Perspectives

Accelerating the health literacy agenda in Europe

Gianluca Quaglio1,*, Kristine Sørensen2, Paul Rübig3, Luigi Bertinato4, Helmut Brand2, Theodoros Karapiperis1, Irina Dinca5, Terje Peetso6, Karin Kadenbach7, and Claudio Dario8

1Scientific Foresight Unit (Science and Technology Options Assessment [STOA]), European Parliamentary Research Service, European Parliament, Brussels, Belgium, 2Department of International Health/CAPHRI, University of Maastricht, The Netherlands, 3MEP, STOA Chairman, European Parliament, Brussels, Belgium, 4Local Health Authority n.20, Veneto Region, Italy, 5European Centre for Disease Prevention and Control (ECDC), Stockholm, Sweden, 6DG Connect, European Commission, Brussels, Belgium, 7MEP, European Parliament, Brussels, Belgium, and 8Local Health Authority n.16, Veneto Region, Italy

*Corresponding author. E-mail: gianluca.quaglio@europarl.europa.eu

Summary

Health literacy can be defined as the knowledge, motivation and competence to access, understand, appraise and apply information to make decisions in terms of healthcare, disease prevention and health promotion. Health literacy is a European public health challenge that has to be taken seriously by policymakers. It constitutes an emerging field for policy, research and practice. However, recent research has shown that health literacy advancement is still at its infancy in Europe, as reflected in the scarce scientific health literacy literature published by European authors. From a total of 569 articles published until 2011 on this subject, the first author of only 15% of them is from Europe. This article conveys recommendations of different European stakeholders on how to accelerate the health literacy agenda in Europe. A general introduction on the current status of health literacy is provided, followed by two cases applying health literacy in the areas of prevention of communicable diseases and promotion of digital health. The current EU strategies integrating health literacy are listed, followed by examples of challenges threatening the further development of health literacy in Europe. Recommendations as to how European stakeholders involved in research, policy, practice and education can promote health literacy are given. It is vital that the European Commission as well as European Union Member States take the necessary steps to increase health literacy at individual, organizational, community, regional and national levels.

Key words: health literacy, public health, Europe, agenda setting

INTRODUCTION

Health literacy is a fairly new field of research and activity in the area of medicine and health (Pleasant and Kuruvilla, 2008). Health literacy can be defined as the knowledge, motivation and competence to access, understand, appraise and apply information to make decisions in terms of healthcare, disease prevention and health promotion.
in order to maintain and promote health and quality of life (Sørensen et al., 2012). After its first introduction in the 1970s (Simonds, 1974), the concept received increased attention in the early 1990s, with a progressive growth to date. While the concept gained momentum at an early stage in the USA and Canada, it was less prevalent in Europe, as reflected in the scarce scientific health literacy literature published by European authors. The European Union (EU) is a unique economic and political partnership between 28 European countries (Member States—MSs) that together cover much of the continent. From a total of 569 peer-reviewed articles published until 2011 on health literacy, the first author of only 86 articles (15.2%) is from an EU MSs. Several EU MSs are represented by a single publication (Czech Republic, Denmark, Italy, Portugal, Romania, Slovakia) (Pleasant, 2013).

However, health literacy has recently gained relevance on the European health agenda, when it was integrated in the European Commission (EC) health strategy Together for Health 2007–2013 (European Commission, 2007). Yet, a newly published report on the status of health literacy in Europe with regard to policy action and interventions emphasizes that health literacy is still in its infancy in most European countries and further initiatives are needed to unfold its potential (Heijmans et al., 2015). Facilitated by the STOA (Science and Technology Options Assessment) Panel, which is the European Parliament’s in-house source of independent analysis of public policy issues related to science and technologies, the challenges associated with promoting health literacy were discussed in a workshop for European stakeholders (Scientific Foresight, STOA, 2015). This article reflects the outcome of the discussion and the recommendations put forward to accelerate the health literacy agenda in Europe. First, a general overview of health literacy in Europe is presented, including two cases concerning non-communicable diseases and digital health literacy. Subsequently, the role of European policy in promoting health literacy is described. Lastly, challenges associated with health literacy are listed followed by recommendations to researchers, practitioners and decision-makers to address the needs of health literacy in the EU.

HEALTH LITERACY: WHERE EUROPE STANDS

Data from the European Health Literacy Survey (HLS-EU) revealed for the first time that health literacy is a public health challenge in eight EU MSs (Sørensen et al., 2015). The fraction of the population that can be considered health literate varies from 30 to 60% depending on the country studied. New national population studies from additional countries verify the trend (Government of Malta, 2014; Espanha et al., 2015). People with low education, the elderly and those with a low socio-economic status are most affected (van der Heide et al., 2013; Sørensen et al., 2015). Although the HLS-EU represent the first European comparative assessment into how health literacy levels differ in the EU MSs, it is important to recognize the limitations of the study. For example, the field testing for the survey was limited to three countries, the survey was carried out in only 8 EU MSs, and the sample size was restricted to 1000 respondents for each sample country. More analysis and further research will be necessary in the future.

Health literacy has been applied in different areas. The following sections describe two examples of health literacy: one on preventing communicable disease and the second for promoting digital health.

Health literacy in the prevention of communicable diseases

Despite the fact that non-communicable diseases dominate the public health debate, communicable diseases still pose significant challenges, for example, re-emergent diseases (e.g. tuberculosis), imported diseases (e.g. Dengue, Ebola, etc.) and increasing anti-microbial resistance (Quaglio et al., 2012). The European Centre for Disease Prevention and Control (ECDC) carried out a review of interventions for improving health literacy for communicable diseases for disadvantaged populations (D’Earth et al., 2012). This review was initially sought to identify evidence reviews on health literacy interventions in Europe. A database search identified the absence of relevant literature in Europe, necessitating a widening of the search to reviews of health literacy interventions internationally.

The study, that covered the period 2000–10, identified five reviews, mostly done in North America (Pignone et al., 2005; Santo et al., 2005; Schaefer, 2008; Clement et al., 2009; DeWalt and Hink, 2009). The only interventions related to communicable diseases involved treatment adherence for anti-HIV medication, which has been documented as a serious issue in this area. While all studies reported improvements, these were mostly recorded at the level of improved knowledge rather than healthy behaviours or health outcomes. Few revised studies provided analysis stratified across literacy levels, thereby making it impossible to measure the impacts on people with different levels of health literacy. The review draws the general conclusion that there is a gap in Europe in the evidence concerning which interventions are most effective in improving health literacy in the area of communicable diseases. This conclusion is especially important in the context of the EU MSs which lack the capacities and capabilities to design
interventions aimed at supporting their population to prevent communicable diseases, to ‘navigate through’ health systems and to combat threats from communicable diseases. This would be one of the principal ways to be able to address critical situations such as measles, a disease which has had a number of outbreaks in several EU countries over the last 5 years (Muscat, 2011).

Digital health literacy in Europe

Digital literacy has been defined in different ways. Merchant (Merchant, 2007) defines digital literacy as ‘the study of written or symbolic representation that is mediated by new technology’. Others (Lankshear and Knobel, 2008) suggested a more broad view, defining digital literacy as ‘the myriad of social practices and conceptions of engaging in meaning making by texts that are produced, received, distributed, exchanged, etc., via digital codification’. Building on these definitions, Mein et al. (Mein et al., 2012) refer digital health literacy to ‘meaning-making with health texts mediated by new technologies’.

A recent report carried out for the EU on eHealth underlined the importance of digital health literacy as patients are playing a more active role in managing their health as well as their diseases (European Commission, 2012a). Furthermore, in the eHealth Action Plan 2012–2020, the role of digital health literacy in effective implementation of eHealth is highlighted (European Commission, 2012b). A survey on digital health literacy was carried out in 2014 in the 28 EU MSs (European Commission, 2014a) and 26,566 respondents from different social and demographic groups were interviewed. The survey assessed the extent to which Europeans already use the Internet and online resources to help manage their own health. Six per cent of respondents have used the Internet for searching health-related information in the last 12 months and over half said they did so at least once a month. This percentage is highest in the 25–34 years age group and then decreases steadily thereafter. General information on health-related topics, such as sports, diet and exercise, are the topics for which information is most often (55%) searched followed closely by information on specific diseases, injury or symptoms (54%). Eighty-nine per cent of respondents said they were satisfied with the information they found. However, 40% did not think the information came from a trustworthy source.

As the survey was conducted in the context of health literacy, people were asked also about their understanding of the information they found. Eighty per cent of respondents think that the health-related information they found online was useful; in addition, 9 out of 10 respondents agree that their research on the Internet helps them improve their knowledge of health-related topics. These results are in line with the results of the HLS-EU survey carried out in eight EU MSs, which showed that in general most people can easily find and understand information. Yet, appraising the information for relevance and applying it for further health-related action is perceived to be much more difficult (van der Heide et al., 2013; Sørensen et al., 2015). Moreover, health literacy does not only concern knowledge and awareness, but also consists of the ability for critical reflection and civic orientation to be able to act and navigate in the society and its systems (Peerson and Saunders, 2009).

THE ROLE OF EU POLICY TO IMPROVE HEALTH LITERACY

Previously, the concept of health literacy was primarily used in the context of healthcare. However, it is now being recognized as a policy priority by EU decision-makers and mentioned in public health and policy documents. The EC white paper entitled Together for health: a strategic approach for the EU 2008–2013 pointed out the necessity for policy efforts at the EU level as well as fundamental principles and values for EC action on health (European Commission, 2007). Citizens’ empowerment is highlighted as a core value because healthcare is becoming increasingly patient-centred and individualized, with the patient becoming an active subject rather than an object of healthcare. The document stated that ‘community health policy must take citizens’ and patients’ rights as a key starting point. This includes participation in and influence on decision-making, as well as competences needed for wellbeing, including health literacy’ (European Commission, 2007).

In 2014, the EC launched the programme Health for Growth in the context of the EU2020 strategy to increase productivity and to meet the challenges of an ageing population and chronic diseases (European Commission, 2011). Although health literacy is not explicitly mentioned in the EU 2020 strategy, one of the prerequisites for healthy ageing is a good level of health literacy. This has been shown to have an impact on the management of chronic conditions, productivity levels, mortality rate and overall healthcare costs (Broering et al., 2006; Gross et al., 2007; Nitri and Stewart, 2009; Institute of Medicine, 2011; Manafo and Wong, 2012).

The Vilnius Declaration: sustainable health systems for inclusive growth in Europe agreed to by health ministers during the Lithuanian Presidency of the Council of the EU calls on European governments and the EU to take immediate action to increase investment in health promotion and disease prevention. This should be done, among others, with ‘more investment in primary, secondary and
tertiary prevention as well as health literacy’ (The Vilnius Declaration, 2013).

The Riga Roadmap: investing in health and wellbeing launched by the Latvian Presidency of the Council of the EU in 2015 highlights the need for developing an effective health promotion and disease prevention agenda. It calls for a strengthening of the role of healthcare professionals, recognizing that healthcare workers play an indispensable role in educating patients and promoting health literacy, particularly in education and workplace settings. Furthermore, a regular HLS-EU needs to be implemented across all EU MSs to collect comparative data, as well as investment in health literacy interventions under various financial instruments (e.g. the Health Programmes or through the Structural Funds) (The Riga Roadmap, 2015).

Apart from the EC, the World Health Organisation (WHO), Regional Office for Europe, has recently paid attention to the health literacy challenge. A document published in 2012 stated that health promotion programmes based on principles of engagement and empowerment, including improved health literacy, can offer real benefits to the European population. It also emphasized the involvement of youth organizations and school-based health literacy programmes (WHO, 2012). A more recent publication, Health literacy: the solid facts, presents strong evidence for why policy action to address health literacy is needed and highlights a wide range of promising interventions to strengthen health literacy in Europe (Kickbusch et al., 2013).

CHALLENGES FOR HEALTH LITERACY IN EUROPE

Poverty and social inequalities
Low socio-economic status is a recognized risk factor for a low level of health literacy (van der Heide et al., 2013; Sørensen et al., 2015). There is a growing interest in the EU on the impact of low levels of health literacy on health and wellbeing and the relationship with inequalities in health outcomes. One of the five targets of the Europe 2020 strategy headline indicators is to reduce poverty by lifting at least 20 million people out of the risk of poverty or social exclusion by 2020. Deprivation, poverty and social inequalities are important factors associated with limited health literacy. In the EU-28, 16.7% of the population were at-risk-of-poverty in 2013 (Eurostat, 2015). This means that their disposable income was below their national at-risk-of-poverty threshold. Health inequalities within and between EU MSs persist and, in some cases, are increasing (WHO, 2014; Farrer et al., 2015). The economic crisis has exacerbated the health risks for disadvantaged population groups (McDaid et al., 2013; Quaglio et al., 2013).

Educational levels in the EU
Lower levels of education are a recognized risk factor for a low level of health literacy. The Europe 2020 strategy sets out a target of reducing school drop-out rates to <10% and increasing the share of the population aged 30–34 having completed tertiary or equivalent education to at least 40% by 2020 (European Commission, 2014b). Although the EU target for early leavers from education and training has been transposed into national targets by practically all MSs, the problem is far from being solved. In 2013, rates of early leaving varied dramatically across EU MSs. The lowest proportion was in Croatia, Slovenia, the Czech Republic and Poland with <6%; the share was highest in Spain, Malta, Portugal, Romania and Italy, with 17% or more (Eurostat, 2015). As far as the share of the population aged 30–34 that have completed tertiary or equivalent education is concerned, while 16 EU MSs (particularly from Northern and Central Europe) already exceed the overall EU target of 40% of tertiary graduates, others have still much work to do, particularly Romania and Italy, both countries having <25% having completed tertiary education of equivalent (Eurostat, 2015).

Health literacy and the elderly population
Health literacy affects the elderly disproportionately, especially in relation to utilization of medicines and contacts with health services. In the EU 28 MSs, the number of people aged 65 or above relative to those aged 15–64 is projected to increase from 27.8% (2013) to 50.1% (2060) (European Commission, 2015).

HEALTH LITERACY IN EUROPE: WHERE TO GO FROM HERE

According to the HLS-EU survey, roughly 50% of the population does not have enough health literacy in Europe (Sørensen et al., 2015). Based on this result, health literacy becomes a political matter, which cannot be neglected and EU decision-makers are starting to pay increasing attention to it. EU MSs do not make use of the same social models, but welfare states in Europe do share several broad characteristics and to have such low levels of health literacy is not acceptable. In 2010, the average percentage of GDP spent on social welfare protection in the EU was 29.4%, a large part of MSs governments’ costs (Needham, 2013). It is important to be clear when communicating with decision-makers what the dimensions of health literacy are and what it is that needs to be addressed (Kickbusch et al., 2013). Some recommendations to accelerate the integration of health literacy in actions across Europe are described below.
The level of overall literacy needs to increase and the level of social inequality needs to decrease to improve health literacy

Literacy is a social determinant of health: low literacy levels both directly and indirectly affect health status. Improving health literacy in the population is fundamentally dependent upon levels of literacy. Programmes to promote improved access to education, reduce early leaving from education and increase tertiary education would address this issue. Social inequalities require determined action at EU and also at national level (Allmendinger and von den Driesch, 2014).

Health literacy leadership across EU society

As many other aspects of public health, health literacy needs champions and leadership across society. In Europe, there are good examples that can be extended to all EU MSs (Dutch Health Literacy Alliance, 2015; Global Working Group on Health Literacy, 2015; Health Literacy Europe, 2015). Political champions at the European Parliament and national parliaments and local administrations are also important to inform colleagues about health literacy similarly to what is being done for other public health issues (European Patients Forum, 2015).

Patients need to increase their digital skills and access to broadband

In Europe, the number of mobile subscriptions exceeds the population in many countries (Ericsson Mobility Report, 2015). Thus, the role of the Internet as a source of health information continues to increase and it is important to carefully address all aspects of digital health literacy. When the above-mentioned survey on digital health literacy asked why people did not use the Internet to look for health-related information, 34% said that they do not have access to the Internet (European Commission, 2014a). This implies the requirement to provide access to broadband as well as to improve digital skills of citizens, particularly elderly and people with disabilities.

Regular comparative and longitudinal EU population studies of health literacy combined with economic analysis

Health literacy needs to be recognized as an indicator in the EU monitoring systems to ensure a continuous insight in the health literacy status of populations in the EU. For the future, it will be important for EU MSs to include health literacy in official health statistics and health reporting on a regular basis. A systematic approach to measuring health literacy levels in the population is also recommended. Furthermore, health literacy can be a valuable indicator for a health system’s performance along with economic analysis about the costs of limited health literacy in the EU.

Development of national and local policy strategies

To develop national and local strategies for health literacy can be a strong added value and some EU MSs have already moved in this direction. For example, in Wales, health literacy is an important part of the strategy to overcome inequalities in health, and Scotland has recently launched a national action plan for advancing health literacy (Welsh Assembly Government, 2011; Scottish Government, 2015). In 2013, Austria approved the first impact-oriented federal contract on health for the period 2013–16 (Bundes-Zielsteuerungsvertrag, 2013). Overall, the federal contract defines 12 strategic goals and stipulates, among others, the priority of enhancing the health literacy of the population (Hofmarcher, 2014). Ireland also provides other interesting experiences (NALA, 2009). Providing support through health literacy policies will enhance the related actions in the fields of research, practice and education.

Implementation of (complex) interventions

Overcoming the European health literacy gap revealed by recent surveys requires the expansion and testing of different types of interventions. In addition to healthcare settings, it will be crucial to work in schools, with specific disease groups and at community level. Health literacy services targeting the elderly population need to be better supported and strengthened. Related to this, there is a great potential for eHealth and mobile health initiatives which needs to be explored further.

CONCLUSIONS

Health literacy is a European public health challenge that cannot be neglected. However, recent research has shown that health literacy advancement is still at its infancy in many European countries. It is vital that the EC as well as EU MSs take the necessary steps to increase health literacy at individual, organizational, community, regional and national levels. There is a need to provide people with the possibility of making ‘healthy’ choices so as to have an active role in the protection of their health. People need to be aware of means to attain the necessary skills to manage their health. Patients need to be supported to survive in increasingly complex healthcare systems. They need to be educated to communicate effectively with health professionals and in turn health professionals must be able to communicate adequately with patients (Kickbusch, 2013). To accomplish these tasks, there is a need for systematic and sustainable integration of health literacy in healthcare services, outcomes and management. Strengthening the competence of people to manage their health, as well as improving health-literacy friendliness
of professionals and systems in general, will help generate the needed change.

CONFLICT OF INTEREST STATEMENT

The views expressed in this publication are the sole responsibility of the authors and do not necessarily reflect the views of the affiliated organizations.

REFERENCES


