

European Health Forum Gastein 2004 – Special Interest Session

## Improving Health literacy – A key priority for enabling good health in Europe

Friday, 8<sup>th</sup> October 2004

15.00 – 17.30

### Background paper

## Improving Health Literacy in the European Union: towards a Europe of informed and active health citizens

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### *Introduction*

Advancements in public health have transformed Europe. The member states of the European Union (EU) for the most part have become, or are on their way to becoming, *health societies*, defined by six dimensions:

- A high life expectancy and ageing populations
- An expansive health and medical care system
- A rapidly growing private health market
- Health as a dominant theme in social and political discourse
- Health as a major personal goal in life
- Health as a right of citizenship

Health is a co produced good – and in a health society, access to health information and utilization of health knowledge play a crucial role for the fulfillment of personal and societal expectations and for enabling citizens to make healthy choices. Within the EU this is expressed in two major policy initiatives:

- the *Public Health Framework Programme*,<sup>1</sup> with the aim to provide an integrated approach to protecting and promoting health, puts a special emphasis on the dissemination of information and knowledge; and
- the initiative on the *Information Society* includes as one of its key strategic areas the development of new e-health possibilities “for almost every aspect of health care, from making medical care systems more powerful to providing better health information to everyone.”<sup>2</sup>

Both of these policy initiatives put the active European citizen in the center of their deliberations on health with the intent to empower communities, consumers and patients. Indeed it is proposed

to put all EU policies in the service of good health – as recently expressed by Commissioner David Byrne – as an effort to bring Europe closer to its citizens, improve the quality of life and help bridge gaps of inequity and participation. Access to health information is on a par with access to health care: it is considered a right of citizenship. In a Europe of the future, “*Everybody has easy and prompt access to affordable, high quality health care – whoever and wherever they are...people will have no trouble finding clear and reliable information on how to be in good health and about diseases and treatment options.*”<sup>3</sup> European Ministers have asserted that the needs of EU citizens must be the center of attention in the development of high quality health-related information services and that the widespread availability of high quality health information creates the potential for citizen empowerment.<sup>4</sup>

One way to capture this new central policy component that combines health knowledge with health action is the concept of health literacy. Health literacy will need to become a key literacy in European society. “Literacy is part and parcel of the pursuit of freedom, itself a central tenet of development...”<sup>5</sup> Health literacy is at least as important and economically relevant as basic literacy, digital literacy and information society literacy (which are the three types of literacy emphasized by the European Commission’s policy area on Lifelong Learning in *Making a European Area of Lifelong Learning a Reality*<sup>6</sup>).

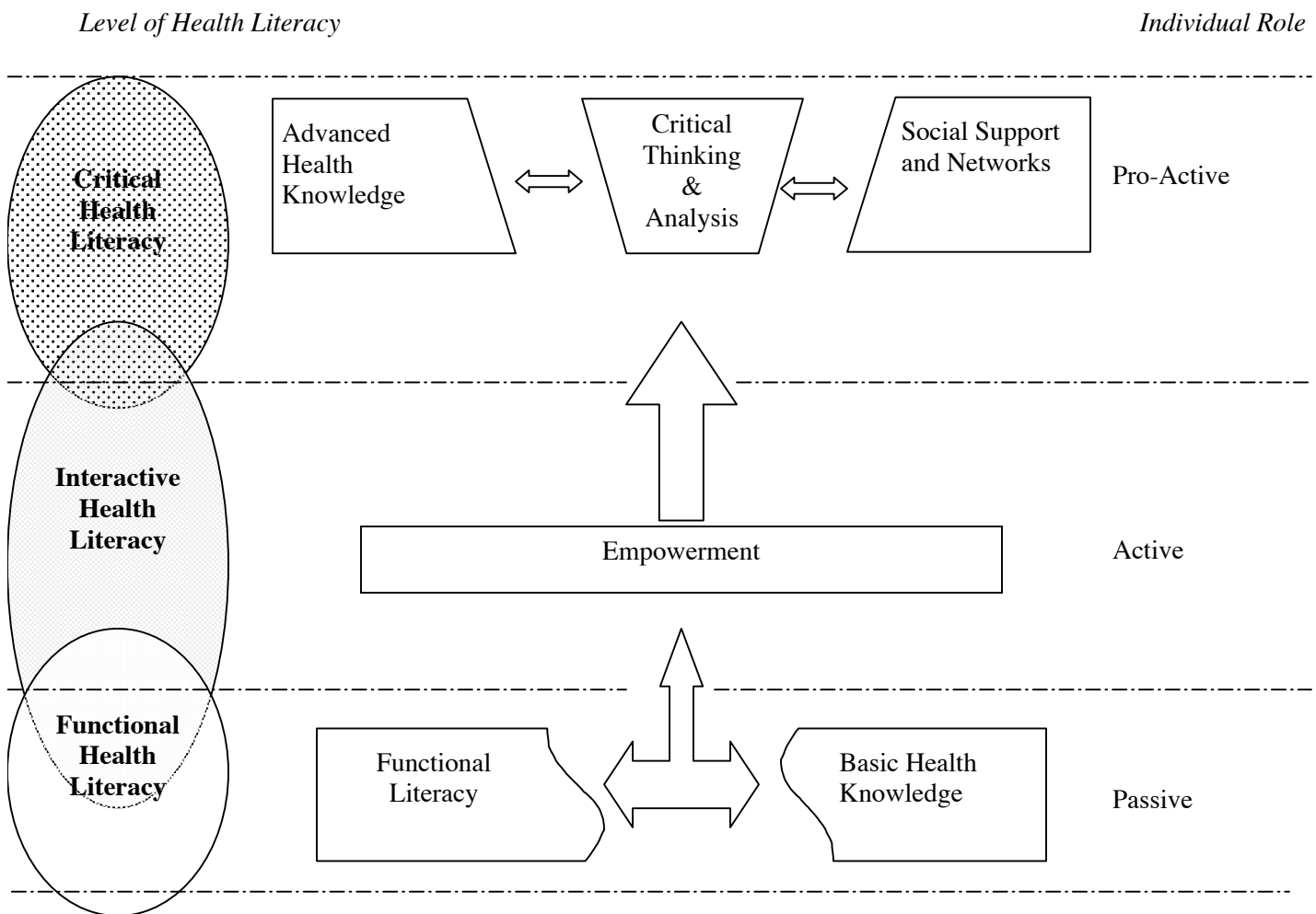
### ***What is health literacy?***

The World Health Organization (WHO) has defined health literacy as “the cognitive and social skills and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.”<sup>7</sup> An individual who is health literate has the knowledge, skills and confidence to manage health on a daily basis. This includes being able to know when to enter the health care system and how to navigate through it in order to make the best use of health services. It means understanding doctor advice and also being empowered to actively participate with health professionals in the process of creating health. Empowerment, an educational process designed to help patients develop the knowledge, skills, attitudes and degree of self-awareness necessary to effectively assume responsibility for their health-related decisions,<sup>8</sup> is a key element of health literacy. “To have the capacity to exercise greater control over their health, people need information, knowledge and understanding. This gives confidence and a will to assert control.”<sup>9</sup> Health literacy also includes understanding one’s right in relation to health and the health care system, and it enables patients to understand and act in their own interest.

The notion of health literacy also extends beyond the health system. Health literate individuals have the knowledge and ability to make healthy choices and adopt healthy lifestyles. They employ health skills, which are a subset of their life skills. A recent report by the National Consumer Council in the UK summarizes the key skills of health literacy as 1) navigating health care systems, 2) engaging in self-care and 3) participating in decision-making - and doing all of these with self-confidence.<sup>10</sup> Those who are health literate are also able to take an active role in addressing determinants of health. Health literacy is becoming increasingly important for social, economic and health development.<sup>11</sup>

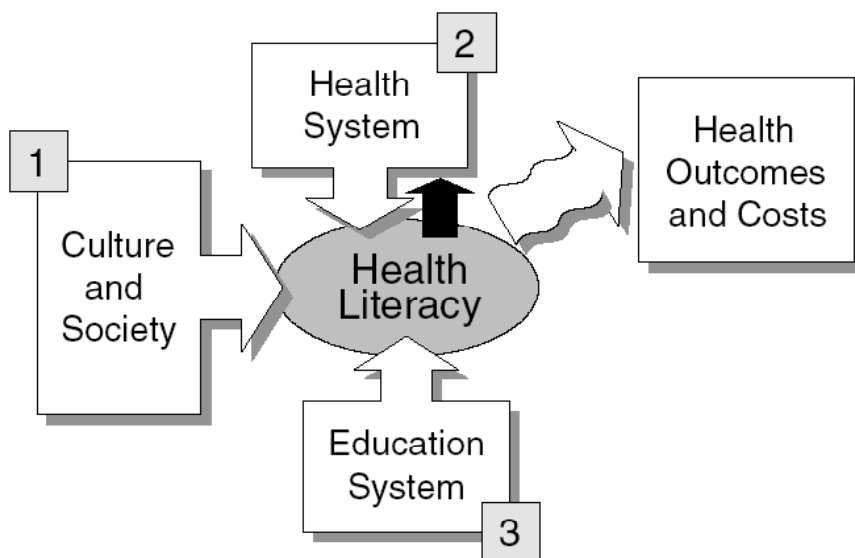
Three domains of health literacy, as put forward by Don Nutbeam, include functional, interactive and critical.<sup>12</sup> (See Figure 1.<sup>13</sup>) First, functional health literacy refers to the basic skills of reading and writing that allow an individual to function effectively in regards to health, such as ability to read basic health education materials on health risks or how to use the health system. Second, interactive health literacy encompasses more advanced cognitive, literacy and social skills that can be utilized to participate in health activities, to understand different forms of communication of health messages and to apply health information to changing circumstances. And, finally, critical health literacy refers to the more advanced cognitive and social skills, which can be used to critically analyze health information, to improve individual and community capacity, to act on social and economic determinants of health, and to understand the political and economic dimensions of health.

**Figure 1: Health Literacy Framework**



A framework for health literacy, developed by the Committee on Health Literacy at the Institute of Medicine, shows the three major points of intervention in the health literacy framework: educational systems, health systems, and culture and society (see Figure 1).<sup>14</sup> According to the framework, these three systems may ultimately contribute to health outcomes and costs. This figure also shows clearly that societal investments in health literacy will need to be made in all three systems. For example, culture and society investments for health literacy can be made in social marketing and advertisements of health products, while in the education system, investing in schools and institutions of adult education can promote health literacy.

**Figure 2: Potential Points of Intervention in the Health Literacy Framework**



Health literacy is undoubtedly reliant on basic literacy skills and cognitive development. Poor literacy not only hinders health literacy but can also limit an individual's personal, social and cultural development.<sup>15</sup> However, low health literacy does not necessarily mean low literacy. Even people with advanced literacy skills can experience difficulty in obtaining, understanding and using health information. A person who functions well in the home or work environment can still have insufficient literacy in the healthcare realm.<sup>16</sup> This is one of the reasons for the rapid development of self-help groups and patients' organizations.

As health expands in modern societies, the role of the individual in health becomes more significant and diverse. In the health marketplace, the individual becomes a consumer; while in the health system, the individual becomes a patient. The individual is also a voter on health issues (and indeed health policy issues are gaining increasing importance in deciding elections in OECD countries) and a social actor in health movements. In these various contexts, health literacy takes on different meanings. One constant factor, however, is what sociologists call the reflexivity of modern social life - that social practices (in this case health practices) are continually reexamined and revised in light of new information. What is healthy today is

unhealthy tomorrow; treatments and medications are continually being improved and expanded. The organization of the health system is changing regularly and the rights of access are being constantly redefined. **Therefore health literacy is an active process; citizens have to continually learn new information and un-learn outdated information in order to maintain good health and act as informed patients.** Empowerment of citizens to participate actively and confidently in this process is critical to population health.

### *Health literacy in the context of health education*

Health literacy is a distinguishable concept from health knowledge, health education and health promotion. The transfer of health information is fundamental but not sufficient to improving health literacy in a population. As mentioned above, health literacy includes helping individuals develop the skills and confidence to act on that knowledge and the ability to work with and support others. Health education improves health literacy by creating opportunities for learning about healthy behavior. However, the top-down strategies of health education interventions of the past did not result in substantial or sustainable behavior change and therefore have had little impact on reducing the health gap between different social and economic groups.<sup>17</sup> Effective health education in the context of a health promotion approach (as outlined in the Ottawa Charter<sup>18</sup>) provides health knowledge, facilitates the development of life skills and provides opportunities for learning that are intended to improve health literacy.

Literacy is the pathway between education and health. Health literacy emerged as a model to show the linkages between health promotion interventions, the determinants of health and the range of outcomes from such interventions. Health literacy is now understood as a health promotion outcome.<sup>19</sup> The Center for Global Assessment provides a useful categorization of health activities as they relate to strategies of health promotion, health protection, disease prevention, health care and maintenance and systems navigation (see Figure 3).<sup>20</sup> This categorization also underlines the important point that as relevant as health literacy is as a health promotion outcome, disease management, systems navigation, and consumer behavior are also very important in this context.

Finally, within the universe of health information we need to consider three crucial dimensions, as outlined by the United States (US) Department of Health and Human Services<sup>21</sup>:

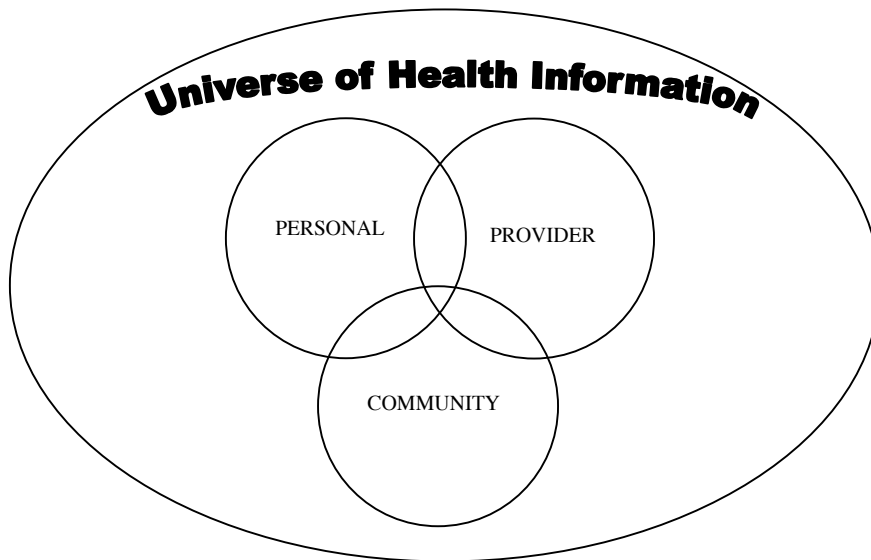
- 1- *Personal health dimension*, which supports management of individual wellness and health care decision-making;
- 2- *Provider dimension*, which encompasses information to enhance the quality and effectiveness of health care; and
- 3- *Community dimension*, which includes a broad range of information, including population-based health data and resources, necessary to improve health.

Each dimension represents key stakeholders with regard to health literacy but (as Figure 4<sup>22</sup> illustrates) while each dimension has information needs that are distinct they also clearly overlap in the context of everyday life.

**Figure 3: Categories of Health Activities with Selected Examples**

| <b>Health Activities</b>                    | <b>Focus</b>   | <b>Examples of Materials</b>  | <b>Examples of Tasks</b>   |
|---|--|---|--|
| <i><b>Health Promotion</b></i>              | Enhance & maintain health                            | Articles in newspapers & magazines, booklets, brochures<br><br>Charts, graphs, lists<br><br>Food & product labels                       | Purchase food<br><br>Plan exercise regimen   |
| <i><b>Health Protection</b></i>             | Safeguard health of individuals & communities        | Articles in newspapers & magazines<br><br>Postings for health & safety warnings<br><br>Air & water quality reports<br><br>Referendums   | Decide among product options<br><br>Use products<br><br>Vote   |
| <i><b>Disease Prevention</b></i>            | Take preventive measures & engage in early detection | News alerts [TV, radio, newspapers]<br><br>Postings for inoculations & screenings<br><br>Letters re: test results<br><br>Graphs, charts | Determine risk<br><br>Engage in screening or diagnostic tests<br><br>Follow up                               |
| <i><b>Health Care &amp; Maintenance</b></i> | Seek care & form a partnership with health providers | Health history forms<br><br>Medicine labels<br><br>Discharge instructions<br><br>Education booklets & brochures                         | Describe & measure symptoms<br><br>Follow directions on medicine labels<br><br>Calculate timing for medicine |
| <i><b>Systems Navigation</b></i>            | Access needed services<br><br>Understand rights      | Maps<br><br>Application forms<br><br>Statements of rights & responsibilities, informed consent<br><br>Health benefit packages           | Locate facilities<br><br>Apply for benefits<br><br>Offer informed consent                                    |

**Figure 4: Universe of Health Information**



***Why health literacy needs to be a priority in the European Union***

*1. Citizens expectations and goals*

European citizens want health information, choice and empowerment.<sup>23</sup> People's appetite for information is often greater than physicians have acknowledged until now, as evidenced by the rapidity with which the Internet has become a major force in providing health information. Public health organizations, health insurance companies, pharmaceutical companies, patient organizations and others are putting more and more health information on the web. The UK National Health Service, for example, has established a national electronic library for health. The Internet has empowered patients to discuss with health professionals in new ways and allowed them to gain competence to manage major health conditions. Yet, people in greatest need of information about preventable or treatable conditions are the least likely to have access to the information.<sup>24</sup> While professionals of the UK National Health Service have universal Internet access via the health service's wide-area network, patients in this system are not afforded the same access to Internet-based health care.<sup>25</sup> With all the potential and real progress comes new danger and inequality in the digital health divide. "Variation in access to information is ultimately disempowering: it reduces people's ability to act promptly and engage in self-care, and it erodes self-confidence and access to services impacting negatively on health."<sup>26</sup>

*2. Ageing society*

Ageing is a predominant issue that will shape the health of many Europeans in the coming years. According to the WHO, in 2002, Europe had the greatest number of countries with the highest proportion of individuals over age 60 of countries with more than 10 million inhabitants. Eight

out of the top 10 were Member States of the EU, and it is projected that in 2025 the ranking will largely stay the same. In Europe, the old-age dependency ratio (that is, the total population aged 60 and over divided by the total population aged 15-60) will increase from 0.36 in 2002 to 0.56 in 2025.<sup>27</sup> The elderly have the greatest health literacy needs due to their high prevalence of chronic diseases, yet they are disproportionately represented among the health illiterate.<sup>28,29</sup> Preventive strategies can in fact improve the health of the ageing population by bringing benefits to major health conditions like obesity, diabetes, cardiovascular disease and osteoporosis. Such measures can help both to improve the quality of life of older people as well as contribute to the control of health care costs in the EU.<sup>30</sup> The European government's responsibility in supporting health literacy programs for healthy ageing is one way to positively address the demographic challenges in the new EU. While a focus on older people is clearly one of the needs for strengthening health literacy in Europe, this must clearly be done within a wider strategy of lifelong learning and an understanding that ageing is a life long process – the basis for which is laid early in life.

### *3. Complexities in an expansive medical system*

In the context of an expansive health and medical care system, Europeans are increasingly confronted with complex decisions regarding their health. Maintaining health or living with disease both require high health literacy and constant decision-making. Nearly every choice is a health choice. Health systems are becoming more complicated to navigate, informed consent documents are often confusing to patients<sup>31</sup> and treatment options are growing as technology advances. Individuals have to weigh different prescription drug options and adhere to complex regimens. Self-management of health and shared decision-making with health professionals are becoming more common. Self-management education includes teaching patients with chronic and long-term conditions problem-solving skills, developing their confidence to improve quality of life and working in partnership with healthcare professionals. Also, according to the National Consumer Council, most patients prefer shared decision-making with health professionals versus strictly professional-based decision-making. These processes are reliant on patients' ability to understand their health condition and manage it.<sup>32</sup>

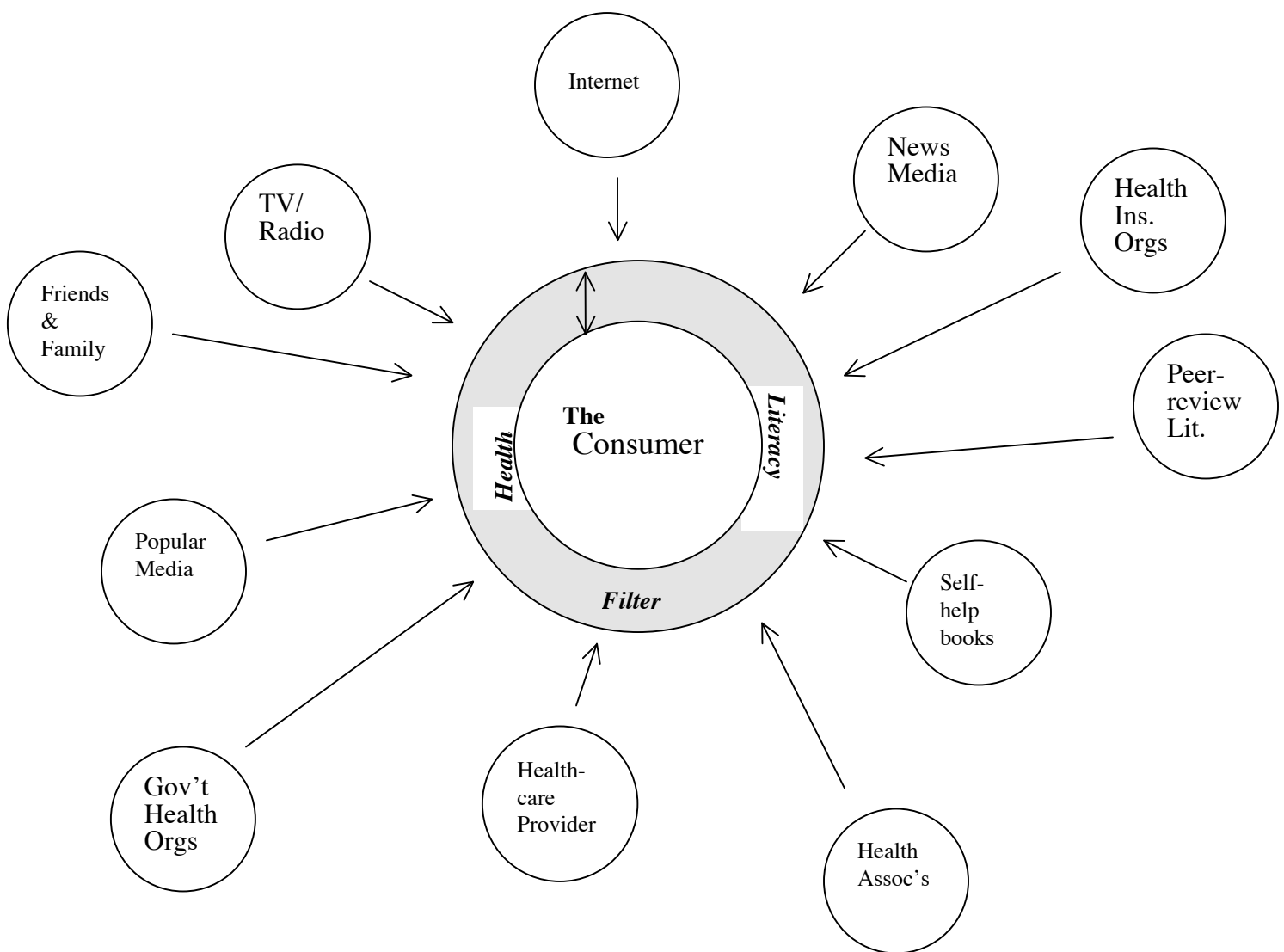
### *4. Increasing information in the health marketplace*

As the health marketplace expands, more and more health information and products influence Europeans in making health decisions. According to the Eurobarometer, health-related information is sought after on the Internet, television, print (newspapers and journals), as well as from traditional medical and health organizations.<sup>33</sup> (See Figure 5.<sup>34</sup>) A “wellness revolution” is occurring, evidenced by increased marketing of wellness products and services including nutritional products (such as supplements), organic food, fitness products and services (yoga and Pilates), voluntary medicine (including cosmetic surgery and lifestyle drugs), alternative health care (such as acupuncture) and resources on wellness (particularly in the media and information sector) and wellness insurance.<sup>35</sup> In the United States alone, the sales of the wellness industry have already reached approximately US\$200 billion and that it is set to achieve sales of US\$1 trillion within 10 years, thus matching the health care industry.<sup>36</sup>



However, unreliable sources, fraudulent claims and conflicting information can create problems for even the most literate citizens. There is a need to create knowledgeable consumers who can exercise choice in a highly unregulated health and wellness market. Individuals therefore need reliable channels of health information as well as the cognitive ability to sift through all of the information in order to make informed decisions. In his reflection process on a new EU health strategy, David Byrne maintained, “European citizens need reliable and user-friendly information about how to stay in good health and the effects of lifestyle on health. When they fall ill, they need authoritative information about their condition and treatment options to help them take decisions. Enabling citizens to make the right choices is indispensable.”<sup>37</sup>

**Figure 5: Health Literacy and the Market: Consumers and the Information Deluge**



### *5. Health gaps in the EU*

The expansion of the EU has resulted in major health gaps between countries. Western European countries enjoy better health and longer life expectancy than the less wealthy countries of Central and Eastern Europe.<sup>38</sup> Among the 25 Member States, life expectancy for men ranges from 64 to 77 years. There is a five-fold difference between EU countries in terms of incidence of lung cancer and a 17-fold difference when it comes to tuberculosis.<sup>39</sup> As choices are expanded in the European health society, this health gap becomes increasingly obvious throughout the region. The EU has, as one of its goals, the achievement of an equitable health status across Member States. But health gaps within EU Member States exist as well. In the Netherlands, for instance, in 2001, better-educated and wealthier individuals experienced on average four additional years of life and 12 additional years of good health than those who were less educated and poorer.<sup>40</sup> The promotion of a health literate Europe can help to reduce health gaps both between and within Member States.

### *6. Movement of people, goods and services*

Movement of people, goods and services also creates a need for improved health literacy. Today, all West European countries have a positive migration balance, and several of the new EU Member States in Central Europe currently follow the same pattern. According to data collected between 2000-01, approximately 18.7 million legal foreign residents lived in the 15 “old” EU Member States (out of a total 381 million inhabitants). (Today, the European Union, or EU 25, has 455 million inhabitants.) Of the 18.7 million legal foreign residents, fewer than 6 million people were EU citizens living in another EU Member State; 13 million were third country nationals.<sup>41</sup> As people migrate in Europe, individuals from diverse cultures enter new health systems. Culture largely shapes perceptions of illness and health, which then influence people’s experience in the health care system.<sup>42</sup> Miscommunication between physicians and migrants is not uncommon, and health messaging that doesn’t take culture into consideration can miss its mark. The movement of goods and services throughout the EU also has implications for the health literacy of Europeans. Articles 28-30 of the European Commission Treaty established the principle of free movement of goods among Member States. Individuals need to be informed about the health effects of different products that are flowing into their communities, such as health products and medicines purchased on the Internet. And the health care system needs to be more user-oriented.

### *7. Effects of poor health literacy*

Insufficient levels of health literacy can lead to inefficiencies in the health care system. While empirical data on the effects of low health literacy in Europe are limited, research from the US Center for Health Care Strategies concluded that individuals with low health literacy are less likely to: 1) understand written and oral information from health professionals, 2) act upon necessary procedure and directions (such as medications and appointments) and 3) be able to navigate the health system to obtain necessary services.<sup>43</sup> A recent Institute of Medicine report shows that individuals with limited health literacy are more likely to be hospitalized and use emergency services.<sup>44</sup> Furthermore, according to Institute of Medicine, people who are health

illiterate are less likely to use preventive services, have less knowledge of disease management and health promoting behaviors, and report poorer health status. A 2004 report by the Agency for Healthcare Quality and Research noted that the 90 million Americans, or nearly half of the United States population, who have difficulty understanding and acting upon health information are less likely to get potentially life-saving tests (mammograms, Pap smears), flu and pneumonia vaccines, and take their children for well child care visits.<sup>45</sup> Low health literacy costs the US up to US\$73 billion every year.<sup>46</sup>

### ***Looking to the Future***

#### *Policy:*

- Europe has the potential to be an *international leader* in shaping policies that *promote health and health literacy*. Health, first and foremost, needs to be at the center of EU policy making.<sup>47</sup> The two key dimensions of an EU health strategy include addressing the determinants of health and strengthening citizens' health literacy. Citizens' needs and rights must be the focus of this strategy. Health literacy needs to be part of all major EU health initiatives and could be incorporated into national systems performance targets.
- Policy makers need to ensure the provision of reliable health information through the establishment of *quality criteria* for health-related portals of information. Yet, it is also essential that quality health information come from not from one source but a variety of reliable sources. The EU could create *guidelines and programs* for specific populations in Europe that are high risk for health illiteracy, such as migrants, the poor and the elderly.
- Since health knowledge comes from so many sources, a larger strategy is needed to generate health literacy throughout society. The EU needs to systematically develop a *health information and literacy infrastructure* at the regional level. This could include the establishment of new resources and roles among health professionals, such as the use of decision aids, support workers and knowledge brokers.<sup>48</sup>
- Improved health literacy also requires European policymakers and leaders outside of the health sector to be aware of the key elements that contribute to health illiteracy.<sup>49</sup> *New alliances* between health and education sectors- at the local, national and regional levels- can help reach the goal of a health literate Europe.<sup>50</sup>

#### *Learning:*

- Health literacy needs to become an integral part of the health system as well as a key component of modern literacy (in schools, adult education, etc.). Incorporating health knowledge and skills into school curricula would help establish a foundation of health literacy in early life.
- Integrating health literacy into the European Commission's policy area of Lifelong Learning is very important. In November 2001, the Commission adopted Communication on *Making a European Area of Lifelong Learning a Reality*, yet the document did not

include any mention of health literacy. Lifelong learning is a core element of the mission of the EU; it is central to competitiveness, employability, social inclusion, active citizenship and personal development.<sup>51</sup> Health literacy needs to be a key component of this strategy.

*e-Health:*

- *e-Health* can be a useful tool in developing health literacy. (e-Health refers to the use of modern information and communication technologies to meet needs of citizens, patients, healthcare professionals, healthcare providers, as well as policy makers.<sup>52</sup>) With new communication technologies, Europeans can become more involved in their health decisions and treatment, and appropriate access to such technologies can help guarantee a health literate public.<sup>53</sup> EU policies can help to bring information and communication technology to the disadvantaged population.
- The *e-Health Action Plan* of the EU, which aims to be in place by the end of 2005, is a crucial step in the pursuit of a health literate Europe, and its implementation should be fully supported by all Ministers. The plan includes electronic health cards, development of health information networks and online provision of health services (including information on healthy living and illness prevention, electronic health records and e-reimbursement).<sup>54</sup> In May 2003, the European Commission, in collaboration with the Greek Presidency, held a high level conference in Brussels on e-Health during which the Ministers expressed their commitment to the development of national and regional e-Health plans in the e-Health Ministerial Declaration. The Declaration outlines ways in which Ministers can 1) promote quality of and enhance efficiency in health care through e-Health applications, 2) facilitate citizen involvement through access to high quality information, and 3) implement and share best practices of e-Health.<sup>55</sup>

*Health and Patient Advocacy Organizations:*

- Support for *patients' organizations* is an important step in promoting health literacy. Such organizations that promote patients' rights and advocate for improved health can be a reliable source of health information. European health societies are reliant on the active participation of patients' organizations, health literate consumers and social movements; this is necessary to advance the health literacy platform throughout the EU. Patients' groups will gain increasing importance in shaping the future of the health society, as the key value that remains is the empowerment of the citizen.
- *Professional associations*, such as the European Medical Association, also have potential to shape health literacy across the EU, particularly in *better training* of health professionals. The American Medical Association, for example, is creating an initiative to combat health disparities by focusing on patient-centered communication. The initiative, which focuses in part on health literacy, will develop practical self-assessment toolkits for health care organizations that address patient-centered communication for vulnerable populations.<sup>56</sup>

*Culture:*

- Health literacy programs and messages need to be rooted in the *context of culture*.<sup>57</sup> Peter Koehn calls on health care professionals to develop ‘transnational competence’ in providing care to migrants.<sup>58</sup> Transnational competence, which encompasses analytic, emotional, creative, communicative and functional skills that facilitate effective communication between the clinician and patient, has the potential to reduce inequities in health care within countries. Such skills could include clinician/patients’ understanding and respect of each other’s personal beliefs and practices regarding the causes, treatment and prevention of illness; ability to express/encourage expression of uncertainties, doubts, health-related worries and questions; and relating in a way that builds trust. It is also imperative that health literacy initiatives *combat social stigma* associated with illiteracy that can hinder people from seeking health advice or care.

*Ageing Population:*

- The EU has a clear role to play in promoting health literacy among those of advanced age. In addition to implementing “*age-friendly*” policies, health literacy initiatives could be created to mitigate the adverse consequences of health illiteracy among the ageing population. Focusing on functional health literacy capacity *over the life course* would help to ensure that future generations of older people are health literate.<sup>59</sup> The WHO Active Ageing Initiative supports efforts the use health literacy as a tool to promote active ageing throughout Europe. The initiative emphasizes autonomy and independence, interdependent solidarity, disability-free life expectancy and improved quality of life.<sup>60</sup>

*Research:*

- Health literacy *research agenda* in the EU needs to be significantly strengthened. Public and private funds should be allocated to health literacy research. New *measures of health literacy* need to be established, as current health literacy measures are largely limited to reading skills. A set of indicators or scales should be developed for the three domains of health literacy (that is, functional, interactive and critical).
- Once measures are established, *tools* can be developed to determine baseline health literacy data in the EU. Comparative assessment of health literacy can be conducted throughout the EU. Differences in levels of health literacy in relation to gender, population and age groups, education and income can be measured over time.<sup>61</sup>
- The EU would benefit from the establishment of a health literacy research program. Available research supports only limited conclusions about causality. An *empirical evidence base* for health literacy- including the costs associated with health illiteracy as well as the health outcomes of a health literate Europe- needs to be established. Research should focus, for example, on the cost of low health literacy in Europe and the link between general literacy and health literacy. Surveys on basic adult literacy could include health components.

- The creation of a *European network or center* on health literacy would help to codify the health literacy information that is generated in the research as well as act as a resource for individuals and organizations to networking, information transfer and skill building. A *European health literacy conference*, held by this network/center or another organization, could help share best practices among the public health community.

### ***Acknowledgements***

The author would like to thank Lea Payne for her contribution to this paper.

### ***Endnotes***

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