

Consensus paper

Making health literacy a priority in EU policy

For quite some time health literacy has had a role on the European agenda and was mentioned in relevant policy documents. The European Commission's Health Strategy "Together for Health" mentions health literacy by linking it with the core principle of citizens' empowerment, highlighting that "healthcare is becoming increasingly patient-centred and individualised, with the patient becoming an active subject rather than a mere object of healthcare"ⁱ. To mention are the World Health Organization Regional Office for Europeⁱⁱ, the Luxembourg Declaration on Patient Safetyⁱⁱⁱ, and the European Parliament^{iv} and more recently, the Council Conclusions on Personalised Medicine.^v Notwithstanding these efforts, policy action to improve health literacy in Europe remains fragmented.

The European Health Literacy Study (HLS-EU), supported by the European Commission, has shown that limited health literacy is a challenge in several countries in Europe. On average, 47% of respondents have limited health literacy across eight countries^{vi} (i.e. Austria, Bulgaria, Germany, Greece, Ireland, Netherlands, Poland and Spain). The values for limited health literacy were 41% for health literacy related to healthcare, 43% for health literacy related to disease prevention and 51% for health literacy related to health promotion. The levels differ considerably between the countries surveyed. This shows limited health literacy is a problem not only for particular vulnerable groups, but also for the general population and society at large.

A follow-up mapping study commissioned in 2014 showed that although health literacy has gained interest in many EU Member States, in most of them it is only now starting to be addressed through policies or initiatives.¹

Health literacy fosters access to health and puts citizens and patients at the centre of health and healthcare. Including health literacy in EU policy (health and other relevant areas) as an overarching objective contributes to the overall objectives of EU's health strategy, which is to strengthen citizen's² role with regard to their health, to improve health outcomes and to reduce the growing burden on healthcare systems.

The Standing Committee of European Doctors (CPME), the European Patients' Forum (EPF), Health Literacy Europe, Maastricht University (UM), and Merck-Sharp & Dohme (MSD) have joined forces in a coalition to develop this Concept Paper on Health Literacy, which aims to **support a better understanding of health literacy among policymakers and key stakeholders, and highlight its value** for individuals, healthcare systems and society.³

What is health literacy?

Health literacy refers to the **capacity to make sound health decisions in the context of everyday life** – at home, in the community, at the workplace, in the healthcare system, in the market place, and in the political arena.^{vii} While several definitions exist concerning the term health literacy, we refer to the definition developed by the

¹ "Study on sound evidence for a better understanding of health literacy in the European Union". Final Report.

RfS Chafea/2014/health/01. June 2015. Available at http://ec.europa.eu/health/health_policies/docs/2015_health_literacy_en.pdf

² In this paper, the term "citizen" is used to refer to the French term "citoyen", which indicates the notion of self-responsible subject. This term is not limited to EU citizens only, but includes all people living in the EU.

³ The European Public Health Alliance (EPHA) and the Pharmaceutical Group of the European Union (PGEU) have been involved in the development of the paper too.

HLS-EU Consortium, which is based on a comprehensive analysis of 17 definitions and therefore it bridges multiple aspects attached to the concept of health literacy:

Health literacy is linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.^{viii}

In addition, a European Glossary on Health Literacy has been developed to guide translations of the term to European languages.^{ix}

What is the impact of health literacy?

High or low literacy levels have different impacts, notably on the individual's health and the efficiency of the health system. People with higher health literacy levels demonstrate healthier behaviours, are more adherent to treatment, report less chronic illness, feel healthier, and live longer.^x

Conversely, low health literacy is associated with reduced use of preventive services and management of chronic conditions, and higher mortality.^{xi} It can also lead to problems such as medication errors, misdiagnosis due to poor communication between providers and patients, low rates of treatment adherence, hospital readmissions, and other related complications or conditions^{xii}. It has been estimated that the costs of low health literacy may account for 3–5% of total healthcare costs at health system level.^{xiii}

The impact of health literacy is threefold: it enables the individual to understand information about his/her health; it enables a person to make informed decisions and act independently based on his/her knowledge; finally, it allows a person to reflect about and explore alternative health-related options.^{xiv}

Why is improving health literacy important for Europe?

Giving citizens and patients a greater role in healthcare through promoting health literacy is vital to address the challenges outlined in the European Commission's Europe 2020 strategy^{xv}:

- **Rise in chronic diseases:** The increasing prevalence of chronic diseases poses a challenge for health systems and specific population groups. Patients play a central role in managing their disease. More effective patient-centered prevention and health promotion strategies, including shared decision-making, self-care and better adherence to therapies, can not only mitigate the adverse effects of chronic diseases and increase the patients' quality of life, but also result in more efficient use of resources.
- **Demographic change:** The demographic change will not only increase the share of older people but also lead to a decrease in the workforce. To compensate this decrease in productivity it is necessary to improve health in the workplace, support people to work longer and foster skills such as empowerment and resilience.
- **Europe's competitiveness:** From a broader perspective, health is increasingly recognised as an important asset for companies and the economy as a whole. Compared to other regions, Europe's competitiveness has been decreasing. Health literacy can play a critical role in improving health in the workplace, which is an important factor for productivity.^{xvi}
- **Sustainability:** Chronic diseases and an older population may place an additional burden on healthcare systems, with expenditures likely to rise. At the same time, member states are currently seeking to make their health systems more sustainable. Health literacy supports citizens and patients to take an

active role in prevention and managing disease, hence contributes to increase the efficiency of healthcare systems and better correspond to the actual needs of the population.

- Persistent **health inequalities** across and within Member States undermine social cohesion and the common European values of equity, solidarity and universal access to good quality healthcare. The most vulnerable and marginalized groups are most affected by austerity measures. Health literacy has the potential to address health inequalities, especially through targeted strategies for marginalized or vulnerable groups.
- With the **emergence of new technologies**, citizens will face more complex health decisions. For instance, the progress in public health genomics and personalized medicine may mean that individuals will be required to collect information and understand the health issues that could affect themselves or their children. Also, future developments such as eHealth and mHealth will pose new ethical and information challenges and require a high level of health literacy of all citizens^{xvii}. The Green Paper^{xviii} on mHealth published by the European Commission in April 2014 highlights the importance of providing funding for mHealth to support the development of digital health literacy of healthcare professionals and citizens as a key to ensure equal access to healthcare. Finally, health information needs to be more easily accessible, understandable and controlled.

What is the role of the European Commission in health literacy?

According to the Treaty on the Functioning of the European Union, the European Union should play a critical role in improving public health through supporting health policy goals across the European Union and facilitating cooperation between Member States^{xix}. Health literacy can therefore play a key role in supporting EU health policy objectives and actions in other policy areas, such as employment and information technology.

Health literacy is not only relevant and beneficial to the three main healthcare areas, health promotion, disease prevention (incl. protection) and health care^{xx}. Moreover, promoting and improving health literacy in Europe helps to support Europe 2020's vision of a "smart, inclusive and sustainable growth", by helping to alleviate a number of financial and societal challenges across EU countries and putting citizens and patients at the center of the Union.

To achieve this, the European Commission (DG SANTE), alongside EU Member States and future EU Presidencies, should take the lead and engage in a reflection process with relevant stakeholders about a strategic approach to promote health literacy, as a means to improve the functioning of healthcare systems, the quality of life of patients and ultimately benefit society as a whole. It would also be important consider ways to include and address it in European and national policies. This would therefore require the European Commission to work towards:

- **Strategy:** Developing an overarching European strategy on Health Literacy that reflects on the critical role of health literacy for citizens and patients in health promotion, prevention, patient-centered care and care, as well as its impact on quality of life, productivity and the economy; adopting a working definition of health literacy to be used as a basis of EU level actions. We suggest that the definition used in this paper can be adopted as a common definition;
- **Targets:** Setting concrete targets, including areas for improvement, on health literacy levels across Europe;
- **Monitoring:** Developing a monitoring mechanism to assess health literacy levels across Member States based on lessons learned from the European Health Literacy Study and the input of relevant stakeholder groups, e.g. through the Eurobarometer.
- **Partnership:** EU actions on health literacy should include stakeholders from all the relevant sectors in order to have an inclusive and comprehensive approach. This also key in terms of subsequent dissemination and follow-up.

Moreover, ongoing activities in the field of health literacy should be leveraged:

- Ensuring health literacy is a cross-cutting priority in the new phase of the European Innovation Partnership for Active and Healthy Ageing (EIP-AHA)
- Providing EU funding and support for further research and projects on health literacy, including the costs linked to health illiteracy. In this context, allocating funding to a second European Health Literacy Survey that includes further Member States and to make it part of the Eurobarometer;
- Promoting investment in health literacy interventions under the EU Structural Funds. The European Commission should help support the work of the collaborative network Health Literacy Europe, notably by involving all interested stakeholders, in order to share best practices and provide a platform for collaborative ventures in Health Literacy.

To support the efforts of the European Commission in making health literacy a priority across the relevant policy areas, Member States should also play a significant role in working towards the inclusion and prioritisation of health literacy across its national policies in healthcare and beyond.

In conclusion, by forming part of European and national strategies and actions, health literacy can be a catalyst for citizen and patient empowerment. This in turn will have a positive impact on ensuring more efficient, appropriate and cost-effective measures for disease prevention, health promotion and treatment options, and therefore reduce the burden on healthcare systems, while ensuring better health outcomes for all European citizens.

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- ⁱⁱ WHO European Office (2012): Health 2020: a European policy framework supporting action across government and society for health and well-being. See http://www.euro.who.int/__data/assets/pdf_file/0009/169803/RC62wd09-Eng.pdf
- ⁱⁱⁱ European Commission (2005): Luxembourg Declaration on Patient Safety. See http://ec.europa.eu/health/ph_overview/Documents/ev_20050405_rd01_en.pdf
- ^{iv} This is seen through various initiatives: Parliamentary Question dated 3 December 2013 tabled by MEP Cristian Silviu Buşoi (ALDE) on *Patient safety aspects relating to the compounding of medicines* (<http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-%2f%2fEP%2f%2fTEXT%2bWQ%2bE-2012-010998%2b0%2bDOC%2bXML%2bV0%2f%2fEN&language=EN>); Parliamentary Question dated 20 December 2011 tabled by MEP Karin Kadenbach (S&D) on *Health literacy* (<http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-%2f%2fEP%2f%2fTEXT%2bWQ%2bE-2011-012042%2b0%2bDOC%2bXML%2bV0%2f%2fEN&language=EN>); amendments including references to health literacy to the Health for Growth Programme tabled by MEP Françoise Grossetête (EPP) on 21.05.12 (<http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//NONSGML+COMPARG+PE-489.545+01+DOC+PDF+V0//EN&language=EN>)
- ^v OJ C422-5, Council conclusions on personalised medicine for patients
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- ^{vii} See Kickbusch I and Maag D Health Literacy. In: Kris Heggenhougen and Stella Quah, editors International Encyclopedia of Public Health, Vol 3. San Diego: Academic Press; 2008. pp. 204-211
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- ^{xviii} European Commission (2014): Green Paper on mobile health ("mHealth"), <https://ec.europa.eu/digital-single-market/news/green-paper-mobile-health-mhealth>
- ^{xix} See OJ C115/123 (09/05/2008), Treaty of the Functioning of the European Union, Article 168; While health policy is in the remit of Member States the Commission can have a promoting role, Art. 168, 2: "Member States shall, in liaison with the Commission, coordinate among themselves their policies and programmes in the areas referred to in paragraph 1. The Commission may, in close contact with the Member States, take any useful initiative to promote such coordination, in particular initiatives aiming at the establishment of guidelines and indicators, the organisation of exchange of best practice, and the preparation of the necessary elements for periodic monitoring and evaluation."
- ^{xx} See the health literacy model in: Sorensen K et al. (2012), Health literacy and public health: A systematic review and integration of definitions and models BMC Public Health 12:80 doi:10.1186/1471-2458-12-80