverage, and how to access prescription medicines.\(^ {30}\)

**Resources**

**Health Insurance Literacy and the Affordable Care Act**

A Little Knowledge Is a Risky Thing: Wide Gap in What People Think They Know About Health Insurance and What They Actually Know


http://goo.gl/uNR1Lu

The issue brief summarizes the results of a national health insurance literacy survey. The survey shows a gap in knowledge and perceived knowledge about health insurance.

JAMA Forum: Why Health Insurance Literacy Matters


http://goo.gl/WT0L3s

This article provides an analysis of a recently conducted Kaiser Family Foundation survey: “Assessing Americans’ Familiarity with Health Insurance Terms and Concepts.” The survey found that consumers understood some insurance concepts and terms, but had a greater difficulty when calculations were involved.

Consumers’ Misunderstanding of Health Insurance


http://goo.gl/xN57tB

The authors surveyed Americans with private insurance to see whether they found co-pay insurance easier to understand and use than traditional insurance, with deductibles and co-insurance. The authors concluded that consumers better understood co-pay only plans, but found only weak evidence that these plans would cause people to make different choices and lower costs.
Developing a Measure of Health Insurance Literacy: Understanding Consumers’ Ability to Choose and Use Insurance
In this issue brief, the authors describe consumer problems selecting and using health. According to the brief, the American Institutes for Research was developing a measure of health insurance literacy to objectively assess what consumers with private insurance do and do not understand about insurance.

Health Literacy Implications of the Affordable Care Act
This study provides an analysis of the ACA and insights into the opportunities it presents for promoting health literacy, including in the areas of coverage expansion, equity, workforce, patient information, public health and wellness and quality.

Knowledge Is Power: Focusing on Health Insurance Literacy May Increase Health Coverage Retention
In this blog post, the author analyzes a nationally-representative post-enrollment consumer survey from April 2014 and concludes that people who enrolled had greater knowledge about the provisions of the ACA, and were more comfortable with the financial commitment than those who remained uninsured.

Large Racial and Ethnic Differences in Health Insurance Literacy Signal Need for Targeted Education and Outreach
Urban Institute Health Policy Center and the Robert Wood Johnson Foundation
This brief examines the differences in health insurance literacy among racial and ethnic groups, and finds that literacy is the highest for white, non-Hispanic adults, and lowest for Hispanic adults.

Low ACA Knowledge and Health Literacy Hinder Young Adult Marketplace Enrollment
This blog post, explaining survey findings, concludes that half of young adults were aware of provision in the ACA allowing individuals up to age 26 to remain on their parents’ private health insurance policies.

Low Levels of Self-Reported Literacy and Numeracy Create Barriers to Obtaining and Using Health Insurance Coverage
The report finds that limited numeracy – mathematical proficiency - is a bigger challenge than limited literacy for nonelderly adults.

Measuring Health Insurance Literacy: A Call to Action, A Report from the Health Insurance Literacy Expert Roundtable
Consumers Union, University of Maryland College Park, American Institutes for Research, February 2012. http://goo.gl/FywWmL
This event called together a group of experts from academia, advocacy, health plans, and private research firms to address the problem of health insurance literacy. Attendees began creating a measure of health insurance literacy, preliminarily decided what a literate person would be able to do, defined health insurance literacy, discussed a preliminary conceptual model and offered suggestions about how a measure would be used.

Newly Insured Americans Don’t Understand Basic Healthcare Terms
This article, by a psychologist who works with cancer patients, highlights the effect of low health and health insurance literacy on treatment decisions.

Preparedness of Americans for the Affordable Care Act
The authors of this paper conclude that large portions of the population are not sufficiently informed to make the best possible choices in marketplace health plans. They cite a survey concluding that half of respondents did not know about marketplaces, and 42 percent could not correctly describe a deductible.
Taking Stock and Taking Steps: A Report from the Field after the First Year of Marketplace Consumer Assistance under the ACA
Grob, Rachel et al., Kaiser Family Foundation, October 1, 2014.
http://goo.gl/QT10WI
In this report, authors analyzed the first year of marketplace assister programs, which are intended to help consumers understand their coverage options, apply for financial assistance and enroll. The report calls for increased education, and emphasizes the role of assisters.

USC survey reveals low health care literacy
http://goo.gl/OsQlhQ
This article concludes that health insurance literacy is particularly low among younger and low-income Americans.

Voices from the Newly Enrolled and Still Uninsured
http://goo.gl/vGHDVf
This document summarizes a national survey of newly-enrolled adults and still-uninsured adults ages 18 to 64 to gain insights into the ACA’s first open enrollment period between April 10 through 28, 2014. The survey finds that knowledge and education levels are barriers to enrollment efforts. According to the results of the survey, news, websites and online searches are top sources of information.

Health Literacy

Health Literacy
National Network of Libraries of Medicine
http://goo.gl/LP9vQ
This federal website provides a summary of basic health literacy terms. It includes a definition of health literacy and addresses cultural considerations, the skills needed for health literacy, the prevalence of health literacy and the economic impact.

Health Literacy at the Food and Drug Administration: Current Initiatives in Prescription and Nonprescription Drugs
Michele, Theresa. IOM Health Literacy Workshop, November 6, 2014.
http://goo.gl/I9iOBf
The author prepared this presentation for the Institute of Medicine (IOM) Health Literacy Roundtable, and addressed health literacy in regards to prescription and nonprescription drugs. The author is the director of the Division of Nonprescription Drug Products, Office of New Drugs at the U.S. Food and Drug Administration.

Health Literacy: Statistics at a Glance
http://goo.gl/WD7Shx
This fact sheet addresses the scope and impact of low health literacy.

Oral Health Literacy – Activities to Educate the Profession
Robinson, Lindsey. IOM Health Literacy Workshop, November 6, 2014.
http://goo.gl/lrStbx
The author prepared this presentation for the Institute of Medicine (IOM) Health Literacy Roundtable, and addressed health literacy concerns when it comes to oral care.

The Health Literacy of America’s Adults: Results From the 2003 National Assessment of Adult Literacy
http://goo.gl/bUufeA
Although this assessment of health literacy was published in 2006, it is frequently cited as a baseline upon which later health literacy study has been built.

Federal Health Literacy Initiatives

New Federal Policy Initiatives To Boost Health Literacy Can Help The Nation Move Beyond The Cycle Of Costly ‘Crisis Care’
http://goo.gl/ik1pNB
The authors, all current or former Obama administration officials, describe three federal policy initiatives and state that both public and private organizations have an important role to play in addressing the challenge of limited health literacy.
Final Guidance on Implementing the Plain Writing Act of 2010
Executive Office of the President, Office of Management and Budget, April 13, 2011.
http://goo.gl/SK3NTx
This document concerns the Plain Writing Act of 2010 that President Obama signed into law in 2010. It requires federal executive agencies to have clear and understandable communication with the public.

Healthy People 2020
http://goo.gl/SzmJPE
This document provides 10-year goals and objectives for health promotion and disease prevention, and includes health literacy limits national objectives.

National Action Plan to Improve Health Literacy
http://goo.gl/tB3zjm
Former Health and Human Services Secretary Kathleen Sebelius launched the National Action Plan to Improve Health Literacy in 2010. The document points out the plan’s basic elements.

Private Sector Health Insurance Literacy Initiatives
New resource on health coverage, Highlights hurdles patients may face accessing needed medicines, October 14, 2014.
Pharmaceutical Research and Manufacturers of America (PhRMA), October 14, 2014
http://goo.gl/JuEfpJ
This news release announced the Pharmaceutical Research and Manufacturers of America’s (PhRMA) patient education website: AccessBetterCoverage.org. The website is intended to educate consumers about health insurance coverage and access to prescription drugs.

Health Literacy and America’s Health Insurance Plans: Laying the Foundation and Beyond
http://goo.gl/JToBTR
In this publication, the health plan association reviews the health literacy programs of 30 member companies. The programs vary in approach and focus on clear communication and the need for increased consumer health literacy.

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Websites

Government

Agency for Healthcare Research and Quality
http://www.ahrq.gov

Center for Consumer Information and Insurance Oversight

Centers for Disease Control and Prevention
http://www.cdc.gov/

Department of Health and Human Services
www.dhhs.gov

HealthCare.gov: https://www.healthcare.gov/

Healthy People.gov - HealthyPeople2020
http://www.healthypeople.gov/

National Institutes of Health http://www.nih.gov

Senate Health, Education, Labor and Pensions Committee http://www.help.senate.gov/

The Plain Language Action and Information Network (PLAIN) http://www.plainlanguage.gov/

Other

AHIP Coverage http://www.ahipcoverage.com/

American Enterprise Institute http://www.aei.org/

American Institutes for Research http://www.air.org/

America’s Health Insurance Plans http://www.ahip.org/

Center for Patient and Consumer Engagement http://aircpce.org/

Consumers Union http://consumersunion.org/

Enroll America http://www.enrollamerica.org

The George Washington University, Milken Institute School of Public Health http://publichealth.gwu.edu/

Institute of Medicine http://www.iom.edu/

Kaiser Family Foundation www.kff.org

National Association of Insurance Commissioners http://www.naic.org/
Endnotes


13 Ibid.


