


IMPROVING HEALTH COMMUNICATIONS

A COLLABORATIVE PLAN TO ADDRESS HEALTH LITERACY IN SAN DIEGO COUNTY



Health Literacy
SAN DIEGO

Revised 2015



HEALTH LITERACY IS NOT A CHARACTERISTIC OF INDIVIDUALS ALONE BUT IS, INSTEAD, AN INTERACTION BETWEEN THE SKILLS THAT PEOPLE HAVE AND THE DEMANDS THAT SYSTEMS MAKE. WE MUST CONSIDER LITERACY IN CONTEXT.

- Dr. Rima E. Rudd, 2010



Health Literacy
S A N D I E G O

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EXECUTIVE SUMMARY

Over the past decade, leaders in the health literacy field have come to realize that health literacy is not a characteristic of individuals alone but rather the interaction between those seeking healthcare and those providing healthcare. Moreover, among those seeking healthcare, only an estimated 12 percent of adults are proficient in health literacy.

From an individual perspective, for people to be truly health literate they must have mastered four key abilities. These include:

- The ability to seek, find and obtain health information
- The ability to comprehend the health information obtained
- The ability to interpret, filter, judge and evaluate the health information obtained
- The ability to communicate and use the information to make a decision to maintain and improve health

Healthcare providers also need to have a set of health literacy skills including:

- Help people find information and services
- Communicate about health and healthcare
- Process what people are explicitly and implicitly asking for
- Understand how to provide useful information and services
- Decide which information and services work best for different situations and people so they can act

This report updates the 2007 health literacy report, *When Words Get in The Way: A Collaborative Plan to Address Health Literacy in San Diego County*, by examining our current understanding of health literacy and some of the issues associated with it, such as numeracy (the ability to apply arithmetic operations and use numerical information in printed materials) and how health literacy is measured. In addition, this report highlights the impact of low health literacy in terms of overall health and wellness, and higher mortality. It presents a multi-dimensional model of health literacy that moves upstream from healthcare and includes both disease prevention and health promotion.

Beginning in 2010, four major federal policy initiatives were launched to address the issue of improving low health literacy. These initiatives include the Affordable Care Act (ACA), National Action Plan to Improve Health Literacy, Plain Writing Act of 2010 and Healthy People 2020. These initiatives raise the importance of health literacy as a key component in an effort to improve the health of the U.S. population, decrease costs, and reduce the number of medical errors.

In addition to the federal policy initiative, the Agency for Healthcare Research and Quality (AHRQ) has developed the Health Literacy Universal Precautions Toolkit, designed to help primary care practices reduce the complexity of health care, increase patient understanding of health information, and enhance support for patients at all health literacy levels. The key element of the toolkit is the assumption that all patients may have difficulty

comprehending health information and accessing health services regardless of their education or socioeconomic status. Rather than screening patients for low literacy or low health literacy levels, the approach of the toolkit is to apply universal precautions to all patients by taking the following actions:

- Simplifying communication with and confirming comprehension for all patients, so that the risk of miscommunication is minimized.
- Making the office environment and healthcare system easier to navigate.
- Supporting patients' efforts to improve their health.

The Toolkit consists of 21 tools using evidence-based guidance to help primary care practices address health literacy, and is divided into the following four areas of emphasis:

- Spoken Communication
 - Written Communication
 - Self-Management and Empowerment
 - Supportive Systems
-

The final element of this report is a call to action to the Health Literacy San Diego (HLSD) task force to develop collaborative partnerships with various community members to address health literacy focusing on the following 10 recommendations:

1. Develop an advocacy strategy to include health literacy as a common thread through all "access to healthcare" related issues, including disease prevention and health promotion in San Diego.
2. Update the HLSD website to include interactive and credible resources for consumers and healthcare professionals.
3. Continue front and back office staff trainings to enhance better understanding of how to deal more effectively with low health literacy populations. Provide technical assistance to providers with developing appropriate communication methods and tools and creating system changes to work with low health literate patients.
4. Implement and add new relevant sections to Health Education and Literacy materials for adult learners. Continue the train-the-trainer workshops.
5. Develop an overall evaluation for health literacy in San Diego, including specific metrics to be tracked over time.
6. Develop a community health literacy outreach plan for both consumers and providers. Provide community forums and education for consumers and providers on specific health literacy related issues, including:
 - Basic understanding of healthcare coverage and terminology
 - Teach back and self-directed teach back methods
 - Specific disease topics and at-risk populations
 - Research and identify credible health information online
7. Start an annual health literacy summit in San Diego, to include research, sharing of best practices, and education.
8. Provide social networking guidance for providers and consumers. Ensure social media sites are monitored and provide credible resources.
9. Provide a centralized service to providers for reviewing health materials and health-related forms to adjust readability level.
10. Create specific mental health literacy education materials and develop a program that aids recognition, management and prevention of mental health issues, including reducing stigma associated with mental illness.



INTRODUCTION

Health literacy, including mental health, is the degree to which individuals have the capacity to obtain and understand basic health information and services needed to make appropriate health decisions. Nationally, only 12 percent of adults are proficient in health literacy. While low health literacy can be found across all demographic groups, it disproportionately affects: non-white racial and ethnic groups; the elderly; individuals with lower socioeconomic status and less education; people with physical and mental disabilities; those with low English proficiency (LEP); and non-native English speakers.

Low health literacy is associated with reduced use of preventive services, poorly managed chronic conditions, and higher mortality. It also leads to medication errors, misdiagnoses due to poor communication between providers and patients, low rates of treatment compliance, hospital readmissions, unnecessary emergency room visits, longer hospital stays, fragmented access to care, and poor responsiveness to public health emergencies. As a result, low health literacy has been estimated to cost the U.S. economy up to \$236 billion annually (Vernon, 2007).

This update to the 2007 health literacy report, *When Words Get in The Way: A Collaborative Plan to Address Health Literacy in San Diego County* examines our current understanding of health literacy and the impact of low health literacy in terms of overall health and higher mortality. This report also reviews a number of major federal policy initiatives for improving health literacy, and contains a brief discussion of a few innovations and promising practices being used by providers and health care systems to address health literacy.

DEFINING AND UNDERSTANDING HEALTH LITERACY

What is health literacy?

How does health literacy differ from literacy?

Literacy refers to basic skills needed to succeed in society, while health literacy requires some additional skills, including those necessary for finding, evaluating and integrating health information from a variety of sources. It also requires some knowledge of health related vocabulary as well as the culture of the health system.

(Rootman et al., 2012)

Health literacy can mean different things to various audiences. Some examples include:

- “The constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment, including the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials.” – American Medical Association’s Ad Hoc Committee on Health Literacy 1999 (JAMA, 1999).
- “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” – Healthy People 2010 & Institute of Medicine
- “Health literacy is linked to literacy and entails people’s knowledge, motivation and competencies to access, understand, appraise and apply health information in order to make judgments and make decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course.” – European Health Literacy Consortium 2013

These definitions present health literacy as a set of individual capacities that allow a person to acquire and use new information. The assumption behind each of these definitions is that health literacy can improve as the person acquires and uses new information.

An alternative definition of health literacy is an ability to function in the health care environment that is dependent upon characteristics of both the individual and the health care system. From this perspective, health literacy is dynamic and may change during a health care encounter. In other words, an individual’s health literacy may vary depending upon the medical problem being treated, the health care provider and the system providing the care (Baker, 2006).

Yet another group of Institute of Medicine (IOM) experts has divided the domain of “health literacy” into cultural and conceptual knowledge, oral literacy, including speaking and listening skills, print literacy, including writing and reading skills, and numeracy. In 2014, a group of experts at a roundtable on health literacy stated it well: “Although health literacy is commonly defined as an individual trait, it does not depend on the skills of the individual alone. Health literacy is the product of the interaction between individuals’ capacities and the health-related demands and complexities of the health care system” (IOM, 2014).

Health literacy is multifaceted and includes not only the individual’s literacy level but also cultural and societal norms and how effectively healthcare providers and health systems interact with the individual to enhance health outcomes.

MENTAL HEALTH LITERACY

The concept of mental health literacy includes the same elements as physical health literacy, i.e., “the individual’s capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (IOM, 2010). The definition of mental health literacy closely parallels health literacy “as the ability to gain access to, understand and use information in ways which promote and maintain good mental health.” Mental health literacy also refers to knowledge and beliefs about mental disorders that aid their recognition, management or prevention. (Lauber et al., 2003). In addition to looking at functional, interactive, and critical dimensions of literacy, mental health literacy also includes the role that beliefs play in the recognition, prevention, and management of mental disorders (Francis et al., 2002).

According to data collected in 2013, nearly 1 in 5 American adults experienced a mental health issue and more than 1 in 10 adolescents experienced a period of major depression. In addition, nearly 1 in 20 American adults lived with a serious mental illness, such as schizophrenia, bipolar disorder, or major depression. (SAMHSA, 2014)

The components of mental health literacy are:

- The ability to recognize specific disorders or different types of psychological distress
- Knowledge and beliefs about risk factors and causes
- Knowledge and beliefs about self-help interventions
- Knowledge and beliefs about professional help available
- Attitudes that promote recognition and appropriate help-seeking
- Knowledge of how to seek mental health information (Jorm, 2000)

Unlike physical health literacy, the framework for mental health literacy is extremely complex. Given that only 12 percent of U.S. adults are proficient enough in physical health literacy to understand and use health information effectively, the lack of abilities and knowledge related to mental health literacy creates a challenge for the mental health professional.

Improving an individual’s mental health literacy has many of the same benefits as improving a person’s physical health literacy, including:

- Prevention
- Early recognition
- Intervention

In the U.S., mental health literacy is discussed in terms of public health promotion and disease prevention, including communication and education. Unlike Canada and Australia, which have explicit mental health literacy programs, there is very little research related directly to mental health literacy in the U.S. There is, however, a wealth of



information related to specific mental health conditions such as depression, anxiety, and bipolar disorder, to name a few. Moreover, there are numerous web-based, topic-specific sources of information and educational materials for both individuals with various forms of mental disorders and their caretakers.

Unlike physical health literacy, there are no programs designed to assist providers to better meet the needs of their mental health patients such as the universal precautions approach. However, the same approaches used to address physical health literacy could be used for mental health literacy.

One of the biggest barriers to seeking mental health treatment is stigma, which can be seen as an overarching term that contains three elements (Clement, 2014):

- Problems of knowledge (ignorance)
- Problems of attitudes (prejudice)
- Problems of behavior (discrimination)

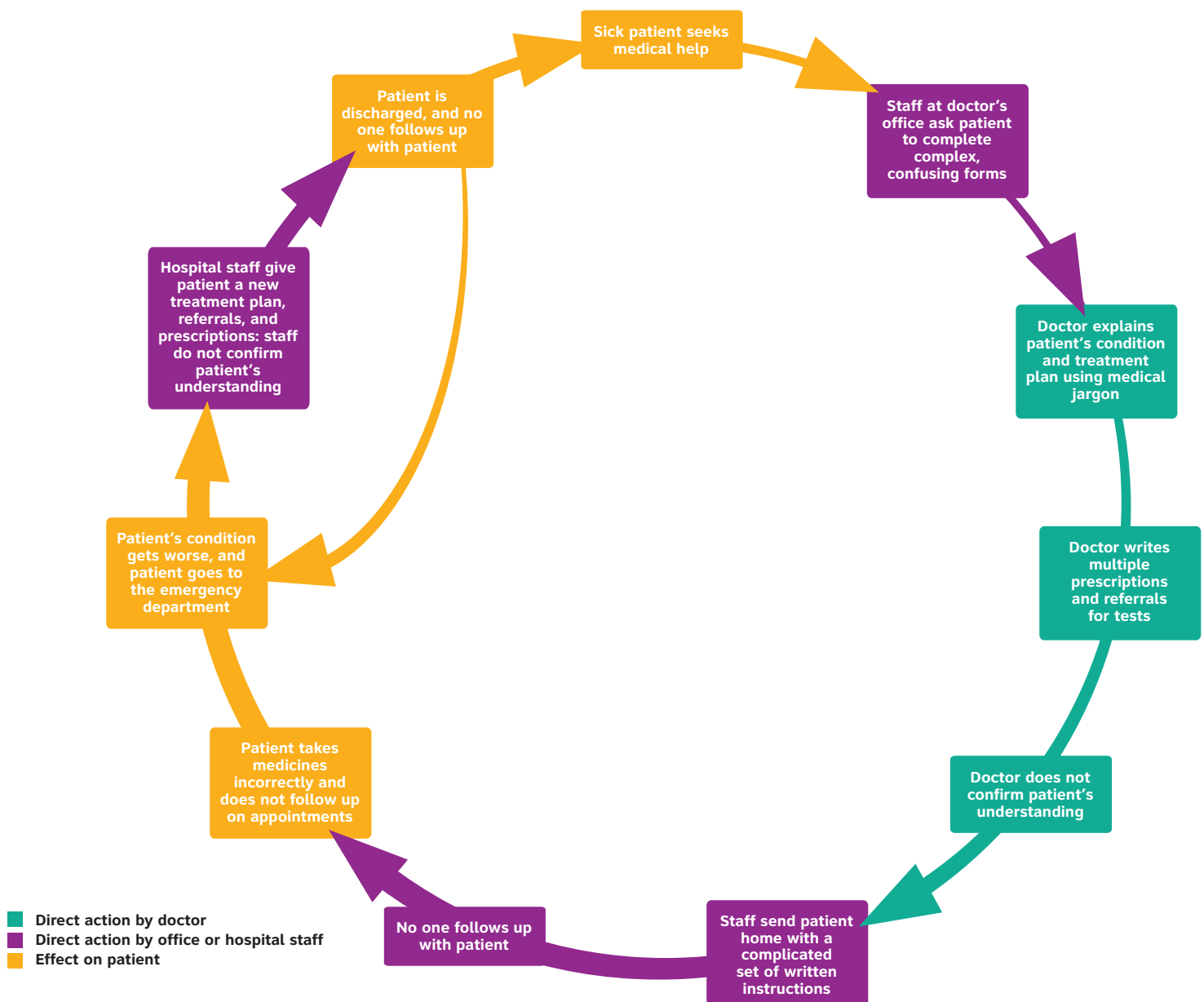
All three of these elements directly relate to a lack of mental health literacy on the part of the individual with the mental health illness and the general public.

In addition to the stigma of mental health, limited literacy also presents some unique challenges to someone who has both low literacy and mental illness. Limited literacy presents the same challenges to mental health care as physical health care, plus the double stigma of both mental illness and low literacy.

CYCLE OF CARE - HEALTH LITERACY FROM THE PATIENT'S PERSPECTIVE

The following flow chart illustrates the various touch points patients and providers experience during a traditional visit to a provider's office when seeking medical care. Notice how the staff and physician have numerous opportunities to improve their communication with patients. If they do not, the result of this experience is the patient's condition gets worse and ends up in the emergency department.

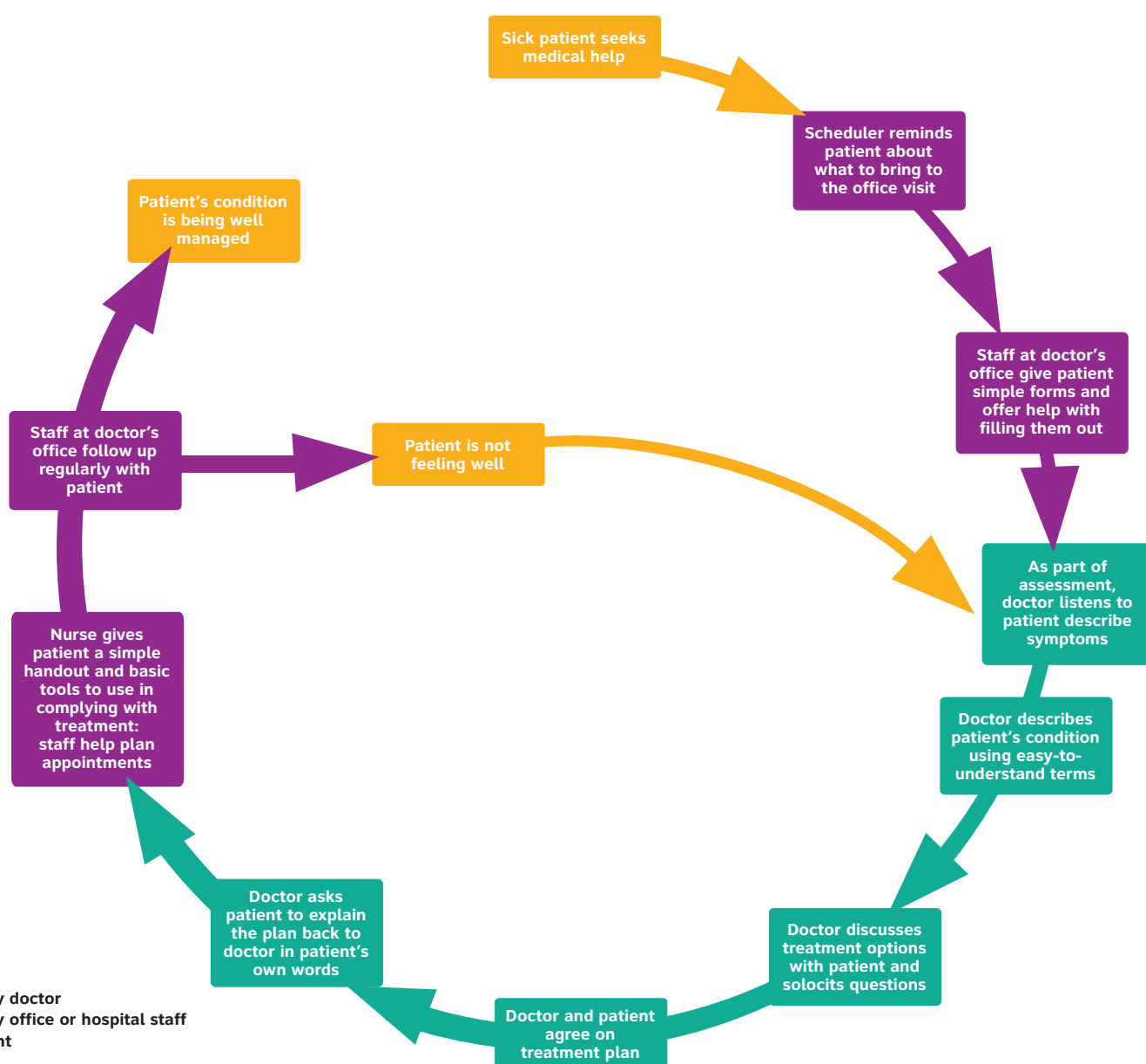
THE CYCLE OF CRISIS CARE: A PATIENT'S EXPERIENCE



(Koh et al, 2013)

The patient visit in this scenario employs health-literate care, which features clear communication, simplified forms, offers of assistance, confirmation of understanding through teach back and commitment to patient follow-up. By making health literacy a key element in the care provided by the physician and office staff the patient avoids use of the emergency department and is well managed.

HEALTH-LITERATE CYCLE OF CARE: A PATIENT'S EXPERIENCE



(Koh et al, 2013)

Patients and their family members often receive an overwhelming amount of health information. The content may be unfamiliar, complicated, confusing, or even frightening. Art's story is an example of the patient not understanding the doctor's recommendations or the consequences of the surgery. Fortunately, Art's daughter had taken notes and was able to explain to Art what the results of the surgery would mean to him.



Art's Story

Art was a 78-year-old retired parole officer with emphysema. He had recently developed recurrent throat cancer. His cancer surgeon recommended surgery to remove the cancer. Art asked for advice from his lung doctor, who had been treating Art for years. The doctor tried to explain what would happen during the surgery and some of the risks. The doctor used many terms, such as "laryngectomy," "hemi-laryngectomy," (later, simply "a hemi"), "palliative trach," "ventilatory problems," "bronchiectasis," and "purulent bronchitis." "OK," said Art. "You've saved my life before. I think I better follow your advice. Let's do it."

Art's adult daughter was in the room, listening and taking notes. She sat next to her father and said, "Dad, what the doctor is saying is that with the surgery, you would have your voice box taken out. You wouldn't be able to talk anymore. You'd have a breathing hole through the front of your throat for the rest of your life. You'd have to keep the hole protected so germs couldn't go straight into your lungs. And you'd have a tube in your breathing pipe that you'd have to take care of every day."

Art's eyes got wide, then angry, and he asked, "What the hell do you mean ... I won't be able to talk?" (Abrams et al, 2014)

12 DIMENSIONS OF HEALTH LITERACY

In 2012 a research study published in BioMed Central (BMC) Public Health, a peer-reviewed journal by Kristine Sorensen presented a systematic review and integration of definitions and models. This research identified 17 definitions of health literacy and 12 conceptual models. The authors reviewed and analyzed each of these definitions and models. Based on their effort they developed an integrated conceptual model of health literacy containing 12 dimensions (see table below) built around four core competencies including accessing, understanding, appraising and applying health-related information. These core competencies allow an individual to navigate the three domains of the health continuum:

- Healthcare (when a person is ill or a patient is in a healthcare setting)
- Disease prevention (when a person is at risk of disease)
- Health promotion (when a person is exposed to efforts in the community to improve health)

This approach places greater emphasis on health literacy outside the healthcare setting and has the potential to have positive impact on both disease prevention and preventive health.

The following table shows how Sorensen defined the 12 sub-dimensions of health literacy based on the three key areas of health which include health literacy related to health care, disease prevention and health promotion.

Health literacy	Access or obtaining information relative to health	Understand information relevant to health	Appraise, judge or evaluate information relevant to health	Apply or use information relevant to health
Health care	Ability to access information on medical or clinical issues	Ability to understand medical information and derive meaning	Ability to interpret and evaluate medical information	Ability to make informed decisions on medical issues
Disease prevention	Ability to access information on risk factors	Ability to understand information on risk factors and derive meaning	Ability to interpret and evaluate information on risk factors	Ability to judge the relevance of the information on risk factors
Health promotion	Ability to update oneself on health issues	Ability to understand health-related information and derive meaning	Ability to interpret and evaluate information on health-related issues	Ability to form a reflected opinion on health issues

Defined this way, health literacy can be visualized as an integrated model (see Appendix 2) which goes beyond a narrow concept of general and health education and the individual's ability to use the information given. It now addresses the environmental, political and social factors that determine health and how well these factors interact with the individual.

At the center of this model are four core health literacy competencies, which are defined as follows:

- **Access** refers to the ability to seek, find and obtain health information.
- **Understand** refers to the ability to comprehend the health information that is accessed.
- **Appraise** describes the ability to interpret, filter, judge and evaluate the health information that has been accessed.
- **Apply** refers to the ability to communicate and use the information to make a decision to maintain and improve health.

The Affordable Care Act (ACA) defines health literacy in a much broader sense, including the individual, the provider and the organization. According to the ACA:

Anyone who **needs** health information and services also needs health literacy skills to:

- Find information and services
- Communicate their needs and preferences and respond to information and services
- Process the meaning and usefulness of the information and services
- Understand the choices, consequences and context of the information and services
- Decide which information and services match their needs and preferences so they can act

Anyone who **provides** health information and services to others such as a doctor, nurse, dentist, pharmacist, or public health worker, also needs health literacy skills to:

- Help people find information and services
- Communicate about health and healthcare
- Process what people are explicitly and implicitly asking for
- Understand how to provide useful information and services
- Decide which information and services work best for different situations and people so they can act

Organizational health literacy is what organizations and professionals do to help people. They:

- Find
- Process
- Understand
- Decide on health information and services

According to the U.S. Department of Education, only 12 percent of English-speaking adults in the United States have proficient health literacy skills. The level of health literacy skills is significantly less among persons with low literacy, those with lower socioeconomic status, and minority groups. (IOM, 2004).

Because health information and services are often unfamiliar, complicated and technical, even for people with higher levels of education, research is showing that health systems and health professionals need to do more to make health information and services understandable and able to be acted upon by everyone (IOM, 2004).

The need for clear, understandable and actionable health information applies to many different sources and media channels, including:

- Doctors, dentists, nurses, physicians' assistants, pharmacists and other health professionals
- Health educators and public health officials
- Nutrition and medicine labels
- Product pamphlets and safety warnings
- TV, radio and newspapers
- Schools and libraries
- Websites and social media

POPULATIONS MOST IMPACTED BY LOW HEALTH LITERACY

According to the Health Literacy Component of the 2003 National Assessment of Adult Literacy (NAAL), the only large-scale survey of health literacy of the U.S. population, those most likely to experience low health literacy are:

- Adults over the age of 65
- Non-white racial and ethnic groups
- Recent refugees and immigrants
- People with less than a high school diploma or GED
- People with income levels at or below the poverty level
- Non-native English speakers
- Persons with a wide variety of physical and mental disabilities and difficulties or illness including mental illness and traumatic brain injury

(Kutner, Greenberg, Jin, Paulsen, 2006)

According to this data, limited health literacy as a population-level problem affects nearly 9 out of 10 English-speaking adults in the U.S. However, the NAAL does not provide data on the health literacy skills among adults with limited English language skills.

The NAAL is managed by the Department of Education and is currently the only source of national data on health literacy. The assessment is scheduled to be repeated again in 2015. (IOM, 2009)

The health literacy levels used in the NAAL are all based on academic literacy skills of the individual, which are measured by reading and comprehension test scores. Health literacy, however, is not restricted to a person's ability to read and write, and does not apply only to the written word. Other factors that play a role in how well someone understands and uses health information that they are told, see, hear, or read include:

- Past experience with the health care system
- Cultural and linguistic factors
- The format of materials
- How information is communicated



Health literacy reflects the dual nature of communication:

- What information is being disseminated, and
- How people understand the information given to them. (IOM, 2012)

While academic literacy skills are important, there are other types of health literacy measures such as functional health literacy and interactive literacy that play important roles in health literacy. Functional literacy is about what adults do rather than what they are capable of doing. For example, functional health literacy enables people to use the health care system and take care of themselves, but not necessarily to read insurance documents or understand medical terminology. Interactive health literacy requires social skills such as listening and speaking to complete more complicated interaction tasks such as making an appointment, getting to the appointment, describing symptoms and listening to treatment instruction (IOM, 2009).

NUMERACY AND HEALTH LITERACY

Health numeracy is defined as “The degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, bio-statistical, and probabilistic health information needed to make effective health decisions” (Golbeck, 2005).

Golbeck’s four overlapping categories of numeracy skill levels offer a simple way to look at this very complex concept. These categories are:

- Basic skills, ability to identify and read numbers
- Computational skills, ability to do counting and arithmetic procedures
- Analytical skills, inference, estimation, proportion, percentage, frequencies, and basic graphs
- Statistical skills, probability, statistics, error, and risk

Analytical skills play a large role in health care and in clinicians’ directions to patients because these skills enable patients to interpret information. Statistical skills allow patients to compare things and understand probability, which are important concepts in health care. Patients need all of these numeracy skills to some extent when they receive care, follow treatment plans, and pay for medical care. “The ability to understand, evaluate and use numbers is important to making informed health care choices” (IOM, 2014).

Unfortunately, a majority of the population lacks these basic numeracy skills. NAAL findings indicate that 55% of the population performed at the lowest two of the four levels in quantitative literacy. This compares to 43% in prose literacy and 34% in document literacy (IOM, 2004). The Adult Literacy and Life Skills (ALL) Survey conducted between 2006 and 2008, an international comparative study including the United States, measured the literacy and numeracy skills of a nationally representative sample of 16 to 65-year olds. The ALL found that 58.6% of the U.S. population scored at the lowest levels of the numeracy scale (DOE, 2005). Clearly, based on past research, the average numeracy skills of the U.S. population must be taken into consideration when addressing health literacy.

The health numeracy challenge for providers is similar to the literacy challenge. Providers need to focus their efforts in two areas: decrease the demand on the patients and increase the provider's communication skills. (IOM, 2014)

HEALTH LITERACY, CULTURE AND LANGUAGE

Low health literacy, cultural barriers, and limited English proficiency have been coined the “triple threat” to effective health communication by The Joint Commission (Schvye, 2007). To help address the cultural barriers that can impact care, it's useful for providers to have basic information about some of the various cultures residing in this region and have a basic understanding of some of their beliefs and practices related to health and healthcare. However, it is critical that every patient be seen as an individual. Most importantly, stereotyping a patient can lead to misconceptions about the person seeking care resulting in a poor outcome.

The following are some resources that may be useful when treating patients from different prevalent cultures in San Diego County.

- **EthnoMED:** Integrating cultural information into clinical practice website available at <http://ethnomed.org>
- **Culture Clues** provides tip sheets that offer health care preferences and perceptions of patients from 10 different cultures available at <http://depts.washington.edu/pfes/CultureClues.html>
- **Health Care Providers' Handbook** on Muslim Patients available at http://www.health.qld.gov.au/multicultural/support_tools/islamgde2ed.pdf
- **American Association of Family Physicians Quality Care for Diverse Populations** offers seven 3- to 8-minute videos showing clinicians thoughtfully communicating with diverse populations. Available at <http://www.aafp.org/patient-care/public-health/cultural-proficiency.html>

Examples of how culture, ethnic customs and religious beliefs can influence how patients interact with providers.

- **Health beliefs:** In some cultures, people believe that talking about a possible poor health outcome will cause that outcome to occur.
- **Ethnic customs:** Differing roles of women and men in society may determine who makes decisions about accepting and following through with medical treatments.
- **Religious beliefs:** Religious faith and spiritual beliefs may affect health care-seeking behavior and people's willingness to accept specific treatments or behavior changes. (Brega et al, 2015)



PROJECT SHINE

There currently are an estimated 30,000 Iraqi refugees and immigrants living in El Cajon, California, accounting for roughly 30% of the city's population. Many are refugees who fled Iraqi to save their lives and the lives of their family members. Once here they have found a very different world, one in which they need to learn many basic skills that most of us take for granted. Culturally, many refugees are unaccustomed to the U.S. healthcare system and experience confusion about whether to go to their family physician or the emergency room for care.

Project SHINE, an intergenerational refugee program developed at the Intergenerational Center at Temple University in Philadelphia, has been implemented by the Continuing Education & Workforce Training program at Cuyamaca Community College. The program's goal is to teach refugees to manage their own preventive and ongoing healthcare, decreasing the strain on emergency departments and other healthcare resources. A major focus of this program is health literacy, covering a wide range of topics including how to interact with doctors, dealing with hospitals, managing illness, healthy aging and taking medications. For each of these topics, participants in the SHINE program learn the vocabulary and discuss how U.S. healthcare is different from that received in Iraq.

Project SHINE trains college students to work with older refugees to advance their knowledge in English and health literacy. There are a variety of goals for recipients of Project SHINE including: reduce isolation in the community and enhance community integration; increase the understanding of health literacy and access, including the use of the 911 system and emergency room visits; develop cross-cultural relationships; increase confidence in speaking English; learn skills to navigate community health systems; increase contact with English-speakers; and feel a greater sense of social connectedness. In addition, the program helps refugees to find a mentor or coach and assists in reducing barriers to employment.

Through the County of San Diego, Health & Human Services Agency (HHSA), Project SHINE is funded by the State of California's Refugee Programs Bureau, via the federal Office of Refugee Resettlement. HHSA contracts with the Grossmont-Cuyamaca Community College District to administer the program.

HEALTH LITERACY AND HEALTH OUTCOMES

The link between low health literacy and poor health outcomes has been well documented. Comprehensive reports published in 2004 and 2011 concluded that low health literacy is associated with poorer health outcomes and poorer use of health care services (Berkman et al, 2011).

A 2011 review of 96 studies by Berkman designed to determine the relationship of health outcome to health literacy identified the following factors:

Use of health care services and access to care among people with lower health literacy:

- Increased use of emergency care and hospitalization
- Lower probability of mammography screening and influenza immunizations

Health care-related skills among people with lower health literacy:

- Poorer skills in taking medications
- Poorer interpretation and understanding of prescription medications, nutrition labels, and health messages

Disease prevalence and severity among people with lower health literacy:

- More likely to have symptoms of depression or to be considered depressed

Global health status of elderly persons with lower health literacy:

- Poorer health status among elderly persons

Death among persons with lower health literacy:

- Higher all-cause mortality rates among elderly persons

In summary, the 2011 study by Berkman found that persons with lower health literacy used health services such as emergency and hospital care more often, used preventive services less, and had problems interpreting medication labels and health messages. Moreover, elderly persons with low health literacy had poorer overall health and higher mortality (Berkman et al., 2011).

NOTE: all of the above findings were restricted to English-language only articles.

Low health literacy is not only linked to worse health outcomes and greater mortality risk, but to unnecessary health care services use and costs. A recent analysis of the aggregate cost of low health literacy in the United States estimated that 7% to 17% of all personal health care expenditures, between \$106 billion and \$238 billion annually, can be attributed to low health literacy (Vernon et al., 2008).

HEALTH LITERACY AND KNOWLEDGE OF SPECIFIC HEALTH ISSUES

Review of recent studies designed to measure the relationship between literacy level and knowledge of specific health issues presents mixed results. Earlier studies reported many direct relationships between selected health conditions and health literacy. However, follow-up studies tended to report less impact of low health literacy. Following is a review of findings of studies designed to measure the relationship between literacy and health outcomes for select conditions.

Cancer

Low literacy adversely impacts cancer incidence, mortality, and quality of life (Merriman, 2002).

- Cancer screening information can be ineffective, resulting in patients being diagnosed at a later stage.
- Treatment options may not be fully understood, resulting in patients not receiving treatments that best meet their individual needs.
- Informed consent documents are too complex for many patients, resulting in patients not making appropriate decisions about accepting or rejecting interventions.

Hypertension and Diabetes

A recent systematic review of studies related to health literacy and health outcomes for people with diabetes concluded that the current understanding of the effect of low health literacy on the health of people with diabetes is limited (Fatima, 2013). The only definitive finding of this review is that low health literacy is consistently associated with poorer diabetes knowledge.

Patients with hypertension or diabetes, both requiring chronic disease self-care, have similar issues related to adequate health literacy, and numeracy health literacy. Those with significantly less knowledge of their disease and essential self-management skills had lower adherence to activities known to help improve these conditions, such as special diets and other behavioral modifications (Hutchison, 2014).

Asthma

Asthma self-management requires adequate reading and numeracy health literacy skills to reduce ER visits and hospitalizations resulting from asthma attacks (Apter, 2006). Low literacy is associated with poor knowledge of asthma and improper inhaler use.

ADDRESSING HEALTH LITERACY THROUGH POLICY INITIATIVES

In 2010, four major federal policy initiatives launched to address the issue of improving low health literacy. These initiatives include the Affordable Care Act (ACA), National Action Plan to Improve Health Literacy, Plain Writing Act of 2010 and Healthy People 2020. These initiatives raise the importance of health literacy as a key component in an effort to improve the health of the U.S. population, decrease costs, and reduce the number of medical errors.

AFFORDABLE CARE ACT

Several ACA provisions directly acknowledge the need for greater attention to health literacy, and many others imply it. The law includes provisions to communicate health and health care information clearly; promote prevention; be patient-centered by creating medical homes that provide coordination of care; assure equity and cultural competence; and deliver high-quality care. Health literacy provides a critical path for achieving the goals of the ACA; without a health literate population, meaningful health care reform will not happen (IOM, 2011).

Several sections of the ACA directly addressing health literacy include:

Shared Decision-Making – Section 3506 requires the Department of Health and Human Services (HHS) to “facilitate collaborative processes between patients, caregivers, authorized representatives and clinicians that enable decision-making, provide information about tradeoffs among treatment options and facilitate the incorporation of patient preferences and values into the medical plan.” Moreover, it authorizes a program to update patient decision aids to assist health care providers and patients. Decision aids must reflect diverse levels of health literacy (ACA, 2010).

Medication Labeling – Section 3507 directs the HHS to determine whether standardizing prescription drug labels and print advertising will improve decision-making (ACA, 2010).

Workforce Development – Section 5301 allows the HHS to provide training grants in the primary care medical specialties, with preference for applicants that “provide training in enhanced communication with patients in cultural competence and health literacy.”

Additionally, with the implementation of the ACA in 2010, millions of previously uninsured Americans have new-found access to health care. While this is a positive step, it also presents a significant challenge to those with poor literacy and numeracy skills. Because purchasing health insurance has important health and financial implications, it is critical that people have a good understanding of insurance products. Yet, recent research conducted by Consumers Union found that the process of purchasing health insurance presents a number of terminology and numeracy issues for consumers. First, terms such as “deductible,” “out-of-pocket,” “coinsurance,” “copay,” and “annual benefit limit” are complex concepts by themselves. Second, when adding the context of shopping for a health insurance plan the ability to determine actual out-of-pocket costs of an insurance product becomes almost impossible (IOM, 2012).

According to the Consumer Union’s research studies, consumers dread shopping for health insurance because they:

- Doubt the value or question the purpose of health insurance
- View health insurance as prepaid health care rather than health insurance
- Don’t understand the concept that insurance protects against unexpected health crisis
- Don’t understand the basic principle of insurance

THE NATIONAL ACTION PLAN TO IMPROVE HEALTH LITERACY

The *National Action Plan to Improve Health Literacy*, released by the U.S. Department of Health and Human Services (HHS) in 2010, is designed to help organizations, professionals, policymakers, communities, individuals, and families improve health literacy. The plan is based on the following tenants:

- Everyone has the right to health information that helps them make informed decisions.
- Health services should be delivered in ways that are understandable and beneficial to health, longevity, and quality of life.

The *National Action Plan to Improve Health Literacy* has the following seven goals to improve health literacy:

1. Develop and disseminate health and safety information that is accurate, accessible, and actionable.
2. Promote changes in the health care system that improve health information, communication, informed decision making, and access to health services.
3. Incorporate accurate, standards-based, and developmentally appropriate health and science information and curricula in child care and education through the university level.
4. Support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community.
5. Build partnerships, develop guidance, and change policies.
6. Increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy.
7. Increase the dissemination and use of evidence-based health literacy practices and interventions.

Some of the evidence-based strategies recommended in the plan include:

User-centered design – Health professionals are encouraged to use proven health literacy design principles and standards to provide health information and services. Several examples cited include picture-based instructions to promote better understanding of how to take medication and decrease medication errors among patients, and the use of graphs to communicate health risk information to adults with low numeracy skills.

Universal precautions approach – Using the universal precautions approach to health communications is recommended, as 9 out of 10 English-speaking adults have less than proficient health literacy skills. Using clear communication with everyone, regardless of their perceived health literacy skills, becomes the standard to ensure that people receive the information they need to make appropriate health decisions.

Organizational Change – There is a growing awareness of the need for organizations to address health literacy. A wide range of organizations have started looking at the factors needed to ensure that consumers can make informed health care decisions.

One of the outgrowths of the plan has been the development of the ten attributes of health literate health care organizations. The attributes are relevant to organizations that provide health care directly. These organizations include group practices, clinics, inpatients units, hospitals, community health centers, disease management companies, pharmacy practices, and integrated delivery systems. The attributes are also relevant to health care professionals such as doctors, nurses, physicians, medical assistants, pharmacists, dentists, health educators, interpreters, and administrative staff. Finally, many of these attributes are relevant to the broader range of organizations and institutions, such as payers and health plans (e.g., health maintenance organizations, insurance carriers, employee-based plans, the Department of Veterans Affairs, and the Centers for Medicare and Medicaid Services), vendors of health information technology and health education products, accreditation and credentialing organizations, and benefits managers (IOM, 2012).

In 2012, the Institute of Medicine published a discussion paper entitled *Ten Attributes of Health Literate Health Care Organization* which is a must read for anyone interested in how this issue can be applied to a wide variety of organizations involved in health care. According to this publication the 10 attributes state that the health care organization:

1. Has leadership that makes health literacy integral to its mission, structure, and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
3. Prepares the workforce to be health literate and monitors progress.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.

THE PLAIN WRITING ACT OF 2010

The Plain Writing Act of 2010 was signed into law on October 13, 2010. The law requires that federal agencies use “clear Government communication that the public can understand and use.” According to the Act, plain writing is writing that is clear, concise, well-organized and consistent to other best practices appropriate to the subject or field and intended audience. Such writing avoids jargon, redundancy, ambiguity and obscurity. From the perspective of health literacy, this Act directly challenges the person communicating a message in writing to meet an established set of writing guidelines. The guidelines strongly encourage writers to know more about the audience to whom they are writing rather than guessing about their reading skills and knowledge of the subject. The Federal Plain Language Guidelines have been developed and published as part of this Act. This easy to read and use document is available at: <http://www.plainlanguage.gov/howto/guidelines/FederalPLGuidelines/index.cfm>

HEALTHY PEOPLE 2020

Unlike *Healthy People 2010*, which had a communication focus and an objective to improve and address the patient's limited health literacy, *Healthy People 2020* focuses on the health literacy actions of the provider rather than the individual. The following table presents the objectives for this topic along with the action to be measured.

HC/HIT-1	(Developmental) Improve the health literacy of the population
HC/HIT-1.1	(Developmental) Increase the proportion of persons who report their health care provider always gave them easy-to-understand instructions about what to do to take care of their illness or health condition
HC/HIT-1.2	(Developmental) Increase the proportion of persons who report their health care provider always asked them to describe how they will follow the instructions
HC/HIT-1.3	(Developmental) Increase the proportion of persons who report their health care providers' office always offered help in filling out a form
HC/HIT-2	Increase the proportion of persons who report that their health care providers have satisfactory communication skills
HC/HIT-2.1	Increase the proportion of persons who report that their health care providers always listened carefully to them
HC/HIT-2.2	Increase the proportion of persons who report that their health care providers always explained things so they could understand them
HC/HIT-2.3	Increase the proportion of persons who report that their health care providers always involved them in decisions about their health care as much as they wanted
HC/HIT-4	(Developmental) Increase the proportion of patients whose doctor recommends personalized health information resources to help them manage their health

In addition to the emphasis on effective provider communication from the patient's perspective, other objectives in the Health Communication and Health Information Technology topic area focus on the use of electronic and Internet communication with the patient or site user. This topic area provides extensive information on the design of easy-to-use health web sites and presents six strategies that have been extensively tested with low literate and low health literate individuals. These strategies include:

- Learn about your users
- Write actionable content
- Display content clearly
- Organize and simplify
- Engage users
- Evaluate and revise

The *Health People 2020* website has a link to a downloadable PDF guide entitled *A Guide to Writing and Designing Easy-to-Use Health Web Sites* (<http://www.health.gov/healthliteracyonline/index.htm>) that contains extensive how-to information about the entire health website design process.

In addition to the Health Communication and Health Information Technology topic area, health literacy is addressed in the objectives of a wide variety of other *Healthy People 2020* topic areas. Following are explicit examples where a topic objective mentions some type of health literacy activity such as discussion with the provider, health education, formal instructions, counseling, or written care management plans.

Cancer

Increase the proportion of men who have discussed the advantages and disadvantages of the prostate-specific antigen (PSA) test to screen for prostate cancer with their health care provider.

Education and Community-based Programs

This topic area is rich in health literacy with an emphasis on health education from preschool through college. Examples of health literacy objectives include:

ECBP-1 (Developmental) Increase the proportion of preschool Early Head Start and Head Start programs that provide health education to prevent health problems in the following areas: unintentional injury; violence; tobacco use and addiction; alcohol or other drug use; unhealthy dietary patterns; and inadequate physical activity, dental health, and safety.

ECBP-2 Increase the proportion of elementary, middle, and senior high schools that provide comprehensive school health education to prevent health problems in the following areas: unintentional injury; violence; suicide; tobacco use and addiction; alcohol or other drug use; unintended pregnancy, HIV/AIDS, and STD infection; unhealthy dietary patterns; and inadequate physical activity

ECBP-3 Increase the proportion of elementary, middle, and senior high schools that have health education goals or objectives which address the knowledge and skills articulated in the National Health Education Standards (high school, middle, and elementary).

ECBP-4 Increase the proportion of elementary, middle, and senior high schools that provide school health education to promote personal health and wellness in the following areas: hand washing or hand hygiene; oral health; growth and development; sun safety and skin cancer prevention; benefits of rest and sleep; ways to prevent vision and hearing loss; and the importance of health screenings and checkups.

ECBP-7 Increase the proportion of college and university students who receive information from their institution on each of the priority health risk behavior areas (all priority areas; unintentional injury; violence; suicide; tobacco use and addiction; alcohol or other drug use; unintended pregnancy; HIV/AIDS and STD infection; unhealthy dietary patterns; and inadequate physical activity).



Family Planning

FP-12 Increase the proportion of adolescents who received formal instruction on reproductive health topics before they were 18 years old.

Food Safety

FS-5 Increase the proportion of consumers who follow key food safety practices.

Nutrition and Weight Status

NWS-6 Increase the proportion of physician office visits that include counseling or education related to nutrition or weight.

Physical Activity

PA-4 Increase the proportion of the nation's public and private schools that require daily physical education for all students.

PA-11 Increase the proportion of physician office visits that include counseling or education related to physical activity.

Respiratory Diseases

RD-7.1 Increase the proportion of persons with current asthma who receive written asthma management plans from their health care provider according to National Asthma Education and Prevention Program (NAEPP) guidelines.

RD-7.3 Increase the proportion of persons with current asthma who receive education about appropriate response to an asthma episode, including recognizing early signs and symptoms or monitoring peak flow results, according to National Asthma Education and Prevention Program (NAEPP) guidelines.

For each of these objectives and sub-objectives, unless preceded by the word developmental, there are baseline measures, targets, data sources and data from a variety of sources. Most of the data is at a national level and is of little use for determining local rates.

INNOVATIONS AND PROMISING PRACTICES IN HEALTH LITERACY

The following section briefly discusses some promising innovations in promoting health literacy in the health care system.

AHRQ HEALTH LITERACY UNIVERSAL PRECAUTIONS TOOLKIT

The *AHRQ Health Literacy Universal Precautions Toolkit* was designed to help primary care practices reduce the complexity of health care, increase patient understanding of health information, and enhance support for patients at all health literacy levels. The key element of the toolkit is the assumption that all patients may have difficulty comprehending health information and accessing health services regardless of their education or socioeconomic status. This is justified because research indicates that only 12 percent of U.S. adults have the health literacy skills needed to manage the demands of our complex health care system. Rather than screening patients for low literacy or low health literacy levels, the approach of the toolkit is to apply universal precautions to all patients by taking the following actions:

- Simplifying communication with and confirming comprehension for all patients, so that the risk of miscommunication is minimized.
- Making the office environment and health care system easier to navigate.
- Supporting patients' efforts to improve their health.

The Toolkit consists of 21 tools using evidence-based guidance to help primary care practices address health literacy, and is divided into the following four areas of emphasis:

1. Spoken Communication
2. Written Communication
3. Self-Management and Empowerment
4. Supportive Systems

Universal precautions refer to taking specific actions that minimize risk for everyone when it is unclear which patients may be affected.

Each tool in the Toolkit provides an overview of the tool, actions required to implement the tool, resources such as videos, educational materials, examples of how to use the tool, a variety of useful worksheet and a discussion about how to track the progress made after implementing the tool. Additional information and links to the Toolkit and implementation guide are available at <http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html>

The following table provides an example of the focus and goals for 10 of the 21 tools available in the toolkit.

The Toolkit is available at <http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlittoolkit2.pdf>.

Tool	Focus	Goal
1	Form a Team	To assist practices in assembling a health literacy team that includes membership and participation from all areas of practice and is led by a committed champion with authority to direct practice change.
2	Environment Improvement Plan	To help the health literacy team choose and make a plan for the implementation of health literacy-related improvements for the practice to work on.
3	Raise Awareness	To plan and conduct educational activities to help the members of the practice become more aware about health literacy, why it is important, how it affects patients, and how the team can work together to make health-literacy improvements.
4	Communicate Clearly	introduce the practice to effective oral communication strategies as they interact with patients.
5	Use the Teach-Back Method	To provide the practice with examples and helpful advice on performing the Teach-Back Method.
10	Consider Culture, Customs and Beliefs	To help the practices work effectively with an increasingly diverse population of patients.
14	Encourage Questions	To provide practice with strategies for eliciting questions from patients.
17	Get Patient Feedback	To provide the practice with guidance on how to obtain and use patient feedback about health literacy issues.
20	Connect Patients with Literacy and Math Resources	To offer the practice a method for identifying patients in need of literacy and math assistance and for connecting them with these resources
21	Make Referrals Easy	To relieve patients of the burdens involved in being referred for care elsewhere and assure continuous care.

eHEALTH

eHealth is the use of digital information and communication technologies to access health information, improve health and obtain health care. The increasing use of technologies such as the Internet and mobile devices is creating a space for more eHealth tools and resources. Some of the most commonly available ehealth tools and resources include::

- Online access to personal health records
- Online communication with health care providers
- Online health information exchange
- Online health information
- Online health self-management tools
- Online communities and support groups

As previously discussed, the Office of Disease Prevention and Health Promotion (ODPHP) has published a research-based how-to guide for creating health web sites and web content for use by persons that may have limited literacy skills and limited experience using the web that can be accessed at <http://www.health.gov/healthliteracyonline/index.htm>.

To address eHealth literacy among seniors, defined by the National Institute of Health (NIH) as people over age 60, the NIH has developed the NIHSeniorHealth website at <http://nihseniorhealth.gov/welcome.html>. One of the more useful resources on this site is the Toolkit for Trainers, a free, easy-to-use program designed for use by anyone interested in teaching seniors how to use the web to gather eHealth information. It contains downloadable lesson plans, training tools and tips on setting up a senior-friendly classroom, recruitment flyers and an illustrated glossary of computer and internet terms for older adults. The toolkit provides all of the information a person needs to become a trainer and can be used in libraries, senior centers, community colleges and retirement communities. The Toolkit for Trainers is accessible at <http://nihseniorhealth.gov/toolkit/toolkit.html>. The Toolkit was developed by the National Institute on Aging and also features two additional websites from the National Institutes of Health — MedlinePlus.gov and Go4Life.

Online health information exchange allows a health care provider, to access health information from another participating doctor or medical facility. The exchange gives health care providers secure and timely access to information like laboratory and imaging results, medications, allergies, known drug reactions, diagnoses, procedures, hospital discharge summaries and immunization records. This information can help care teams diagnose and treat patients faster, improve efficiency and reduce medical errors. For more information on San Diego's Health Information Exchange please visit the San Diego Health Connect website at <http://www.sdhealthconnect.org>.

mHEALTH

Mobile health, or mHealth, is a subset of eHealth and refers to the use of mobile technologies to track and monitor medical conditions. One of the fastest growing areas of mHealth in the U.S. is wearable technology including the use of devices such as fitness bands and pedometers to track mileage, calories burned and heart rate. According to Nielsen, in January 2014, 45.8 million smartphone owners used a fitness and health app (Nielsen, 2014).

Some of the subcategories of mHealth include:

- Treatment compliance including both reminder messages and apps
- Appointment reminders using voice or SMS messages
- Health promotion
- Mobile telemedicine
- Patient monitoring
- Patient records



SOCIAL MEDIA

Social and mobile media tools have become ubiquitous, with an estimated 241 million worldwide twitter users (December 2013) and 1.2 billion monthly Facebook users (December 2013). Because humans are social creatures, tools like Google, YouTube, Blogger, Tumblr, Twitter, Facebook, and LinkedIn have become ways for people to become meaningfully engaged with others in a social conversation. According to a recent Nielsen report, smartphones and tablet devices are quickly catching up to the computer as the access point to the social networking experience. This increased connectivity is giving consumers more freedom to use social media wherever and whenever they want (Nielsen, 2012).

An important question is: What can all of the connectivity offered by social media bring to health literacy? If the goal of health literacy is to help individuals obtain and understand health information and services needed to make appropriate health decisions, social media offers this potential. The biggest risk is the user's ability to filter, evaluate and understand the online health information being offered by the wide variety of information sources, because anyone can publish whatever they want. How the user of social media for health issues can confirm the reliability and quality of the information being offered is a major issue that has not been solved, because there is no way to remove or stop all of the "bad" information out there.

There are, however, online health communities emerging that can provide patients and their families with reliable peer-to-peer support such as PatientsLikeMe (<http://www.patientslikeme.com/>). This social networking site allows people to connect and share their experiences, give and get support, and compare treatments with people who have similar health conditions.

Another aspect of health related social network sites is their ability to attract targeted audiences. T2X (<http://www.t2x.me/www/t2x/default.aspx>) is a free site founded by Health Net, the UCLA Fielding School of Public Health and EPG technologies that is designed as a teen only site where teens can chat, share and learn from other members about living healthy. The site, founded in 2009, is supported by a team of experts, hosts and advisors. Topics covered on T2X range from sexual health, stress, mental health issues and violence to obesity, bullying and fitness.

DailyStrength (<http://www.dailystrength.org/>) is another moderated, free social media site that allows people to meet and share their knowledge, experiences and support. With over 500 support groups on issues such as depression, divorce, parenting and a wide variety of cancers, DailyStrength offers reliable health information on hundreds of topics.

The critical point when using any form of social media for health literacy is the assurance that the information available on the site or blog is reliable and accurate. To meet this challenge, these sites offer monitoring of discussions by experts to assure accuracy of information. Another key feature of an acceptable site is the ability to keep user information private.

HEALTH LITERATE CARE MODEL

The Health Literate Care Model is a proposed approach to addressing health literacy that uses the universal precautions approach. Under this model of care, a combination of health literacy strategies are applied and merged into the Chronic Care Model. The proposed new model calls for first approaching all patients with the assumption that they are at risk of not understanding their health conditions or how to deal with them, and then subsequently confirming and ensuring patients' understanding. Within organizations adopting the model, health literacy becomes an organizational value and is reflected in all aspects of planning and operations, including self-management support, delivery system design, shared decision-making support, clinical information systems to track and plan patient care, and helping patients access community resources. This model also contains a measurement framework to track the impact of the Health Literate Care Model on patient outcomes and quality of care (Koh et al., 2013).

PRIMARY CARE MEDICAL HOME

The patient-centered medical home (PCMH) is a model of primary care that emphasizes care coordination and communication that focuses on patients and their health care needs. Under this model of care, PCMH providers get to know their patients in long-term partnerships, rather than hurried and sporadic visits. They make treatment decisions together with patients based on individual abilities and preferences. They help patients become better engaged in their own healthy behaviors and health care. Everyone in the practice – from clinicians to front desk staff – works as a team to coordinate care from other providers and community resources. A core feature of PCMHs is the maximization of efficiency by ensuring that highly-trained clinicians are not doing tasks that lower level staff can do. It also works to avoid costly and preventable complications and emergencies by focusing on prevention and managing chronic conditions (NCQA, 2014).

Although there is limited evaluation data available about the effectiveness of the PCMH, a recent systematic review of patient-centered medical home practices found that it does lead to higher quality, and lower costs, and improves both the patients' and providers' experience of care. A key take-away point from this systematic review is that the PCMH is a promising model for organization primary care (Jackson, 2012).

In a recent report focusing on cost and quality impact studies for PCMCs released between 2012 and 2013, the Milbank Memorial Fund found positive findings for a range of categories including cost, utilization, population health, prevention, access to care, and patient satisfaction. This study recommended that additional studies are needed to determine clinician satisfaction. Moreover, the PCMH plays a role in strengthening the larger health care system, specifically Accountable Care Organizations and the emerging medical neighborhood model (Patient Centered Primary Care Collaborative, 2014).

MEASURES OF HEALTH LITERACY

Measuring health literacy is important because it helps determine the success of health literacy interventions. While the Health Literacy Component of the National Assessment Adult Literacy (NAAL) provides information on the health literacy levels of the U.S. adult population and is the only large-scale survey of health literacy, there are a number of different measurement tools available that focus on measuring the health literacy of the individual.

These tools measure the health literacy at the individual level and also function as screening tools.

The focus of these tools is on the capacity of the individual and does not measure a patient's health literacy in the context of providers and the health care system (IOM, 2009). Health literacy is dependent on both individual and systemic factors including:

- Communication skills of lay persons and professionals
- Lay and professional knowledge of health topics
- Culture
- Demands of the healthcare and public health systems
- Demands of the situation/context

The following tools are some of the more common and easily accessed tools available.

- **REALM Rapid Estimate of Adult Literacy in Medicine** is a 3-5 minute test that can be used in the health care setting to estimate adult literacy (there is also a Spanish and teen version). Patients read from a list of common medical terms with increasing numbers of syllables. There are separate versions for medical specialties. The test is based on word recognition and effectively tests reading fluency, but does not reflect whether patients understand the words they are reading. For more information go to <http://www.ahrq.gov/professionals/quality-patient-safety/pharmhealthlit/realm-r.html>
- **TOFHLA: Test of Functional Health Literacy in Adults** measures reading fluency. It consists of a 50-item reading comprehension test to measure prose literacy, and a 17-item numeracy skills section that assesses individuals' capacity to read and understand actual hospital documents and prescription labels. The long version takes 22 minutes to administer, and the short version takes 7-10 minutes. Also available is a Spanish version called S-TOFHLA. For more information go to http://www.peppercornbooks.com/catalog/information.php?info_id=5
- **HALS: Health Activities Literacy Scale** includes prose, quantitative, and document items in five health-related areas: health promotion, health protection, disease prevention, health care and maintenance, and systems navigation. For more information go to <https://www.ets.org/Media/Research/pdf/PICHEATH.pdf>
- **SAHLSA: Short Assessment of Health Literacy for Spanish-speaking Adults** is a health literacy assessment tool containing 50 items designed to assess a Spanish-speaking adult's ability to read and understand common medical terms. For more information go to http://medicine.osu.edu/sitetool/sites/pdfs/ahcpublic/REALM_SAHLSA.pdf
- **NVS: Newest Vital Sign** mirrors a typical health related task. It contains six questions assessing understanding of a nutrition label for ice cream. It takes approximately three minutes to complete and requires document and quantitative skills, including the ability to calculate percentages. For more information go to http://www.pfizer.com/health/literacy/public_policy_researchers/nvs_toolkit
- **eHEALS: eHealth Literacy Scale** is an 8-item measure of an individuals' confidence in their ability to access and evaluate online health information. For more information go to www.jmir.org/2006/4/e27/
- **SILS: Single Item Literacy Screener** is a single item instrument designed to identify patients who need help with reading health-related information. The instrument asks one question "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" with possible responses ranging from "1" (never) to "5" (always). The authors identified the cut-off point as "2" in order to capture all patients potentially in need of assistance (Morris et al, 2006).

CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND SYSTEMS (CAHPS)

CAHPS is funded by the Agency for Healthcare Research and Quality (AHRQ) and provides a broad range of evidence-based surveys for assessing patient's experiences with their health care encounters. Recently, CAHPS developed a set of questions addressing health literacy that can be added to a provider's patient survey. The focus of the assessment is to measure, from the patient's perspective, how well the health care professional communicates health information. Since health literacy partially depends on the individual's skill, the basis of the CAHPS survey is that health literacy also depends on the complexity of health information being presented and how it is communicated.

The questions addressing health literacy consist of 31 supplemental items and cover the following five topic areas (CAHPS, 2015):

- Communication with providers (doctors)
- Disease self-management
- Communication about medicines
- Communication about tests
- Communication about forms

According to the *Clinician and Groups Survey and Instructions* document related to this survey, the CAHPS item set for addressing health literacy was developed to provide health care providers with data that can help them improve their health literacy practices. The survey can be used to identify the following improvement areas:

- Specific topic areas for quality improvement (e.g., communication about test results, medications, and forms)
- Particular behaviors that inhibit effective communication (e.g., talking too fast, using medical jargon)
- The design of safer, shame-free environments where patients feel comfortable discussing their health care concerns (e.g., showing interest in questions, explaining forms)
- Measuring behaviors that promote effective communication (e.g., confirming understanding through teach-back, using visual aids)

The questions in the Item Set for Addressing Health Literacy correspond to recommendations made by the American Medical Association. These recommendations are contained in the CAHPS *Clinician and Groups Survey and Instructions* document and in the AMA's *Health Literacy Education Toolkit 2nd Edition*. More information about the AMA's health literacy kit is available on the AMA website; however, membership in the AMA is required to access the information and resources they offer (AMA, 2015).

The Agency for Healthcare Research and Quality (AHRQ) is part of the United States Department of Health and Human Services, which supports research and is designed to improve the outcomes and quality of healthcare. Additionally, the organization seeks to reduce costs, address patient safety and medical errors and broaden access to effective services.

The following table provides an example of some of the CAHPS questions match to the AMA Health Literacy Education Toolkit recommendations:

Item No.	Question	AMA Recommendation
HL1	In the last 12 months, were any of the explanations this provider gave you hard to understand because of an accent or the way the provider spoke English?	Slow down. Use plain language and short statements. Ask patients to “teach-back” what they learned.
HL2	In the last 12 months, how often did this provider use medical words you did not understand?	Use plain, non medical language.
HL3	In the last 12 months, how often did this provider talk too fast when talking with you?	Slow down. Break information down.
HL4	In the last 12 months, how often did this provider use pictures, drawings, models, or videos to explain things to you?	Use visual aids to help patients understand medical information. Images should be age- and culturally appropriate.
HL5	In the last 12 months, how often did this provider ignore what you told him or her?	Listen rather than speak. Elicit understanding, identify information gaps, and assist patient management of care.
HL9	In the last 12 months, how often did this provider give you all the information you wanted about your health?	Schedule time for patient education. Plan for health literacy help.
HL30	In the last 12 months, how often were you offered help to fill out a form at this provider’s office?	Routinely offer all patients assistance in completing forms.

CALL TO ACTION

These are recommendations of actions that can be done collaboratively through the HLSD task force in partnership with community partners.

1. Develop an **advocacy strategy** to include health literacy as a common thread through all “access to healthcare” related issues, including disease prevention and health promotion in San Diego.
2. Update the HLSD **website** to include interactive and credible resources for consumers and healthcare professionals.
3. Continue **front and back office staff trainings** to enhance better understanding of how to deal more effectively with low health literacy populations. Provide technical assistance to providers with developing appropriate communication methods and tools and creating system changes to work with low health literate patients.
4. Implement and add new relevant sections to **Health Education and Literacy** materials for adult learners. Continue the train-the-trainer workshops.
5. Develop an overall **evaluation** for health literacy in San Diego, including specific metrics to be tracked over time.
6. Develop a **community health literacy outreach plan** for both consumers and providers. Provide **community forums and education** for consumers and providers on specific health literacy related issues, including:
 - Basic understanding of healthcare coverage and terminology
 - Teach back and self-directed teach back methods
 - Specific disease topics and at-risk populations
 - Research and identify credible health information online
7. Start an annual **health literacy summit** in San Diego, to include research, sharing of best practices, and education.
8. Provide **social networking guidance** for providers and consumers. Ensure social media sites are monitored and provide credible resources.
9. Provide a **centralized service to providers** for reviewing health materials and health-related forms to adjust readability level.
10. Create specific **mental health literacy** education materials and develop a program that aids recognition, management and prevention of mental health issues, including reducing stigma associated with mental illness.

Potential Community Partners

- | | |
|--|---|
| • Adult learning programs | • Libraries |
| • Community based organizations | • Literacy coalition |
| • Community colleges | • Medical providers |
| • Community clinics | • Medical insurance brokers |
| • County of San Diego Health and Human Services Agency | • Mental health providers |
| • Health plans | • Refugee / immigrant Service Providers |
| • Hospitals and health systems | • Universities / School of Medicine |

APPENDIX 1 – BEST AND PROMISING HEALTH LITERACY PRACTICES

This appendix presents a brief description of some best and promising health literacy practices and other useful materials uncovered during the development of this report along with a links to additional information.

Virginia Adult ESOL Health Literacy Toolkit – Created by a hospital social worker and ESOL educator, this toolkit offers explanations, tips, materials, and links to help ESOL teachers and programs better understand and address the health literacy challenges faced by adult English language learners in U.S. health care. More information is available at <http://www.valrc.org/toolkit/>

San Antonio Health Literacy Initiative (SAHLI) – The San Antonio Health Literacy Initiative is a resource based on the collaborative efforts of multiple community partners. The SAHLI Health Collaborative is a group of volunteers from community-based organizations, healthcare settings, local colleges, and universities that are facilitated by the SAHLI. The purpose of the SAHLI Health Collaborative is to act as a county-wide expert roundtable in health literacy by bringing together representatives from various entities, both public and private, to share their experiences and possible solutions addressing low health literacy in San Antonio. More information is available at <http://www.sahealthliteracyinitiative.com/about-us>

Building Health Literate Organizations: A Guidebook to Achieving Organizational Change – This guidebook is designed to help health care organizations of any size engage in organizational change to become health literate. It complements many excellent health literacy resources and helps organizations use them effectively and reliably. It includes background, resources, examples, and lessons learned to help build a health literate health care organization. The guidebook is available at <http://www.unitypoint.org/filesimages/Literacy/Health%20Literacy%20Guidebook.pdf>

Health Literacy Program for Minnesota Seniors (HeLP MN Seniors) Evidence-Based Workshop Program
This workshop program provides all of the program materials needed to conduct a health literacy program in the community. The link below has a program guide, assessment and evaluation materials, and workshop materials in downloadable Word, PowerPoint and PDF files. Program materials are available at <http://healthliteracymn.org/resources/help-mn-seniors>

Plain Language Thesaurus for Health Communications – The Plain Language Thesaurus was created by the Centers for Disease Control and Prevention’s National Center for Health Marketing. The thesaurus offers plain language equivalents to often used medical terms, phrases, and references. The thesaurus is a tool to help you find words that people may understand better. The thesaurus is available at https://depts.washington.edu/respcares/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf

Simply put; a guide for creating easy-to-understand materials – Developed by the Centers for Disease Control and Prevention this publication is a guide on how to make a message clear and easy to understand including how to use visuals to tell a story, layout and design and testing for readability. It also contains several checklists related to print materials, communications planning and calculation readability. This resource document is available at <http://stacks.cdc.gov/view/cdc/11938>



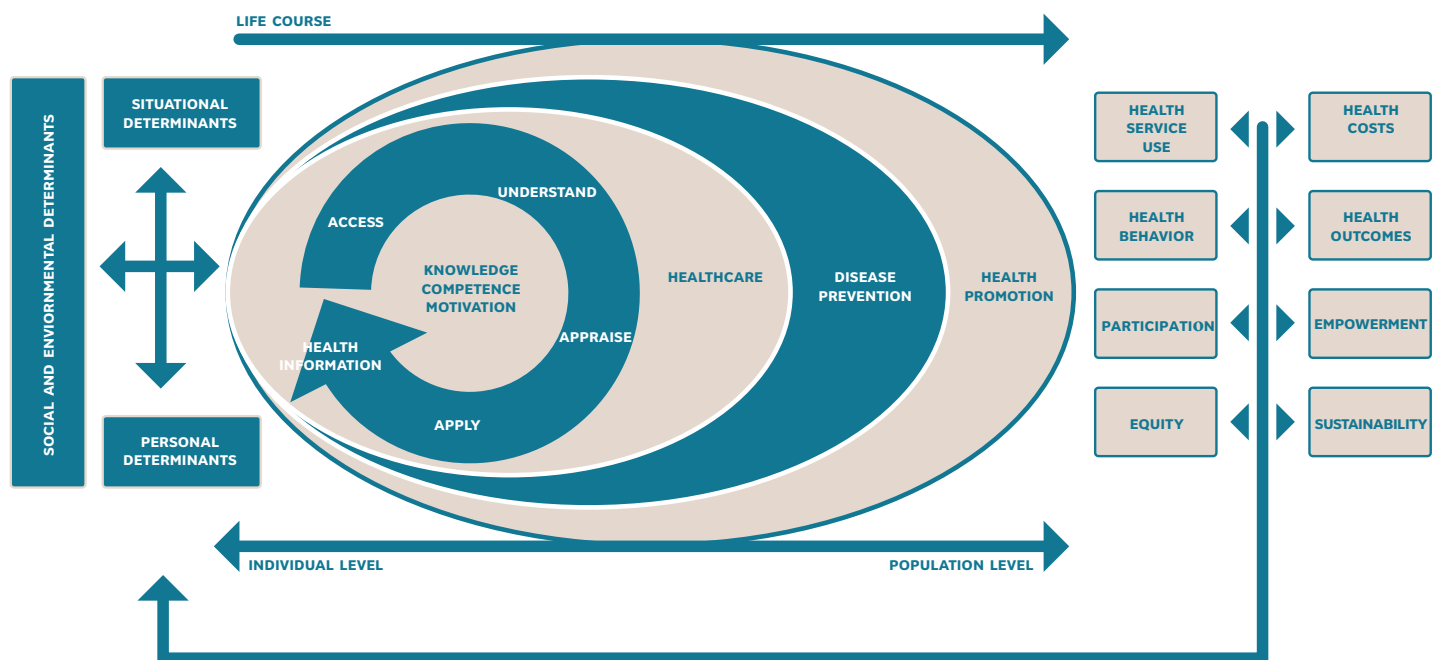
The Patient Education Materials Assessment Tool (PEMAT) and User's Guide – Developed by the Agency for Healthcare Research and Quality, this guide presents a method to assess the understandability and actionability of print and audiovisual patient education materials. It is designed for use by health care providers, health librarians and others involved in the production of high-quality materials for patients and consumers. The PEMAT is available at http://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/pemat_guide.pdf

Project SHINE (Students Helping In the Naturalization of Elders) – Project SHINE, is an intergenerational refugee program developed at the Intergenerational Center at Temple University in Philadelphia, has been implemented by the Continuing Education & Workforce Training program at Cuyamaca Community College. The program's goal is to teach refugees to manage their own preventive and ongoing healthcare, decreasing the strain on emergency departments and other healthcare resources. A major focus of this program is health literacy, covering a wide range of topics including how to interact with doctors, dealing with hospitals, managing illness, healthy aging and taking medications. For each of these topics, participants in the SHINE program learn the vocabulary and discuss how U.S. healthcare is different from that received in Iraq. More information is available at <http://www.projectshine.org/node/247>

APPENDIX 2– INTEGRATED MODEL OF HEALTH LITERACY

Until recently, most evidence on health literacy has come from the U.S. and has mainly focused on the individual's functional health literacy, that is, a person's ability to read and understand basic health-related information, and the ability to manage chronic diseases. In 2013 the World Health Organization (WHO) published *The Solid Facts - Health Literacy*, which focused on the issues and impacts related to health literacy. Based on findings, health literacy has been shown to be one of the strongest predictors of health status along with age, income, employment status, education level and race or ethnic group. The WHO presented Sorenson's concept of health literacy which includes competencies of accessing, understanding, appraising and applying health-related information within health care, disease prevention and health promotion settings (WHO, 2013).

The integrated model of health literacy has been visualized in the following diagram, which introduces a number of additional elements that are not discussed here. The diagram shows the position of health literacy domains in relation to the individual and the core competencies. The research article provides extensive detail about the model and each of its elements and is available at <http://www.biomedcentral.com/1471-2458/12/80>.



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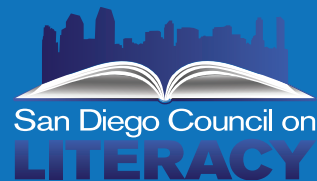


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