

# Health Literacy and Health Promotion

Definitions, Concepts and Examples in the Eastern Mediterranean Region

# Individual Empowerment Conference Working Document



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This paper was prepared as a working document for discussion at the 7th Global Conference on Health Promotion, "Promoting Health and Development: Closing the Implementation Gap", Nairobi, Kenya, 26-30 October 2009.

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### LIST OF ABBREVIATIONS

CQI	Continuous Quality Improvement		
HIV	Human Immunodeficiency Virus		
NCD	Non-communicable disease/s		
PDSA	Plan/Do/Study/Act		
RELEASE	Reflective learning and action systems		
SEAR/SEARO	South East Asian Region/ South East Asian Regional Office		
WPR/WPRO	Western Pacific Region/ Western Pacific Regional Office		

To function well in the 21st century a person must possess a wide range of abilities and competencies, in essence many 'literacies'. These 'literacies'—from being able to read a newspaper to understanding information provided by a health care provider—are multiple, dynamic, and malleable.

'Health literacy' is an emerging concept that involves the bringing together of people from both the health and literacy fields. Health literacy builds on the idea that *both health and literacy are critical resources for everyday living*. Our level of literacy directly affects our ability to not only act on health information but also to take more control of our health as individuals, families and communities. While many definitions for health literacy exist, the definition that has been adopted in this paper is, - The degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course.

The scope of health literacy has three distinct 'levels':

- **Functional literacy:** Skills that allow an individual to read consent forms, medicine labels, and health care information and to understand written and oral information given by physicians, nurses, pharmacists, or other health care professionals and to act on directions by taking medication correctly, adhering to self-care at home, and keeping appointment schedules.
- **Conceptual literacy:** The wide range of skills, and competencies that people develop over their lifetimes to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life.
- **Health literacy as empowerment:** Strengthening active citizenship for health by bringing together a commitment to citizenship with health promotion and prevention efforts and involving individuals in: understanding their rights as patients and their ability to navigate through the health care system; acting as an informed consumers about the health risks of products and services and about options in health care providers, and acting individually or collectively to improve health through the political system through voting, advocacy or membership of social movements.

Why is health literacy an important area to consider when planning health promotion initiatives? The published literature identifies six general themes that help determine why health literacy is important for population health:

- **1. The large numbers of people affected:** some countries within the EMR have high adult literacy rates, however, approximately half have rates below the global developing country average of 79 percent. In most EMRO countries literacy rates are lower among women than men the exceptions being Qatar and the UAE.
- 2. **Poor health outcomes:** there is a clear correlation between inadequate health literacy—as measured by reading fluency—and increased mortality rates.
- **3. Increasing rates of chronic disease:** In the EMR, chronic diseases are estimated to account for almost half (47%) of the total burden of disease. Health literacy plays a crucial role in chronic disease self-management.
- **4. Health care costs:** the additional costs of limited health literacy range from 3 to 5% of the total health care cost per year

- **5. Health information demands:** a mismatch exists between the reading levels of health-related materials and the reading skills of the intended audience. Often, the use of jargon and technical language made many health-related resources unnecessarily difficult to use.
- **6. Equity:** low levels of health literacy often mean that a person is unable to manage their own health effectively, access health services effectively, and understand the information available to them and thus make informed healthy decisions. Improving the health literacy of those with the worst health outcomes is an important tool in reducing health inequalities

The Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional Health Literacy in Adults (TOFHLA), are the most frequently used tools to measure health literacy and the Newest Vital Sign has recently been added to the list of instruments. Unfortunately, none of these tools completely capture health literacy as reflected in the health promotion-related definitions of health literacy that we have considered in this paper. They are mainly measures of reading proficiency. The Health Activity Literacy Scale (HALS) shows great promise in addressing some of these limitations. But even this instrument has inherent limitations: It excludes oral skills, lacks a measure of problem-solving tests and neglects to measure attitudes, values and beliefs. Nonetheless, some researchers consider the HALS to be the best existing measure of health literacy.

What conclusions can be drawn from systematic reviews and the vast amount of research on health literacy that has been completed over the past 25 years?

- Few rigorous evaluations of health literacy-related interventions have been carried out, and most available research has been conducted in the United States. The evaluations that have been done are not definitive.
- Simplifying reading material by using clear language, pictures and symbols is the most widespread initiative reported in the literature to influence literacy levels, yet there is little evidence that this improves health outcomes.
- Multimedia presentations may improve knowledge of people with both low and high literacy skills, but these do not appear to change health-related behaviours;
- Community-based and participatory approaches seem to show some promise. For example participatory education principles and theories of empowerment appear to help parents access, understand and use health information for the benefit of their own and their children's health.

We conducted an extensive literature search to determine the extent of health literacy interventions currently ongoing within countries of the EMR. Six electronic data bases were searched as well as the sites of some United Nations agencies, universities, and selected international and local non-governmental organizations (NGOs). To ensure that as many interventions as possible were identified the scope of our search included health literacy as it pertained to the "empowerment" aspects within health promotion, as well as the dimensions of community development . The criterion for selection included any interventions that addressed health literacy at the; functional (basic skills in reading and writing), interactive (social skills that allow active participation in health care) and critical (the ability to critically analyze and use information to participate in actions conducive to health) level.

Sixteen initiatives spanning from 1994 to 2009 were identified. Most (14) of these initiatives were being implemented or coordinated by academic institutions in collaboration with national partners. Information on these activities was found in research journals (2) and the others in university publications. The interventions came under different titles such as " communication for healthy living", "religious leaders lead the way", "youth first project", "post partum interventions", "Arab women speak" out. Only one study used the term "health literacy" - Mental health literacy in Pakistan. Except for the latter, they all had empowerment objectives and entailed multiple activities such as dissemination of print material, use of media (television, DVD), skill building (training workshops), community mobilization and outreach and provision of services. The primary audiences or beneficiaries of these projects were diverse, ranging from the general public to policy makers, health providers, youth, men, women (first time mothers, those of child bearing age), religious leaders (men and women) and special groups (diabetic patients). The health topics addressed were mainly related to reproductive and sexual health (family planning, maternal and child health, gender, women empowerment, family life education) and mental health, avian flu and diabetes management.

The six interventions that included an evaluation component reported positive outcomes in areas such as increased self efficacy, engaging in positive and protective behaviours, and participation in activities.

We classified the results into one or more of the components identified in the definition of health literacy. Our findings were as follows:

- Access: All of the interventions tried to disseminate knowledge/ information on a certain topic by using multiple channels and techniques.
- Understand

Only one study was identified that attempted to measure mental health literacy using the Mental Health literacy Questionnaire (MHLQ). Besides the questionnaire, two vignettes were used in supporting the data collection process; the vignettes enhanced participants ability to relate to the mental health issues being measured.

• Appraise

Women who participated in the Arab Women Speak Out (AWSO) Initiative training, as compared to a control group, were more likely to know where and how to access information, expressed higher levels of self efficacy to participate in economic opportunities, engage in entrepreneurship and activities that enhanced community welfare.

• Communicate

A study in Jordan called "Religious Leaders Lead the Way" succeeded in increasing the number and frequency of religious leaders who speak publicly about family planning reproductive health and gender equity. Both female and male religious leaders underwent extensive empowerment training that included attending workshops and discussion groups to improve their knowledge, and public communication skills. Results indicated that advocacy for family planning by religious leaders increased from 36% in 1997 to over 60 % in 2001. As a result of our review, the following gaps and recommendations emerged as a result of our review

- **Documentation:** We believe that there are many more health-literacy related projects being implemented than was revealed though our Internet search. The small number of interventions identified indicates that very few projects in the region document their findings. Documentation should ideally be a part of the monitoring and evaluation process of ongoing project /programs. Often however the meaningful recording of progress, process and experiences of many projects is neglected due to lack of time, personnel and skills.
- **Conceptual framework:** None of the studies we reviewed appeared to use a conceptual framework / model or theory. Clearly, by using a framework, project planners can ensure that their intervention activities are connected and coherent. This would also assist them in developing an appropriate evaluation plan.
- **Evaluation:** Most of the studies we reviewed were not scientifically evaluated (i.e. no impact or outcome evaluation was completed). The lack of an evaluation component makes it very difficult if not impossible to determine the effectiveness of an initiative, to draw any conclusions or make recommendations for adoption in other locations. Several barriers to conducting an evaluation were identified including: time, funds and skills on how to do it.
- **Definition of health literacy:** The term health literacy is not one that is either familiar or being used by many project staff involved in this kind of work. We believe that it is important to emphasize the concept of health literacy and reach out to organizations, health faculties and health departments in countries such as the East Mediterranean to make this concept a central, integrated and expected part of their health promotion activities.
- **Scope of Health literacy interventions:** Internationally, many studies have been done in the areas of HIV/AIDS, asthma care, health services use, psychological and physical wellbeing, adherence to medication, chronic disease, diabetes, hospital admission, hypertension, cardiovascular disease, reproductive health, sexually transmitted infections etc. in relation to health literacy of a variety of priority populations. Most of the interventions we identified in the EMR were on issues related to reproductive sexual health.

The 7<sup>th</sup> Global Conference on Health Promotion in Nairobi, Kenya on October 26-30 has identified the importance of health literacy in encouraging individual and collective actions to influence the determinants of health. Conference delegates will focus on four major topics as it relates to health literacy:

- Increasing access to health information through information and communication technologies (ICT)
- Increasing the use of health information through empowerment
- Increasing the flow of information through multi-sectoral collaboration
- Developing appropriate ways of measuring and reporting progress in improving health literacy levels

The purpose of this paper is to provide a background document on health literacy and health promotion in preparation for a presentation the authors will give at the 7<sup>th</sup> Global Conference on Health Promotion on October 26-30, 2009 in Nairobi, Kenya. Specifically this paper will:

- provide an overview and summary of the current research on health literacy;
- develop a conceptual framework that defines relevant terms, describes the relationship between health literacy and health promotion, and explores the implications of health literacy on health outcomes; and,
- provide examples of health literacy initiatives currently occurring in the EMRO/WHO that can illustrate best practices and lessons learned.

Although the literature on health literacy is still in its early stages of development, it is nonetheless a vast and rapidly growing body of knowledge. There is general agreement that a relationship exists

between health literacy and health outcomes; however, debate continues on what actually constitutes 'health literacy', how it is measured, and how health literacy levels can be improved. To date much of the published research on health literacy has come out of developed countries but extensive health literacy activity is now beginning to occur in the developing world.

Much controversy still exists as to what constitutes 'health literacy', how to measure it, and what methods are most effective and cost-effective in modifying health literacy levels.

This paper, therefore, is a work in progress. Much information is sure to be added to the body of knowledge in the next year,

given the steadily rising level of health literacy activity in EMRO. As discussion continues and more refined definitions of health literacy emerge, as research further pinpoints the key determinants of health literacy and leads to better ways to measure health literacy levels across populations and among at-risk groups, and as methods to influence those factors and conditions that contribute to health literacy become more apparent, our understanding of health literacy will increase exponentially.

The paper is organized into eight sections; each asks a specific question and attempts to respond to it. We have tried to make the document readable and have avoided using technical language—'jargon'— as much as possible. In some sections, however, jargon could not be avoided because of the complexity of the issues presented. Our hope is that we have compiled information that will be useful to policy makers, program planners and the academic community, and that this information will ultimately lead to an improvement in the health of people who reside in the Region.

#### WHAT IS LITERACY?

Literacy, in its most direct definition, is the ability to read, write, listen, comprehend, and speak a language. Historically it has been a collection of cultural and communicative practices shared among members of particular groups.<sup>1</sup> But society inevitably changes and so does literacy. In more recent times the term has evolved to refer specifically to the ability to read and write at a level adequate for communication or at a level that lets one understand and communicate abstract ideas.<sup>2</sup>

To function well in the 21st century a person must possess a wide range of abilities and competencies, in essence many 'literacies'. These 'literacies'—from being able to read a newspaper to understanding information provided by a health care provider—are multiple, dynamic, and malleable.<sup>3</sup> The United Nations Educational, Scientific and Cultural Organization (UNESCO) also acknowledges the multidimensionality of literacy, defining it as the "...ability to identify, understand, interpret, create, communicate, compute and use printed and written materials associated with varying contexts. Literacy involves a continuum of learning in enabling individuals to achieve their goals, to develop their knowledge and potential, and to participate fully in their community and wider society."<sup>4</sup>

Using the definition of literacy as the ability to read and write a simple sentence in any language, the United Nations reported that 80% of the world's population was literate in 1998.<sup>5</sup> Other estimates, using the definition "age 15 and over can read and write", placed the overall world literacy rate in 2008 at 82% (87% males and 77% females).<sup>6</sup> Literacy rates vary widely from country to country and even from region to region, a variation that often coincides with the region's wealth or urbanization. However, many factors can play a role; for example, certain social customs limit the education of females in some countries. Figure 1 presents literacy rates for countries around the globe.

Literacy involves enabling individuals to achieve their goals, to develop their knowledge and potential, and to participate fully in their community and wider society.

<sup>1</sup> National Council of Teachers of English. http://www.ncte.org/positions/statements/21stcentdefinition

<sup>2</sup> http://en.wikipedia.org/wiki/Literacy

<sup>3</sup> Ibid

<sup>4</sup> UNESCO Education Sector, The Plurality of Literacy and its implications for Policies and Programs: Position Paper. Paris: United National Educational, Scientific and Cultural Organization, 2004, p. 13, citing a international expert meeting in June 2003 at UNESCO. <u>http://unesdoc.unesco.org/images/0013/001362/136246e.pdf</u>

<sup>5</sup> http://www.economist.com/screensaver/glossary.cfm

<sup>6</sup> World Factbook, Create date Sept 08, 2009. https://www.cia.gov/library/publications/the-world-factbook/fields/print\_2103.html, retrieved September 11, 2009

#### FIGURE 1. GLOBAL LITERACY RATES BY COUNTRY



#### WHAT IS HEALTH LITERACY?

"Health literacy" is an emerging concept that involves the bringing together of people from both the

health and literacy fields.<sup>7</sup> Health literacy builds on the idea that *both health and literacy are critical resources for everyday living.* Our level of literacy directly affects our ability to not only act on health information but also to take more control of our health as individuals, families and communities. While many definitions for health literacy exist, the definition that has been adopted in this paper is, "The degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course"<sup>8</sup>

#### 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 contexts. It also requires some knowledge of health-related vocabulary as well as the culture of the health system.

Rootman, I. (2009) Presentation at UVic

According to the Institute of Medicine (IOM)<sup>9</sup>, health literacy results from the interaction of individuals with the social and informational demands of the health contexts in their environment, which could

<sup>&</sup>lt;sup>7</sup> Gillis, G., & Quigley, A. (2004).Taking off the Blindfold: Seeing how literacy affects health. Health literacy in rural Nova Scotia Research Project. http://www.nald.ca/healthliteracystfx/pubs/takngoff/takngoff.pdf

<sup>&</sup>lt;sup>8</sup> Kwan, B, Frankish, J, Rootman, I (2006). The development and validation of measures of "health literacy" in different populations. Vancouver: University of British Columbia Institute of Health Promotion Research & University of Victoria Centre for Community Health Promotion Research.

<sup>&</sup>lt;sup>9</sup> Institute of Medicine. Washington, DC: National Academies Press; 2004. Health Literacy: A Prescription to End Confusion.

include health care contexts, public health contexts health promotion contexts or chronic disease management contexts. While they appear to focus on the individual, the members of the IOM committee agreed that health literacy is, "...based on the interaction of the individual's skills with health contexts ... the health care system, the education system, and broad social and cultural factors at home, at work, and in the community."<sup>10</sup> This synergy between individuals and contexts led Rootman to propose another definition for health literacy: "...the degree to which there is a fit between the health information processing demands of different situations and the skills of individuals in those situations."<sup>11</sup> The framework depicted in Figure 2 also acknowledges the essential contribution of literacy to health literacy and the fact that health literacy and general literacy can be expected to affect both health outcomes and costs to individuals and society.

FIGURE 2. HEALTH LITERACY FRAMEWORK DEVELOPED BY THE US INSTITUTE OF MEDICINE (2004)



Kwan, Frankish and Rootman have built on this preliminary framework by identifying internal (personal) and external factors that influence the health information context, which in turn influences the acquisition of health knowledge and subsequent health decisions and actions (figure 3).<sup>12</sup>

FIGURE 3. FACTORS AND CONTEXTS THAT INFLUENCE HEALTH KNOWLEDGE, DECISIONS AND ACTIONS

<sup>&</sup>lt;sup>10</sup> Parker, R., & Kindig, D. (2006). Beyond the Institute of Medicine Health Literacy Report: Are the Recommendations Being Taken Seriously? J Gen Intern Med, 21(8): 891–892. http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1831577

<sup>&</sup>lt;sup>11</sup> Rootman, I. (2009). Health Literacy: What should we do about it? Presentation at the University of Victoria, BC. Canada.

<sup>&</sup>lt;sup>12</sup> Kwan, B., Frankish, J., and Rootman, I. (2006). The Development and Validation of Measures of "Health Literacy" in Different Populations, Vancouver: Centre for Population Health Promotion Research. www.ihpr.ubc.ca



Clearly, health literacy is a complex phenomenon involving individuals, families, communities and systems. And within these systems are consumers, patients, caregivers, and other laypersons whose situations may vary with respect to:<sup>13</sup>

- Access (e.g., to audience-appropriate information, media or professionals);
- **Skills** (e.g., to gather and comprehend health information; to speak and share personal information about health history and symptoms; to act on information by initiating appropriate follow-up visits and conveying understanding back to the information source; to make decisions about basic healthy behaviours, such as healthy eating and exercise; to engage in self-care and chronic disease management);
- **Knowledge** (e.g., of health and medical vocabulary, concepts such as "risk", the organization and functioning of healthcare systems);
- **Disabilities** (e.g., sensory, communication, cognitive or physical challenges or limitations);
- The features of their **health care providers and the public health systems** in which these providers practice (e.g., the communication skills of health professionals, platforms employed for patient education, built environments and signage);
- Other important characteristics including developmental or **life stage, cultural, linguistic or educational differences** that affect health beliefs, knowledge and communication.

<sup>&</sup>lt;sup>13</sup> National Institute of Health. http://grants.nih.gov/grants/guide/pa-files/PAR-04-116.html

The concept of 'health literacy' first appeared in the literature in 1974, in relation to health education, and the importance of developing minimum standards for health literacy in the school setting..<sup>14</sup> The concept, however, was not wholeheartedly embraced in health education or other fields until almost two decades later<sup>15</sup>.<sup>16 17</sup> The concept of health literacy emerged in the field of health promotion in a

paper by Kickbusch in 1997.<sup>18</sup> It next appeared in a glossary on health promotion<sup>19</sup> developed by Nutbeam, in which he argued that health literacy is a key outcome of health education activity, which should be situated in the broader concept of health promotion and for which people working in health promotion should be held accountable.<sup>20</sup> Nutbeam asserted that health information and education initiatives are integral to improving health literacy. As well, he identified and defined three distinct 'levels' of health literacy:<sup>21</sup>

The concept of health literacy first appeared in the literature more than 35 years ago. It wasn't until the mid-1990's, however, that interest in this concept began increasing dramatically.

- *functional*: basic skills in reading and writing necessary for effective functioning in a health context;
- *interactive*: more advanced cognitive literacy and social skills that enable active participation in health care; and
- *critical*: the ability to critically analyze and use information to participate in actions that overcome structural barriers to health.

In particular, the latter two levels suggest the expansion of health literacy into the domain of health promotion through their connection with the concept of self-efficacy and "empowerment."<sup>22</sup> Kickbusch suggested that health literacy was one way in which the divide between health and education could be addressed.<sup>23</sup> While not everyone was in agreement with the expansion of health literacy into areas of

<sup>15</sup> Council of Chief State School Officers (CCSSO). (1998). Assessing health literacy: Assessment framework; Santa Cruz, California. ToucanEd Publications.

<sup>16</sup> Baker, DW., Parker, RM., Williams, MV., Clark, WS., & Nurss, J. (1997), The relationship of patient reading ability to self-reported health and use of health services. American Journal of Public Health. 87, 1027-1039.

<sup>17</sup> Williams, MV. et.al., (1995). Inadequate functional health literacy among patients at two public hospitals (comment) JAMA. 274(21), 1677-1682.

<sup>18</sup> Kickbusch, I. (1997). Think health: What makes the difference? Health Promotion International, 12, 265-272.

<sup>19</sup> Nutbeam, D. (1998). Health Promotion Glossary, Health Promotion International, 13. 349-364.

<sup>20</sup> Nutbeam, D. (2000). Health literacy as a pubic health goal: A challenge for contemporary health education and communication strategies in the 21<sup>st</sup> century. Health Promotion International, 15, 259-267.

 $^{21}$  Nutbeam , D. (2000) Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the  $21^{st}$  century. Health Promotion International, 15(3):259–267.

<sup>22</sup> Rootman. I. (2002). Health Literacy and Health Promotion. Ontario Health Promotion E-Bulletin. http://www.ohpe.ca/index2.php?option=com\_content&do\_pdf=1&id=175

<sup>23</sup> Kickbusch, I. (2001). Health Literacy: Addressing the health and education divide. Health Promotion International. 16, 289-297.

<sup>&</sup>lt;sup>14</sup> Simonds, SK. page 9.

empowerment and social action,<sup>24</sup> most in the field agreed that the concept amounted to more than merely a set of technical skills applied within a health care setting.

Since then the field has become increasingly active in its attempt to construct a sound definition for health literacy and to solidify its scope. A recent literature review by Jochelson<sup>25</sup> identified three key approaches in conceptualizing health literacy. The following table summarizes these approaches.

<sup>&</sup>lt;sup>24</sup> Tones, K. (2002). Health Literacy: New Wine in Old Bottles. Health Education Research.17:287-290

<sup>&</sup>lt;sup>25</sup> Jochelson, K. (2008). Health Literacy Review Paper. National Social Marketing Centre. https://webmail.shaw.ca/attach/Health\_Lit-

 $review \% 20 paper.pdf?sid=\&mbox=INBOX\&charset=escaped\_unicode\&uid=8386\&number=4\&filename=Health\_Lit-review \% 20 paper.pdf$ 

Approach	Focus	Description
Functional Health Literacy	A set of generic technical skills applied in a healthcare environment	Skills that allow an individual to read consent forms, medicine labels, and health care information and to understand written and oral information given by physicians, nurses, pharmacists, or other health care professionals and to act on directions by taking medication correctly, adhering to self-care at home, and keeping appointment schedules.
Conceptual Health Literacy	A multi-dimensional approach that links generic skills with a body of technical and cultural knowledge that give meaning to the skills, and situates the individual in a social context.	<ul> <li>The wide range of skills, and competencies that people develop over their lifetimes to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life is based on the following literacies:</li> <li>Science (e.g. knowledge of risk and probability)</li> <li>Culture (e.g. awareness of how local belief may influence perceptions of public health messages)</li> <li>Civic (e.g. understanding the local government system)</li> <li>Computer (e.g. ability to web-search and understand the credibility of the information)</li> <li>Media (e.g. understanding the credibility of an advertisement)</li> </ul>
Health Literacy as Empowerment	Focuses on the interactive nature of literacy and power, situates the individual in a social context and suggests that literacy is a contested exchange between less and more powerful individuals, institutions and political contexts.	Strengthening active citizenship for health by bringing together a commitment to citizenship with health promotion and prevention efforts and involving individuals in: understanding their rights as patients and their ability to navigate through the health care system acting as an informed consumers about the health risks of products and services and about options in health care providers, and acting individually or collectively to improve health through the political system through voting, advocacy or membership of social movements

#### FIGURE 4. APPROACHES TO CONCEPTUALIZING HEALTH LITERACY

The published literature identifies six general themes that help determine why health literacy is important for population health:

- 1. The large numbers of people affected;
- 2. Poor health outcomes;
- 3. Increasing rates of chronic disease;
- 4. Health care costs;
- 5. Health information demands; and
- 6. Equity.

#### 1. THE LARGE NUMBERS OF PEOPLE AFFECTED

According to the United Nations Educational, Scientific and Cultural Organization (UNESCO) Institute

of Statistics (UIS) an estimated 776 million adults – or 16 per cent of the world's adult population – lack basic literacy skills.<sup>26</sup> About two-thirds are women. Figure 5 presents the projected (2010) literacy rate for adults 15 years of age and older for the countries within the EMRO.<sup>27</sup> While some countries within the EMRO have high adult literacy rates, approximately half have rates below the global developing country average of 79 percent.<sup>28</sup>

About 16 per cent of the world's adult population lack basic literacy skills. About two-thirds of these are women.

<sup>28</sup> Ibid

<sup>&</sup>lt;sup>26</sup> UNESCO. (2009). http://www.unesco.org/en/efa-international-coordination/the-efa-movement/efa-goals/adult-literacy/

<sup>&</sup>lt;sup>27</sup> Note: The national estimates, made available through targeted efforts by UIS to collect recent literacy data from countries, are obtained from national censuses or surveys between 1995 and 2005. Where recent estimates are not available, older UIS estimates, produced in July 2002 and based mainly on national data collected before 1995, have been used instead. In collecting literacy data, many countries estimate the number of literate people based on self-reported data. Some use educational attainment data as a proxy, but measures of school attendance or grade completion may differ. Because definitions and data collection methods vary across countries, literacy estimates should be used with caution.



Figure 6 presents the 2010 projections for adult literacy rates for EMRO countries by gender. In most EMRO countries literacy rates are lower among women than men - the exceptions being Qatar and the UAE.



Low literacy is common in other parts of the world as well. For example:

• Forty million adult Americans scored at the lowest of five levels (Level 1) of the National Adult

- Literacy Survey (NALS); another 50 million scored at Level 2.<sup>29</sup> Proficiency at these levels corresponds to having trouble finding pieces of information or numbers in a lengthy text, integrating multiple pieces of information in a document, or finding two or more numbers in a chart and performing a calculation.<sup>30</sup>
- A recent survey on health literacy among 2,000 adults in the United Kingdom found that one in five people had difficulty with the basic skills required for understanding simple information that could lead to better health.<sup>31</sup>

Just as low literacy is linked to low health status, so does low health literacy contribute to socioeconomic disadvantage. Furthermore, low health literacy may also prevent individuals from fully engaging in society and achieving their life goals.

Navigating Health: The Role of Health Literacy. (2005). (http://www.emhf.org/resource\_images/Navigating

Health\_FINAL.pdf

• 60% of adult Canadians (ages 16 and older) lack the capacity to obtain, understand and act on health information and services, and also the ability to make appropriate health decisions on their own. In addition, the proportion of adults with low levels of health literacy is significantly higher among certain groups, a finding that raises questions of equity.<sup>32</sup>

Similar findings have been reported in Europe<sup>33</sup>, Australia<sup>34</sup>, Latin America and numerous other countries.<sup>35</sup>

#### 2. RELATED TO POOR HEALTH OUTCOMES

Although literacy levels are associated with education, ethnicity and age,<sup>36</sup> a number of studies have shown that having limited literacy or numeracy skills also acts as an independent risk factor for poor health,<sup>37 38 39</sup> often because of medication errors<sup>40 41</sup> and a poorer understanding of disease and

<sup>31</sup> National Consumer Council (2004). Health Literacy: being able to make the most of health. Written by Saranjit Sihota and Linda Lennard. London: 2004. Available on www.ncc.org.uk.

<sup>32</sup> http://www.ccl-cca.ca/NR/rdonlyres/CB3135D3-5493-45FA-B870-1A3D3ABD6EC4/0/HealthLiteracyinCanada.pdf

<sup>33</sup> Department for Education and Science. The skills for life survey: a national needs and impact survey of literacy, numeracy and ICT skills. London: Department for Education and Skills; 2003, <u>http://www.dfes.gov.uk/research/data/</u> uploadfiles/RR490.pdf.

<sup>34</sup> Health literacy Australia (2006). Australian Bureau of Statistics.
 http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/73ED158C6B14BB5ECA2574720011AB83/\$File/42
 330\_2006.pdf

<sup>35</sup> Save the Children (2000) *State of the World's Mothers*. Save the Children, Westport, CT, USA.

<sup>36</sup> Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielson-Bohlman LT, Rudd RR. (2005). The prevalence of limited health literacy. J Gen Intern Med ;20:175–84.

<sup>37</sup> Baker DW, Parker RM, Williams MV, Clark WS. (1998). Health literacy and the risk of hospital admission. J Gen Intern Med ;13:791–800.

<sup>&</sup>lt;sup>29</sup> Kirsch I, Jungeblut A, Jenkins L, et al. (2002) *ADULT LITERACY IN AMERICA: A FIRST LOOK AT THE FINDINGS OF THE NATIONAL ADULT LITERACY SURVEY*. 3rd edition. Vol. 201. Washington, D.C.: National Center for Education, U.S. Department of Education.

<sup>&</sup>lt;sup>30</sup> Ibid

treatments.<sup>42</sup> A recent systematic review of the relationship between literacy and health outcomes concluded that limited literacy is linked to several adverse health-related variables, including knowledge about health and health care, hospitalization, global measures of health, and some chronic diseases.<sup>43</sup> Limited literacy also comes with other hardships. Qualitative research has shed light on the shame and practical difficulties that patients with limited literacy can experience when interacting with the health care system, and also on the coping strategies they employ to circumvent these difficulties.<sup>44</sup>

In exploring the link between literacy and mortality, Baker and colleagues found a clear correlation between inadequate health literacy—as measured by reading fluency—and increased mortality rates (see Figure 7).<sup>45</sup> The prospective cohort study in the United States showed that among a group of Medicare plan members there is a 50 to 80 percent increased mortality risk for people with inadequate health literacy ( the crude mortality rates for participants with adequate, marginal, and inadequate health literacy were 18.9%, 28.7%, and 39.4%, respectively). As well, the study found that poor health literacy is a stronger indicator of mortality risk than overall years of schooling.

<sup>38</sup> Wolf MS, Gazmararian JA, Baker DW. (2005). Health literacy and functional health status among older adults. Arch Intern Med;165:1946–52.

<sup>39</sup> Sudore RL, Yaffe K, Satterfield S, Harris TB, Mehta KM, Simonsick EM.(2006). Limited literacy and mortality in the elderly: the health, aging, and body composition study. J Gen Intern Med;21:806–12.

<sup>40</sup> Williams MV, Baker DW, Parker RM, Nurss JR.(1998). Relationship of functional health literacy to patients' knowledge of their chronic disease: a study of patients with hypertension and diabetes. Arch Intern Med;158:166–72.

<sup>41</sup> Wolf MS, Davis TC, Tilson HH, Bass PF, Parker RM.(2006). Misunderstanding of prescription drug warning labels among patients with low literacy. Am J Health-Syst Ph;63:1048–55.

<sup>42</sup> Williams MV, Baker DW, Parker RM, Nurss JR.(1998). Relationship of functional health literacy to patients' knowledge of their chronic disease: a study of patients with hypertension and diabetes. Arch Intern Med;158:166–72.

<sup>43</sup> DeWalt DA, Berkman ND, Sheridan S, Lohr KN, Pignone MP. (2004). Literacy and health outcomes. J Gen Intern Med ;19:1228–39.

<sup>44</sup> Wolf MS, Davis TC, Tilson HH, Bass PF, Parker RM.(2006). Misunderstanding of prescription drug warning labels among patients with low literacy. Am J Health-Syst Ph;63:1048–55.

<sup>45</sup> Baker, D., Wolf, M., Feinglass, J., Thompson, J., Gazmararian, J., Huang,J. (2007). Health Literacy and Mortality Among Elderly Persons. *Arch Intern Med.* 167(14):1503-1509

#### (n = 3260 Medicare plan members)



Health literacy is fundamental to patient engagement. If people cannot obtain, process and understand basic health information, they will not be able to look after themselves well or make sound health-related decisions. Improving health literacy is critically important in tackling health inequalities. People with low health literacy have poorer health status and higher rates of hospital admission, are less likely to adhere to prescribed treatments and care plans, experience more drug and treatment errors, and make less use of preventive services.<sup>46</sup>

If people cannot obtain process and understand basic health information, they will not be able to look after themselves well or make good decisions.

#### 3. INCREASING RATES OF CHRONIC DISEASE

The WHO document entitled *Chronic Disease: A Vital Investment* concluded that the majority of deaths worldwide for all ages are due to chronic diseases. Cardiovascular diseases (mainly heart disease and

In the EMRO chronic diseases are estimated to account for almost half of the total burden of disease. stroke) are responsible for 30% of all deaths.<sup>47</sup> Cancer, chronic respiratory diseases, and diabetes are also major causes of mortality. In the EMRO, chronic diseases are estimated to account for almost half (47%) of the total burden of disease.<sup>48</sup> One of the ways to address the anticipated escalation in chronic disease rates and the subsequent demands this will place on the health care system is to engage patients in more effective self-management. Self-management includes all of the "tasks that an individual must undertake to live well with one or more chronic conditions. These tasks

include gaining confidence to deal with medical management, role management and emotional management."<sup>49</sup> An emphasis on self-management would be well placed: Recent evidence suggests

<sup>47</sup> World Health Organization. *Preventing chronic diseases—a vital investment*. Geneva, WHO, 2005. <u>www.who.int/chp/chronic\_disease\_report/en/</u> (accessed 13 Oct 2006).

<sup>48</sup> Ibid

<sup>&</sup>lt;sup>46</sup> Board on Neuroscience and Behavioral Health, Institute of Medicine. (2004) Health literacy: a prescription to end confusion. Washington, DC, National Academies Press.

<sup>&</sup>lt;sup>49</sup> McGowan, P. (2005). Self-Management: A Background Paper. Paper presented at New Perspectives: International Conference on Patient Self- Management, September 2005.

that patients who engage in effective self-management generally experience positive health outcomes and place fewer demands on the health-care system.  $^{50}$ 

Health literacy plays a crucial role in chronic disease self-management. In order to manage chronic or long-term conditions on a day-to-day basis, individuals must be able to understand and assess health information, which often includes a complex medical regimen, plan and make lifestyle adjustments, make informed decisions, and understand how to access health care when necessary.<sup>51 52</sup> A lack of skill in these areas prevents many patients from engaging in effective self-management.

The populations most likely to experience difficulty with self-management are those with low-literacy levels—typically older adults, ethnic minorities, people with low levels of formal education and people with low income levels.<sup>53</sup> Low functional health literacy is a particular issue among the elderly, even among those who are more affluent and educated than the national norm. In 2003, the Institute of Medicine, in its priority areas for national action, identified poor self-management and low health literacy as factors that permeated many health problems. "Improved health literacy was put forward as a condition necessary to enable active self-management by patients for most conditions."<sup>54</sup>

<sup>53</sup> Nielson-Bohlman, L., Panzer, A., Kindig, D. (Editors, Committee on Health Literacy, Institute of Medicine (IOM)). (2004). Health Literacy: A Prescription to End Confusion. National Academy of Sciences. Washington, DC.

<sup>54</sup> Schloman, B. (2004). Health Literacy: A Key Ingredient for Managing Personal Health. Online Journal of Issues in Nursing, February.

<sup>&</sup>lt;sup>50</sup> Heneghan, C., Alonso-Coello, P., Garcia-Alamino J., et al. (2006). Self-monitoring of oral anticoagulation: a systematic review and meta-analysis. Lancet, 367, 404–11.

<sup>&</sup>lt;sup>51</sup> Institute for Health Improvement, Message to health care providers on a program on self-management support.

<sup>&</sup>lt;sup>52</sup> Johnston Lloyd, L., Ammary, N., Epstein, L., Johnson, R. & Rhee, K. (2006). A Transdiciplinary Approach to Improve Health Literacy and Reduce Disparities. Health Promotion Practice, 3.

#### 4. HEALTH CARE COSTS

Assessing the economic costs associated with low health literacy is fraught with difficulty, in part due to the considerable debate about what constitutes health literacy and the lack of sufficient data on the prevalence of low health literacy. These obstacles, however, have not prevented some researchers from estimating the costs, especially to the health care system, and also to patients who access and utilize services. Researchers who compiled data for the Institute of Medicine's report on health literacy concluded that an evaluation of the impact of limited health literacy must include a cost component as well. "Although a robust estimate for the effect of limited health literacy on health expenditures is lacking, the magnitudes suggested by the few studies that are available underscore the importance of addressing limited health literacy from a financial perspective."<sup>55</sup>

• People with low literacy have poorer overall health.

- Low literacy leads to misuse of medication or misunderstanding of health information.
- Low literacy leads to preventable uses of health services, including emergency care.
- People with low literacy skills often wait longer to seek medical help so health problems reach a crisis state.

http://www2.literacy.bc.ca/facts/health.htm

A number of studies on the economic costs of low literacy have emerged from the United States (and therefore transferability of the results to other countries is unclear). Baker and his colleagues found that public hospital patients with limited health literacy had higher rates of hospitalization than those with adequate health literacy and concluded that this increased hospitalization time could be

It has been estimated that 1 in 3 individuals with diabetes has limited health *literacy.* Given the low comprehension rates of diabetes-related terminology that we demonstrated among patients with limited health literacy, public health practitioners and clinicians must partner with such populations to develop more effective ways to communicate concepts critical to *chronic* disease prevention and management.

Castro, C. (2007).

that this increased hospitalization time could be associated with greater resource use by those with limited health literacy.<sup>56</sup>

The findings of a recent health literacy costs study that was based on an analysis of US National data revealed that the cost of low health literacy to the U.S. economy is in the range of \$106 billion to \$238 billion annually and that, "When one accounts for the future costs of low health literacy that result from current actions (or lack of action), the real present day cost of low health literacy is closer in range to \$1.6 trillion to \$3.6 trillion"<sup>57</sup>

The first systematic examination of the cost of low health literacy to health care was completed by Eichler et.al in 2009.<sup>58</sup> The researchers combed

through electronic data bases and other relevant literature and, after applying a screening process to

<sup>55</sup> Institute of Medicine. (2004). Health Literacy: A Prescription to End Confusion. http://www.iom.edu/?id=19750

<sup>57</sup> Vernon, J.A., Trujillo, A., Rosenbaum, S., DeBuono, B. (October, 2007). Low health literacy: Implications for national health policy.

<sup>58</sup> Eichler, K., Wieser, S., Bru<sup>°</sup>gger, U. (2009). The costs of limited health literacy: a systematic review. International Journal of Public Health, http://www.springerlink.com/content/n7327r1tl81665t3/fulltext.pdf

<sup>&</sup>lt;sup>56</sup> Baker DW, Gazmararian JA, Williams MV, Scott T, Parker RM, Green D, Ren J, Peel J. 2002. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health.* 92(8): 1278–1283.

over 2,000 studies, extracted data 1 from 10—out of Norway, Italy, Canada, Bermuda, Mexico, the US, and Switzerland—that met the specific criteria for inclusion. What they found was that the additional costs of limited health literacy ranged from 3 to 5% of the total health care cost per year. At the patient level the additional expenditures per year for each person with limited health literacy as compared to an individual with adequate health literacy range from US \$143 to 7,798.

#### 5. HEALTH INFORMATION DEMANDS

More than 800 peer-reviewed studies on the assessment of various health-related materials such as informed consent forms and medication package inserts have been conducted in the last three decades. These studies have found that a mismatch exists between the reading levels of the materials and the reading skills of the intended audience.<sup>59</sup> In fact, it was found that most of the assessed materials exceeded the reading skills of the average high school graduate. Often, the use of jargon and technical language made many health-related resources unnecessarily difficult to use.<sup>60</sup>



Figure 8. Jargon use during physician visits

But reading is only one avenue of conveying information. Castro et. al.<sup>61</sup> assert that successful communication, at least in part, requires that all participants draw from a mostly common vocabulary and experience. This may be especially important for patients with chronic medical conditions like type 2 diabetes, a condition with significant self-management demands, and for patients with barriers to communication, such as limited health literacy. The researchers explored physicians' use of jargon with 74 non-hospitalized diabetes patients with limited health literacy and found that physicians frequently overestimated the health literacy of their patients. Often, in the rush of the day, they lapsed into using medical jargon, a practice that tends to heighten the patient's reluctance to ask for clarification. Eighty-one percent of physician-patient encounters contained at least one "unclarified medical term" or jargon term, with a mean of four such terms used per visit. Thirty-seven percent of jargon use occurred when making recommendations and 29% when providing health education. Patient comprehension rates were generally low and never reached and adequate level of

<sup>60</sup> Rudd RE, Colton T, Schacht R. 2000b. An Overview of Medical and Public Health Literature Addressing Literacy Issues: An Annotated Bibliography. Report #14. Cambridge, MA: National Center for the Study of Adult Learning and Literacy.

<sup>61</sup> Castro, C., Wilson, C., Wang, F., Schillinger, D. (2007) Babel Babble: Physicians' Use of Unclarified Medical Jargon with Patients, Am J Health Behav.7;31(Suppl 1):S85-S95

<sup>&</sup>lt;sup>59</sup> Rudd, R., Anderson, J., Nath, C. & Oppenheimer, S. (2007). Health literacy: An update of medical and public health literature, in Review of Adult Learning and Literacy, J. Comings, B. Garner & C. Smith (eds.), National Centre for the Study of Adult Learning and Literacy, Vol. 7, Chapter Six.

understanding. Recent research in this area confirmed that many of the communication tactics deemed most effective by literacy experts are often the ones least commonly used by clinicians.<sup>62</sup>

### 6. EQUITY

A person's literacy level is influenced by many factors and conditions; these determinants of literacy are similar to the determinants of health commonly referred to in the health promotion literature.<sup>63</sup>

#### FIGURE 9. FACTORS AND CONDITIONS THAT INFLUENCE LITERACY RATES



A number of studies have examined the relationship among that factors that predict low health literacy and the subsequent health outcomes. For example, a recent study in the United Kingdom indicated that low health literacy is associated with poorer health outcomes, and each incremental increase towards higher health literacy is associated with a greater likelihood of engaging in a healthy lifestyle, specifically eating at least five portions of fruits and vegetables a day and being a non-smoker.<sup>64</sup> The authors concluded that, "…low levels of health literacy often mean that a person is unable to manage their own health effectively, access health services effectively, and understand the information available to them and thus make informed healthy decisions" and that "…improving the health literacy of those with the worst health outcomes is an important tool in reducing health inequalities".<sup>65</sup>

<sup>&</sup>lt;sup>62</sup> Schwartzberg, J. G., A. Cowett, J. Vangeest, and M. S. Wolf. 2007. "Communication Techniques for Patients With Low Health Literacy: A Survey of Physicians, Nurses, and Pharmacists." American Journal of Health Behavior 31 (Suppl 1): S96-104.

<sup>&</sup>lt;sup>63</sup> Rootman, I., & Ronson, B. (2003) Literacy and Health in Canada: What We Have Learned and What Can Help in the Future? http://www.cpha.ca/uploads/portals/h-l/literacy\_e.pdf

<sup>&</sup>lt;sup>64</sup> von Wagner, C., Knight, K., Steptoe, A., & amp; Wardle, J. (2007). Functional health literacy and health promoting behaviour in a national sample of British adults. J Epidemiol.Community Health, 61,

<sup>&</sup>lt;sup>65</sup> http://www.dh.gov.uk/en/Publichealth/Healthimprovement/Healthliteracy/DH\_095382

Volandes and Paache-Orlow argue that poor health outcomes resulting from limited health literacy is an ethical issue and should be considered a fundamental injustice of the healthcare system.<sup>66</sup> They offer three proposals that could help to rectify this injustice: universal precautions that presume limited health literacy for all health care users, expanded use of technology-supported communication, and clinical incentives to improve health literacy.

#### HOW ARE HEALTH LITERACY AND HEALTH PROMOTION RELATED?

The term health literacy was first used in the health education context over thirty years ago.<sup>67</sup> Today it is considered an important concept, not only among health education practitioners, but also among those involved in the broader aspects of health promotion. A redefinition of the term health literacy first appeared in the WHO Glossary where it was suggested that, "Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health."<sup>68</sup> In addition, the

To be a health literate society, we need a health literate public, health literate health professionals and health literate politicians and policy-makers.

http://www.emhf.org/resource\_images/Navigating Health\_FINAL.pdf glossary notes that, "Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is crucial to empowerment."

This definition represents a considerable expansion of earlier functional definitions of health literacy such as "being able to apply literacy skills to health related

materials such as prescriptions, appointment cards, medicine labels, and directions for home health care"<sup>69</sup>, or the following the U.S. National Library of Medicine definition of health literacy: "the degree to which people can obtain, process and understand basic health information and services they need to make acceptable health decisions".<sup>70</sup>

Abel, in a recent editorial, differentiates between the role of health literacy in medical settings vs. health promotion contexts.<sup>71</sup> In the former case, health literacy would be concerned with:

"...people's abilities to read and understand medical information, be it in written form or conveyed in personal encounters such as doctors visits. Improving people's understanding of what is provided in the realm of medical services is seen as a major factor that contributes to increased quality of care and adherence to expert advice. Measurement of health literacy is needed to

<sup>66</sup> Volandes, A., & Paasche-Orlow, M. (2007). Health literacy, health inequality and a just healthcare system. American Journal of Bioethics. 7(11), 5-10. http://www.ncbi.nlm.nih.gov/pubmed/18027287

<sup>67</sup> Ratzan, S.C. (2001) Health literacy: communication for the public good. Health Promotion International, 16: 207-214.

<sup>68</sup> Nutbeam, D. (1998) Health promotion glossary. Health Promotion International, 13, 349-364

<sup>69</sup> Parker, R.M., Baker, D.W., Williams, M.V., Nurss, J.R. (1995) The test of Functional Health Literacy in Adults: a new instrument for measuring patients' literacy skills. Journal of General Internal Medicine, 10: 537-541.

<sup>70</sup> US National Network of Libraries of Medicine as defined in Healthy People 2010 (2000).

<sup>71</sup> Abel, T., (2008). Measuring health literacy: moving towards a health – promotion perspective, Int J Public Health 53 (2008) 169–170

identify those patients that do not understand medical information or the range of services offered. Only if we know about those patients or subgroups with low degrees of health literacy, we can adjust our services respectively or provide specific teaching programs for patients."

In a health promotion context, health literacy differs from "medical literacy" in that:

"Health promotion approaches do not focus on illness experiences or optimal use of medical services. In health promotion the focus usually is much broader and emphasizes healthy general living conditions and people's chances to live healthy lives. Moreover, health promotion calls for improving the resources people need in order to be active for their health, their own personal health, the health of their families and communities, including the power to change things for the better. In this perspective, health literacy refers to people's knowledge about how health is maintained and improved in promotion perspective every day life including ... the ability to make sound health decisions". Health literacy also includes the skills to obtain and use appropriate knowledge about health and its determinants. Emphasizing the empowerment component in health promotion, ... health literacy approaches should also address people's knowledge and skills necessary to work on and change those factors that constitute their health chances: In health promotion practice, health literacy means to understand the conditions that determine health and to know how to change them'.

As a result of a series of meetings or workshops on the conceptualization of health literacy including one at the 5th WHO Global Conference on Health Promotion, it was, "...resolved to widen the glossary definition to include dimensions of community development and health related skills beyond health promotion, and to understand health literacy not only as a personal characteristic, but also as a key determinant of population health".<sup>72</sup>

Health promotion is much broader in focus and emphasizes healthy general living conditions and people's chances to live healthy lives.

Rootman<sup>73</sup> identified a number of reasons to support the acceptance of the broader, redefined version of health literacy based on the following:

• Health literacy is a "key outcome from health education"<sup>74</sup> for which health promotion could legitimately be held accountable; Health literacy "significantly broadens the scope and content of health education and communication",<sup>75</sup> both of which are critical operational strategies in health promotion;

<sup>75</sup> Ibid

<sup>&</sup>lt;sup>72</sup> Kickbusch, I. (2001) Health Literacy: addressing the health and education divide. Health Promotion International, 16, 289-297.

<sup>&</sup>lt;sup>73</sup> Rootman. I. (2002). Health Literacy and Health Promotion. Ontario Health Promotion E-Bulletin. http://www.ohpe.ca/index2.php?option=com\_content&do\_pdf=1&id=175

<sup>&</sup>lt;sup>74</sup> Nutbeam, D. (2000) Health literacy as a public health goal: a challenge for contemporary health education and

communication strategies into the 21st Century. Health Promotion International, 15, 259-267.

- Expansion of the concept is consistent with current thinking in the field of literacy studies;<sup>76</sup> Health literacy helps strengthen the links between the fields of health and education.<sup>77</sup>
- The expanded definition implies that "health literacy" not only leads to personal benefits, but to social ones as well, such as the development of social capital;
   <sup>78</sup>"Health literacy as a discrete form of literacy is becoming increasingly important for social and economic development";<sup>79</sup>
   Health literacy is a key outcome from health
- Health literacy enhances the focus on overcoming structural barriers to health;<sup>80</sup>
- "Measuring health literacy could be the first major step in constructing a new type of health index for societies";<sup>81</sup>

Health education, as one component of health promotion, could therefore be viewed as a major mechanism for fostering health literacy by increasing individuals' capacities to access and use health information so as to make appropriate health decisions and improve and maintain basic health.

#### WHAT MODELS AND FRAMEWORKS EXIST TO DESCRIBE HEALTH LITERACY?

A number of models and frameworks have been developed over the past five years that attempt to explain the constructs and variables that either predict health literacy rates (i.e. the antecedents to health literacy) or describe the outcomes associated with the level of health literacy in a population. Many of these models and frameworks are currently rudimentary since research is still in its infancy—although growing rapidly—and not enough time has yet passed to allow for the evolution of more sophisticated and well-grounded models. It is anticipated that over the next decade, as the area of study on health literacy matures, that an increasing number of models will be posited.

One of the first models used to describe health literacy and the potential points of intervention was proposed by the Institute of Medicine (IOM) in the US in 2004. Based on the model presented in Figure 10, the IOM committee members argued that the responsibility for health literacy

FIGURE 10. HEALTH LITERACY FRAMEWORK – US INSTITUTE OF MEDICINE (2004)

<sup>78</sup> Ibid

<sup>79</sup> Ibid

- <sup>80</sup> Ibid
- <sup>81</sup> Ibid

outcome from health education for which health promotion could legitimately be held accountable.

<sup>&</sup>lt;sup>76</sup> Ibid

<sup>&</sup>lt;sup>77</sup> Kickbusch, I. (2001) Health Literacy: addressing the health and education divide. Health Promotion International, 16, 289-297.



Improvement must be shared by these various sectors and that the health care system carries "significant but not sole responsibility for health literacy improvement." The report issued a set of recommendations including the following:<sup>82</sup>

- Increased federal and non-federal funds for health literacy research are urgently needed;
- **New measures** of health literacy must be developed and evaluated;
- Accreditation requirements for schools should call for the **implementation of National Health Education Standards** and demonstration programs should be funded to support efforts to achieve such standards;
- Professional schools should incorporate health literacy into their **curricula** and areas of competence;
- Public and private health care systems should develop and support demonstrations to **identify the most effective ways** the health care system can reduce the negative effects of limited health literacy; and
- Accreditation bodies should **incorporate health literacy into their standards**: health literacy assessment should be a part of health care information systems and quality data collection.

The Canadian Public Health Association Expert Panel<sup>83</sup> recently proposed the framework presented in Figure 11. This framework identifies a number of sectors across society that are beyond the health system but need to be involved in a comprehensive strategy for influencing health literacy outcomes. As well, the framework identifies the individual and system barriers that must be reduced for a successful outcome and also the enablers that require enhancement.

 <sup>&</sup>lt;sup>82</sup> Parker, R., & Kindig, D. (2006) Beyond the Institute of Medicine Health Literacy Report: Are the Recommendations
 Being Taken Seriously? J Gen Intern Med. August; 21(8): 891–892
 http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1831577

<sup>&</sup>lt;sup>83</sup> Adapted from Rootman, I. & El-Bihbety, D.(2008). *A Vision for a Health Literate Canada*, Ottawa: CPHA.

# FIGURE 11. CANADIAN PUBLIC HEALTH ASSOCIATION EXPERT PANEL MODEL OF HEALTH LITERACY



Gillis introduced a logic-model type of framework to describe the relationship among interventions, health literacy, and outcomes.<sup>84</sup> The importance of influencing provider practice and the broader social determinants of health are prominently featured in this model.

<sup>84</sup> Gillis, D. (2006).



#### FIGURE 12. HEALTH LITERACY FRAMEWORK (GILLIS 2006)

Nutbeam's conceptual model on health literacy adopts an "empowerment" approach to influencing an individual's capacity to comprehend and act upon health-related information.<sup>85</sup> Four key skills and processes that interact with a person's ability to acquire improved health literacy are identified in this model:

- Skills in social organization and advocacy
- Skills in negotiation and self-management
- Engagement in social action for health
- Participation in changing social norms and practices

#### FIGURE 13. CONCEPTUAL MODEL OF HEALTH LITERACY AS AN ASSET (NUTBEAM 2008)

 <sup>&</sup>lt;sup>85</sup> Nubeam, D. (2008). The evolving concept of health literacy. Social Science & Medicine, Volume 67, Issue 12, 2072-2078 and Presentation at the 2009 Regional Ministerial Meeting on "Promoting Health Literacy" 29-30 April

Beijing, China http://www.un.org/ecosoc/newfunct/amr2009chinastatmnt.shtml



Rootman and his colleagues at the University of Victoria recently proposed the framework illustrated in Figure 14.<sup>86</sup> This framework was developed after extensive consultation with a broad range of stakeholders in the field of health promotion and literacy. The model not only draws upon the social determinants of health and corresponding actions necessary to bring about change but also introduces the concepts of how general literacy is related to health literacy and how the direct and indirect outcomes are related to health literacy level. As Gillis and Quigley so eloquently stated:

"Literacy influences health both directly and indirectly. The direct effects are the most obvious. They can include difficulty understanding and using health information and finding our way through a complicated health system. Less obvious but often more profound are the indirect effects, including the personal and socioeconomic challenges that often go with limited literacy: self-confidence, employment, income, housing, healthy eating, and the stress that comes from constant worry about meeting these basic human needs for ourselves and our families."<sup>87</sup>

FIGURE 14. HEALTH LITERACY CONCEPTUAL FRAMEWORK (ROOTMAN, 2009)

<sup>87</sup> Gillis, D., Quigley, A. (2004). Taking off the blindfold: Seeing how literacy affects health.

<sup>&</sup>lt;sup>86</sup> Rootman, I. (2009). Health Literacy: What should We Do About It? Presentation at the University of Victoria, BC Canada.



#### HOW IS HEALTH LITERACY MEASURED?

Over the past decade or so, advances in psychometrics, cognitive theory and household survey methods have enabled researchers to conduct direct assessments of adult skill levels. Existing health literacy measures<sup>88</sup> include various versions of the Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional Health Literacy in Adults (TOFHLA), Health Activities Literacy Scale (HALS), Newest Vital Sign (NVS), Stieglitz Informal Reading Assessment of Cancer Text (SIRACT), Medical Achievement Reading Test (MART), Literacy Assessment for Diabetes (LAD), and the Short Assessment of Health Literacy for Spanish speaking Adults (SAHLSA). New tests are continuously being devised and implemented. For instance, in the United States alone the Agency for Healthcare Research and Quality (AHRQ) is preparing a "health literacy item set" for the Consumer Assessment of Healthcare Providers and Systems surveys,<sup>89</sup> As well, the 2003 National Assessment of Adult Literacy (NAAL) included a health literacy assessment and its Joint Commission is starting to develop health literacy standards as part of its hospital accreditation process.

<sup>&</sup>lt;sup>88</sup> Pleasant, A. (2009). Measuring health literacy: A challenge to curriculum design and evaluation. http://www.centreforliteracy.qc.ca/publications/briefs/measuring/measuring.pdf

<sup>&</sup>lt;sup>89</sup> Agency for Health Care Research and Quality (AHRQ) (2007, Feb. 9, 2007). CAHPS health literacy item set. Retrieved July 16, 2007, from <u>http://www.cahps.ahrq.gov/content/products/HL/PROD\_HL\_Intro.asp</u>

The REALM and TOFHLA are the most frequently used tools to measure health literacy and the Newest Vital Sign has recently been added to the list of instruments. Unfortunately, none of these tools

completely capture health literacy as reflected in the health promotionrelated definitions of health literacy that we have considered in this paper. They are mainly measures of reading proficiency. For example, the REALM asks participants to read a list of medical terms with varying degrees of difficulty and scores them on their ability to do so.

The field currently lacks a comprehensive measure of health literacy.

While these instruments may offer a useful way for medical professionals to assess whether their clients have a problem with literacy or health literacy, they lack robustness as research tools as well as the breadth required for including a health promotion context. Pleasant<sup>90</sup> suggests that existing measures of health literacy:

- are not based on an underpinning theory of health literacy
- are limited because they rely excessively on the cloze formatted reading test
- focus on word recognition versus actual understanding
- lack cultural sensitivity and are biased toward certain population groups
- are not directly useful for informing or evaluating health promotion and communication interventions (e.g. a pre-post design), curricula, policy, or schemes to pay physicians based on performance
- place a problematic burden and label on patients
- do not evaluate spoken communication skills
- do not consider health literacy as a public health (health promotion) issue

All of this has led Baker to conclude that despite the number of assessment tools available, the emerging consensus is that the field is still currently without a comprehensive instrument for measuring health literacy.<sup>91</sup> Current tests are limited in terms of their ability to: measure applied literacy skills, measure literacy in different contexts, test for a variety of tasks, and test oral proficiency. Still, some progress has recently been made in developing a more robust measure of health literacy that addresses the first three of these limitations.

According to Rootman, the Health Activity Literacy Scale (HALS) shows great promise in addressing some of these limitations.<sup>92</sup> But even this instrument has inherent limitations: It excludes oral skills, lacks a measure of problem-solving tests and neglects to measure attitudes, values and beliefs. Nonetheless, Rootman considers the HALS to be the best existing measure of health literacy.<sup>93</sup>

A new measure of health literacy clearly has the potential to inform the broader health research agenda, the design and assessment of specific interventions, policy needs, medical school and health professional curricula, and the performance evaluation of health professionals. Achieving this

<sup>&</sup>lt;sup>90</sup> Pleasant, A. (2009). Measuring health literacy: A challenge to curriculum design and evaluation. http://www.centreforliteracy.qc.ca/publications/briefs/measuring/measuring.pdf

<sup>&</sup>lt;sup>91</sup> Baker, D (2006). The meaning and the measure of health literacy. *Journal of General Internal Medicine*, 21: 878-83.

<sup>&</sup>lt;sup>92</sup> Rootman, I. (2009) Health Literacy: What do we do about it? University of Victoria presentation.

<sup>&</sup>lt;sup>93</sup> Rootman, I. (2009). Health Literacy, What should we do about it? Presentation the Faculty of Education at the University of Victoria. British Columbia Canada. Personal Communication.

potential, according to Pleasant,<sup>94</sup> requires a comprehensive measure of health literacy that reflects the following attributes:

- It is explicitly **built on a testable theory or conceptual framework** of health literacy
- It is **multi-dimensional in content and methodology**, that is, based on multiple conceptual domains (e.g. fundamental, civic, science, culture) and practical components (e.g. finding, understanding, evaluating, communicating, and using)
- It treats health literacy as a **latent construct** for measurement purposes (health literacy is not explicit; you cannot "see" health literacy) and varies across individuals and contexts
- It honours the principle of **compatibility** (a measure of health literacy should not focus solely on the clinical setting but also consider health promotion behaviours and outcomes)
- It allows **comparison and/or is commensurate across contexts** including culture, life course, population group, and research setting (the measure should be translatable or developed in parallel in different target languages)
- It prioritizes **social research and public health** applications over clinical screening (resources in clinical settings are better directed toward lowering barriers to enhance access for all rather than toward identifying and labeling individuals)

Continued work on developing new health literacy measures or modifying previous ones may well be the next significant and necessary task facing health literacy research and practice. In the meantime, however, each new health literacy activity will be faced with the hurdle of uncertainty as to its impact on programs. Comparison across differing initiatives will also be limited.

#### WHAT METHODS EXIST TO IMPROVE HEALTH LITERACY?

Many factors affect individuals' ability to comprehend—and in turn use or act on—health information and communication. Proficiency in reading, writing, listening, interpreting, oral communication, and visual analysis is necessary not only to appropriately navigate a complex health system but to function as a participant in modern society.

<sup>&</sup>lt;sup>94</sup> Pleasant, A. (2009). Measuring health literacy: A challenge to curriculum design and evaluation. http://www.centreforliteracy.qc.ca/publications/briefs/measuring/measuring.pdf
One day an elderly patient arrived at Dr Paul Cappon's family practice with what appeared to be some cardiac complications. "I explained to her at great length what I considered the issue to be," he says. "I thought I was being understood." But when she came in for a follow-up a month later, he realized she hadn't understood a thing he'd said and hadn't taken any of the medications he had prescribed. "This is not an uncommon occurrence," he sighs.

http://www.nationalreviewofmedicine.co m/issue/2007/04\_15/4\_patients\_practice 07\_7.html Both individuals and families must be able to:

- communicate with health professionals;
- understand the health information in mass communication;
- understand how to use health- related print, audiovisual, graphical and electronic materials;
- understand basic health concepts and vocabulary; and
- connect this health-related knowledge to health decision-making and action-taking.

Too often people with the greatest health burdens have limited access to relevant health information.

In part, this is due to the complex and cumbersome ways health information is often presented. Many people have a limited ability to fully interpret and understand complex health terminology and instructions, and to make personal decisions related to risk avoidance or risk reduction strategies.

To date, four extensive systematic reviews of the literature have been completed on interventions intended to improve health-related outcomes of persons with low health literacy. The methods, major findings and conclusions of these reviews are presented in Annex 1. Our findings are broadly in line with the conclusion of these authors in that large gaps remain in our understanding of how health literacy can be improved.

What conclusions can be drawn from the systematic reviews outlined above and the vast amount of research on health literacy that has been completed over the past 25 years?

- Few rigorous evaluations of • health literacy-related have interventions been carried out, and most available research has been conducted in the United States.<sup>95</sup> The evaluations that have been done are not definitive.
- Simplifying reading material

For our societies to become health literate, all actors involved need to increase their health literacy:

- *Citizens* need to be making decisions about their health for themselves, not merely responding to decisions made for them by others,
- *Patients* need to be truly engaged and empowered to participate in care decisions,
- **Professionals** need to tailor their communication to meet the needs of their patients and see it as their responsibility to foster their health literacy,
- *Politicians* need to incorporate the notion and paradigm of health literacy into their design of policy, their research agendas and their objectives for population health.

http://www.emhf.org/resource\_images/NavigatingHealth\_FINAL.pdf

<sup>95</sup> Rootman, I., & Gordon-El-Bihbety, D. (2008). : A Vision for a Health Literate Canada. CPHA. http://www.cpha.ca/uploads/portals/h-l/report\_e.pdf by using clear language, pictures and symbols is the most widespread initiative reported in the literature to influence literacy levels, yet there is little evidence that this improves health outcomes. $^{96}$ 

- Multimedia presentations may improve knowledge of people with both low and high literacy skills, but these do not appear to change health-related behaviours;<sup>97</sup>
- Community-based and participatory approaches seem to show some promise. For example participatory education principles and theories of empowerment appear to help parents access, understand and use health information for the benefit of their own and their children's health.<sup>98</sup> In addition, initiatives that empower single parents by enhancing their parenting skills, combined with public health, skills development, and recreation interventions, have been shown to improve health literacy, health status and community participation, and to reduce reliance on social assistance<sup>99</sup>

Although evaluations of health literacy interventions to date do not provide clear answers on how best to create a health literate population, there are hints of potentially promising directions. Some recent research findings on the determinants of health literacy also point to possible directions. For example, the Canadian Council on Learning<sup>100</sup> found that reading practices in daily life (e.g., reading books, newspapers, magazines, letters, notes or e-mails) are strongly related to health literacy. The second strongest factor to explain health literacy proficiency (independent of reading practices) was educational attainment. Conversely, a mother tongue that was different from the language of assessment had a strong negative impact on health literacy score.<sup>101</sup>

## WHAT EXAMPLES EXIST IN THE EMRO THAT DESCRIBE BEST PRACTICES AND LESSONS LEARNED?

We conducted an extensive literature search to determine the extent of health literacy interventions currently ongoing within EMRO countries. Specifically, the purpose of the literature search was to:

- better understand how health literacy is defined within the Region
- identify and describe health literacy interventions being implemented in the Region and describe their effectiveness

<sup>98</sup> Ouellet, F., Dufour, R., Durand, D., René, J.-F. & Garon, S. (2000). L'empowerment dans

Naître égaux – Grandir en santé. Montreal, QC: Direction de la santé publique de

Montréal-Centre.

<sup>99</sup> Browne, G., Byrne, C., Roberts, J., Gafni, A., Whittaker, S. (2001). When the bough breaks: Provider-initiated comprehensive care is more effective and less expensive for sole support parents on social assistance. *Social Science and Medicine*, *53*(12), 1697–1710.

<sup>100</sup> Canadian Council on Learning (2008). *Health Literacy in Canada: A Healthy Understanding.* Ottawa: Author.

101 Ibid

<sup>&</sup>lt;sup>96</sup> Hauser, J. & Edwards, P. (2006). *Literacy, health literacy and health: A literature review* Ottawa: Expert Panel on Health Literacy, Canadian Public Health Association.

<sup>&</sup>lt;sup>97</sup> Ibid

- identify gaps that may exist in current programs and services
- suggest recommendations to improve the state of health literacy in the Region

### METHOD

Six electronic data bases were searched:

- Global Health
- Index Medicus for WHO Eastern Mediterranean (IMEMR)
- CINAHL (EBSCO)
- Medline (OVID)
- PubMed
- Google Scholar

As well, we searched the sites of some United Nations agencies, universities, and selected international and local non-governmental organizations (NGOs)

For this paper the following definition of health literacy was used: "...the degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life course".<sup>102</sup>

In the East Mediterranean region the term "literacy" is still widely used to mean the ability to read, write and comprehend a language. As such, the existing research on health literacy, although scarce, mainly examines "literacy and education" and views this as one determinant of health and health behavior. To ensure that as many interventions as possible were identified the scope of our search included health literacy as it pertained to the "empowerment" aspects within health promotion, as well as the dimensions of community development . The criterion for selection included any interventions that addressed health literacy at the; functional (basic skills in reading and writing), interactive (social skills that allow active participation in health care) and critical (the ability to critically analyze and use information to participate in actions conducive to health) level.<sup>103</sup> Therefore the search comprised any studies done within the Eastern Mediterranean Region that contained terms such as: *health literacy, functional health literacy, family health literacy, health literacy interventions/initiatives/programs, mental health literacy, Test of Functional Health Literacy in Adults, health promotion, health interventions, health communication.* 

#### **OVERVIEW OF FINDINGS**

Sixteen initiatives spanning from 1994 to 2009 were identified: Egypt (2), Morocco, Jordan (4), Pakistan (2), Lebanon (2), Iran, Tunis, Yemen, Palestine, Arab community in Israel (see Annex 2). Most (14) of these initiatives were being implemented or coordinated by academic institutions in

 $^{103}$  Nutbeam , D. (2000) Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the  $21^{\rm st}$  century. Health Promotion International, 15(3):259-267.

<sup>&</sup>lt;sup>102</sup> Kwan, B, Frankish, J, Rootman, I (2006). The development and validation of measures of "health literacy" in different populations. Vancouver: University of British Columbia Institute of Health Promotion Research & University of Victoria Centre for Community Health Promotion Research.

collaboration with national partners. Information on these activities was found in research journals (2) and the others in university publications.

The interventions came under different titles such as " communication for healthy living",<sup>104</sup> "religious leaders lead the way",<sup>105</sup> "youth first project",<sup>106</sup> "post partum interventions",<sup>107</sup> "Arab women speak" out.<sup>108</sup> Only one study used the term "health literacy" - Mental health literacy in Pakistan.<sup>109</sup> Except for the latter, they all had empowerment objectives and entailed multiple activities such as dissemination of print material, use of media (television, DVD), skill building (training workshops), community mobilization and outreach and provision of services. The primary audiences or beneficiaries of these projects were diverse, ranging from the general public to policy makers, health providers, youth, men, women (first time mothers, those of child bearing age), religious leaders (men and women) and special groups (diabetic patients). The health topics addressed were mainly related to reproductive and sexual health (family planning, maternal and child health, gender, women empowerment, family life education) and mental health, avian flu and diabetes management.

The six interventions that included an evaluation component reported positive outcomes in areas such as increased self efficacy, engaging in positive and protective behaviors, and participation in activities.

#### SPECIFIC FINDINGS

•

After reviewing the objectives, activities and evaluation results (if available) of each intervention we classified the results into one or more of the components identified in the definition of health literacy. Our findings were as follows:

Access All of the interventions tried to disseminate knowledge/ information on a certain topic by using multiple channels and techniques. The Avian flu response in Egypt,<sup>110</sup> for example, used an integrated package of communication interventions including: TV spots, print materials and

<sup>104</sup> Health Communication Partnership (2007). Communication for Healthy Living's Campaign Improves Response to Avian Influenza in Egypt. Communication Impact, Number 22.

<sup>105</sup> Johns Hopkins Bloomberg School of Public Health: Center for Communication Programs (2005). Religious Leaders (RL) Lead the Way. <u>http://www.jhuccp.org/neareast/jordan/leaders.shtml</u>

<sup>106</sup> Johns Hopkins Bloomberg School of Public Health: Center for Communication Programs (2005). Pakistan Youth-First Project. <u>http://www.jhuccp.org/asia/pakistan/youth.shtml</u>

Johns Hopkins Bloomberg School of Public Health: Center for Communication Programs

<sup>107</sup> Osman, H., Chaaya, M., Wick, L., Nassar, A., & Saliba, M. (2008). Postpartum Interventions: Can we facilitate the transition into motherhood?. American University of Beirut, Faculty of Health Sciences.

<sup>108</sup> Health Communication Partnership (2001). Arab Women Speak Out (AWSO) Program Helps Arab Women Redirect their Lives. Communication Impact, Number 13.

<sup>109</sup> Suhail, K. (2005). A study investigating mental health literacy in Pakistan. *Journal of Mental Health*; 14(2), 167-181.

<sup>110</sup> Health Communication Partnership (2007). Communication for Healthy Living's Campaign Improves Response to Avian Influenza in Egypt. Communication Impact, Number 22. community outreach (wide access) activities to impact knowledge and protective behavior among community members. Evaluation results indicated improved knowledge about the disease and involvement in at least one protective behavior.

• Understand

Only one study<sup>111</sup> was identified that attempted to measure mental health literacy using the Mental Health literacy Questionnaire (MHLQ). Besides the questionnaire, two vignettes were used in supporting the data collection process; the vignettes enhanced participant's ability to relate to the mental health issues being measured.

• Appraise

The Arab Women Speak out (AWSO) Initiative<sup>112</sup> implemented in 6 countries in the region used life histories of women who achieved their goals by overcoming social economic or political obstacles. AWSO training used discussion groups and videos to help women analyze and discuss (critical skills) potential opportunities and obstacles. Women who participated in the training, as compared to a control group, were more likely to know where and how to access information, expressed higher levels of self efficacy to participate in economic opportunities, engage in entrepreneurship and activities that enhanced community welfare.

A study in Pakistan called "Youth First Project "<sup>113</sup> attempted to empower young people to make positive, well-informed life choices on issues related to family planning, marriage, and education through the use of a social drama, hotlines, counselling, print materials and training. Results showed that 1.1 million youth were reached through the mass media and 100,000 through hotlines, community outreach and school-based education programs. Major findings indicated that 42.3 % of the target population used newlywed counselling, 51% were exposed to family planning messages and 20% were exposed to the TV spots. Qualitative interviews indicated that in addition to taking action, young people exposed to the Youth First Project reported having discussed the drama with their family members and friends.

• Communicate

A study in Jordan called "Religious Leaders Lead the Way"<sup>114</sup> succeeded in increasing the number and frequency of religious leaders who speak publicly about family planning reproductive health and gender equity. Both female and male religious leaders underwent extensive empowerment training that included attending workshops and discussion groups to improve their knowledge, and public communication skills. Results indicated that advocacy for family planning by religious leaders increased from 36% in 1997 to over 60 % in 2001.

<sup>&</sup>lt;sup>111</sup> Suhail, K. (2005). A study investigating mental health literacy in Pakistan. *Journal of Mental Health*; 14(2), 167-181.

<sup>&</sup>lt;sup>112</sup> Health Communication Partnership (2001). Arab Women Speak Out (AWSO) Program Helps Arab Women Redirect their Lives. Communication Impact, Number 13.

<sup>&</sup>lt;sup>113</sup> Johns Hopkins Bloomberg School of Public Health: Center for Communication Programs (2005). Pakistan Youth-First Project. <u>http://www.jhuccp.org/asia/pakistan/youth.shtml</u>

<sup>&</sup>lt;sup>114</sup> Johns Hopkins Bloomberg School of Public Health: Center for Communication Programs (2005). Religious Leaders (RL) Lead the Way.

A study in Jordan called "The Jordan Youth Campaign",<sup>115</sup> a mass media campaign and community- based RH program used drama, TV spots, and training to improve youths' knowledge and skills to enhance their active participation in RH activities and to promote dialogue with parents, appropriate adults and later spousal communication.

#### GAPS AND RECOMMENDATIONS

• Documentation:

We believe that there are many more health-literacy related projects being implemented than was revealed though our Internet search. The small number of interventions identified indicates that very few projects in the region document their findings. Most of the existing documentation was done by academic institutions and only when academic institutions were involved in the interventions. Documentation should ideally be a part of the monitoring and evaluation process of ongoing project /programs. Often however the meaningful recording of progress, process and experiences of many projects is neglected due to lack of time, personnel and skills. Documentation is crucial for project success, reporting data and for learning purposes.

• Conceptual framework:

None of the studies we reviewed appeared to use a conceptual framework / model or theory. When we mapped/ dissected objectives, activities and outcomes of each intervention, many seemed to be comprised of the components contained within the Nutbeam model of "health literacy as an asset" (see page 30 of this report). Clearly, by using a framework such as this one, project planners can ensure that their intervention activities are connected and coherent. This would also assist them in developing an appropriate evaluation plan.

• Evaluation:

Most of the studies we reviewed were not scientifically evaluated (i.e. no impact or outcome evaluation was completed). The lack of an evaluation component makes it very difficult if not impossible to determine the effectiveness of an initiative, to draw any conclusions or make recommendations for adoption in other locations. Several barriers to conducting an evaluation were identified including: time, funds and skills on how to do it.

• Definition of health literacy:

The nomenclature remained a great barrier to our search. While we believe that there is a great deal of health-literacy related activity happening in the region, the term is not one that is either familiar or being used by many project staff involved in this kind of work. We believe that it is important to emphasize the concept of health literacy and reach out to organizations, health faculties and health departments in countries such as the East Mediterranean to make this concept an integrated and expected part of their health promotion activities.

• Scope of Health literacy interventions: Most of the interventions we identified were on issues related to reproductive sexual health; however in other areas of the world, health literacy has become a critical part of public health work. Pharmaceutical companies have also become involved in this issue in both the USA and in France. Among those companies are Pfizer, Johnson & Johnson, and GlaxoSmithKline who

<sup>&</sup>lt;sup>115</sup> Johns Hopkins Bloomberg School of Public Health: Center for Communication Programs (2005). Jordan Youth Campaign Launch: May 1998-A Mass Media & Community Based RH Program for Jordanian Youth 1999-2003. <u>http://www.jhuccp.org/neareast/jordan/youth.shtml</u>

are involved in developing guides for creating accessible and understandable health information, supporting initiatives to convey information to patients and training health professionals.<sup>116</sup>

Other organizations around the world have also begun planning and implementing their own initiatives related to health literacy. The Alzheimer's and Related Dementias Association in South Africa, and Alzheimer's Disease International in India have both started projects that keep in mind cultural themes using either posters, illustrations or even cartoons on the topic. The American Cancer society on the other hand has used "touch screen kiosks" in clinics around the USA. These kiosks contain information designed for low-literacy patients on about 40 different kinds of cancer in both English and Spanish.<sup>117</sup>

Additionally, many studies have been done in the areas of HIV/AIDS, asthma care, health services use, psychological and physical wellbeing, adherence to medication, chronic disease, diabetes, hospital admission, hypertension, cardiovascular disease, reproductive health, sexually transmitted infections etc. in relation to health literacy of a variety of priority populations. Studies like this may be found in a number of countries such as USA, Australia, Japan, Canada, UK and many others.

#### NEXT STEPS

The 7<sup>th</sup> Global Conference on Health Promotion in Nairobi, Kenya on October 26-30 has identified the importance of improving health literacy as fundamental component to encouraging individual and collective actions that can influence the determinants of health. For this to occur, health literacy interventions must go beyond relying solely on information diffusion. Instead, they must focus on the ways in which information is shaped, how and by whom it is accessed, how it is critically analyzed and how it can be more effectively used to bring about genuine community action. With this understanding, the conference delegates will focus on four major strategies for the advancement of health literacy.

• Increasing access to health information through information and communication technologies (ICT)

Information technology now makes it possible to distribute information in ways that are inexpensive, widely and easily accessible and potentially creative and entertaining. ICT can efficiently reach large numbers of people and is therefore an important tool for enhancing both population-wide and targeted-group health literacy levels. To be effective, however, the information being distributed must be relevant, timely, user-friendly and of sound quality. The next steps for harnessing ICT's immense potential for influencing health literacy levels may be to find the mechanisms that can develop private-public partnerships, share best/promising practices and reduce the inequities caused by lack of accessibility.

• Increasing the use of health information through empowerment

Health literacy involves much more than the simple dissemination of information. As an important element within health promotion, it also provides a, "... means for fostering participation and ownership, facilitating mutual understanding and building trust among key

<sup>&</sup>lt;sup>116</sup> The Patient's Network (2003). http://www.patientsorganizations.org/showarticle.pl?id=44;n=319

<sup>&</sup>lt;sup>117</sup> Ibid

stakeholders...<sup>\*118</sup> and encouraging community involvement. Enhancing health literacy is one way to empower people to take control over the factors that affect their health and lives. By acquiring relevant knowledge, skills and competencies, they are not only better able to engage in self-development activities but are also better equipped to influence the contexts in which they live. <sup>119</sup>

• Increasing the flow of information through multi-sectoral collaboration

To date, efforts to improve health literacy have been led mainly by those within the health sector. The next major step to improving health literacy in many countries will require the combined and coordinated efforts of other sectors along both 'horizontal' and 'vertical' planes. On the horizontal plane meaningful partnerships must be forged with key stakeholders in the education and business sectors. In addition, the roles they may have in influencing health literacy must be clarified and nurtured. On the vertical plane coordinated approaches among local, regional and country levels are ideally required to promote synergy, avoid duplication and more efficiently address the determinants of health literacy.

• Developing appropriate ways of measuring and reporting progress in improving health literacy levels

Currently we lack the mechanisms for monitoring health literacy and measuring the effectiveness of interventions aimed at improving health literacy. The methods that do exist appear to lack cultural specificity and tend to be more appropriate for use in clinical settings rather than the broader area of health promotion. Developing new health literacy measures or modifying previous ones may well be the next significant and necessary task facing health literacy research and practice.

<sup>&</sup>lt;sup>118</sup> Mefalopulos, P. (2005) Communication for sustainable development: applications and challenges. In Hemer, O. & Tufte,O. (eds) Media and Glocal Change: Rethinking Communication for Development. Nordicom and CLACSO.

<sup>&</sup>lt;sup>119</sup> UNESCO (2009). Regional Preparatory Meeting on Promoting Health Literacy Beijing, China https://webmail.shaw.ca/attach/ChinaMeetingHealthLiteracyBackgroundPaperv2.pdf?sid=&mbox=INBOX&charset=es caped\_unicode&uid=8358&number=4&filename=ChinaMeetingHealthLiteracyBackgroundPaperv2.pdf

# ANNEX 1. MAJOR SYSTEMATIC REVIEWS OF HEALTH LITERACY, BEHAVIOURS AND OUTCOMES

Pignone, et al., 2005 <sup>120</sup>	Hauser and Edwards, 2006 <sup>121</sup>
<b>Method:</b> Systematic review of research published between 1980-2003 on the effect of interventions on the health outcomes of persons with low health literacy.	<b>Method:</b> Reviewed research on health literacy interventions published prior to 2007
Included controlled and uncontrolled trials that measured literacy and examined the effects of interventions for people with low literacy on health knowledge, health behaviours, use of health care resources, intermediate markers of disease status, and morbidity or mortality.	<b>Findings:</b> Few rigorous evaluations exist. While most widespread initiative used is simplifying reading material using clear language and pictures, there is no evidence that this improves health outcomes. Although multimedia presentations may improve knowledge in both the literate and the less literate, they do not appear to change health-
<b>Findings:</b> Only 5 articles examined the interaction between literacy level and the effect of the intervention.	related behaviours.
Mixed results.	<b>Conclusions:</b> Community development is a promising avenue that requires more exploration. Creation of
<b>Conclusions:</b> Drawing conclusions difficult because of limitations in study design, interventions tested and outcomes assessed. Further research required.	innovative evaluation tools required.
King, 2007 <sup>122</sup>	Clement et al., 2009 <sup>123</sup>
<b>Method:</b> Review of published and grey literature related to health literacy interventions in Canada and internationally. Also conducted key informant interviews.	<b>Method:</b> Systematic review of randomized and quasi- randomized controlled trials that focused on complex interventions for people with limited literacy or numeracy. Searched eight databases from 1966 to 2007.
<b>Findings:</b> Majority of health literacy interventions to involve accessing and understanding, with very few	Predominantly North American.
focused on appraising or communicating health information. Very limited information found on the effectiveness of health literacy interventions. Some	<b>Findings:</b> Knowledge and self-efficacy were outcomes most likely to improve but not necessarily related to health outcomes.
evidence exists to support the finding and general understanding that a participatory educational and empowerment approach is effective.	<b>Conclusions:</b> While the review focused on two specific aspects of health literacy (reading ability and numeracy) many interventions included wider empowerment and/or
<b>Conclusions:</b> Barriers to evaluation of programs were time, money and lack of provider expertise. Further investigations suggested :	community participation aspects. The implementation of literacy/numeracy interventions might most usefully be embedded within this broader approach to health literacy.
<ul> <li>health literacy interventions focused on appraising health information</li> <li>cultural issues</li> <li>health care professional training</li> <li>sources of health information</li> <li>learner and patient perspectives</li> </ul>	

<sup>120</sup> Pignon, M., DeWalt, D., Sheridan, S., Berkman, N., & Lohr, K. (2005). Interventions to Improve Health Outcomes for Patients with Low Literacy: A Systematic Review. Journal of General Internal Medicine. 20, 2. 185-192

<sup>121</sup> Hauser, J. & Edwards, P. (2006). *Literacy, health literacy and health: A literature review* Ottawa: Expert Panel on Health Literacy, Canadian Public Health Association.

<sup>122</sup> King, J. (2007). Environmental Scan of Interventions to Improve Health Literacy. National Collaborating Centre for Determinants of Health

<sup>123</sup> Clement, S., et. al. ((2009). Complex Interventions to improve the health of people with limited literacy: A systematic review. Patient Education and Counceling. 75, 340351.

Johns Hopkins Bloomberg School of Public Health: Center for Communication Programs (2005). Pakistan Youth-First Project. <u>http://www.jhuccp.org/asia/pakistan/youth.shtml</u>

Johns Hopkins Bloomberg School of Public Health: Center for Communication Programs (2005). Morocco Family Planning and Maternal & Child Health Project, Phase V Safe Motherhood. http://www.jhuccp.org/neareast/morocco/fp.shtml

Suhail, K. (2005). A study investigating mental health literacy in Pakistan. Journal of Mental Health; 14(2), 167-181.

Health Communication Partnership (2007). Communication for Healthy Living's Campaign Improves Response to Avian Influenza in Egypt. Communication Impact, Number 22.

Health Communication Partnership (2001). Arab Women Speak Out (AWSO) Program Helps Arab Women Redirect their Lives. Communication Impact, Number 13.

Osman, H., Chaaya, M., Wick, L., Nassar, A., & Saliba, M. (2008). Postpartum Interventions: Can we facilitate the transition into motherhood?. American University of Beirut, Faculty of Health Sciences.

Johns Hopkins Bloomberg School of Public Health: Center for Communication Programs (2005). Jordan Youth Campaign Launch: May 1998-A Mass Media & Community Based RH Program for Jordanian Youth 1999-2003. <u>http://www.jhuccp.org/neareast/jordan/youth.shtml</u>

Johns Hopkins Bloomberg School of Public Health: Center for Communication Programs (2005). Religious Leaders (RL) Lead the Way. <u>http://www.jhuccp.org/neareast/jordan/leaders.shtml</u>

Health Communication Partnership (2003). Men in Jordan Get Involved in "Together for a Happy Family". Communication Impact, Number 14. <u>http://www.jhuccp.org/neareast/jordan/men.shtml</u>

Zamir, D. (2007). Culturally Appropriate HealthCare by Culturally Competent Health Professionals: Community Intervention for Diabetes Control Among Adult Arab Population. <u>http://scholar.google.com/scholar?hl=en&q=%22community+intervention+for+diabetes+control+am</u> <u>ong+adult+arab+population%22</u>

Banihashemi, S.A., Amirkhani, M.A., Haghdoost, A.A., Alavian, S.M., Asgharifard, H., Baradaran, H., Barghamdi, M., Parsinia, S. & Ranjbar, S.F. (2007). Health literacy and the affecting factors: a study in five provinces of Iran. Journal of Medical Education Development Center; 4(1), 1-9.





7th Global Conference on Health Promotion Promoting Health and Development: Closing the Implementation Gap Nairobi, Kenya, 26-30 October 2009