

INT/874 Digital health literacy

OPINION

European Economic and Social Committee

Digital health literacy – for citizen-friendly healthcare in Europe in times of demographic change (Own-initiative opinion)

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	Own-initiative opinion
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(for/against/abstentions)	153/0/2

1. Conclusions and recommendations

- 1.1 The European Economic and Social Committee (EESC) endorses the European Commission's efforts to make Digital Health Literacy a high priority within the eHealth Agenda. The EESC recommends the development of an overarching EU strategy with clear and closely monitored health literacy targets to support people's rights in health and avoid inequalities through digital devices.
- 1.2 The EESC supports the results of the IC-Health project1; the recommendation to involve active citizens in these efforts is particular noteworthy. The EESC therefore recommends continuing implementation of the IC-HEALTH project in order to pursue the online training programmes already under way.
- 1.3 The EESC emphasises that different generations need different approaches for the improvement of digital health literacy, depending on their use of digital tools in daily life. Citizens of all age groups, cultures and types of impairments as well as migrants must be integrated into the development of digital information sources. The focus should be on people of the older generations who are increasingly addressed in the management of their own well-being and health care.
- 1.4 The EESC recommends widening efforts to include digital information about medicines and medical devices and engaging every organisation that might contribute. The EESC recommends establishing a link to the efforts made by the European Medicines Agency EMA, Heads of Medicines Agencies (HMA) and the European Commission.
- 1.5 The EESC supports the view that eHealth solutions should be used as cost-effective tools in healthcare systems. Attractive digital tools could increase people's openness towards digital media.
- 1.6 However, the EESC stresses that the advantages of digital services can only be fully leveraged if people are able to access and properly understand the information provided. Reading skills and a basic knowledge of mathematics are key prerequisites for peoples' health literacy and must be achieved during school education in order to empower people.
- 1.7 The EESC emphasises that the eHealth Action Plan needs to stimulate broad collaboration and cover people's entire life spans. At local level, the starting point of digital health literacy is in kindergartens and in schools. Childcare workers, teachers, parents and grandparents should develop initiatives to improve digital health literacy, together with relevant personnel in health services (e.g. doctors, midwives, nurses, pharmacists and carers). In particular the close collaboration between doctors (general practitioners) and pharmacists can help increase patients' health literacy. This experience must be incorporated into the further development of the action plan. An action plan to improve digital health literacy must be developed and implemented by the Member States.

¹ This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 727474.

2. Introduction

- 2.1 Digital information plays a growing role in society. Citizens' digital health literacy is an essential element for successful eHealth deployment. Health literacy is the ability to look for, understand, appraise and apply information related to health care, prevention or health promotion. This requires, on one hand, personal skills and, on the other, conducive framework conditions such as the provision of information in comprehensible language. These are the first steps; using the internet for this purpose requires additional skills.
- 2.2 Digital health literacy aspects can be described in a very pragmatic way: It is not so much a matter of finding information about health, rather than of finding out where to look for information, whether the information sources that are accessed give adequate and useful information, and whether the health information sources are reliable².
- 2.3 "Digital health tools" refers to digital services providing general health information for users, health applications (follow-up to and monitoring of treatment), tools that will help people stay in their own homes (remote monitoring for elderly people), shared medical files, digital tools for health professionals (secure messaging service, telemedicine, tele-expertise) and general digital health information.
- 2.4 In 2012, the European Commission published an action plan setting out the obstacles to the full use of digital solutions in Europe's healthcare systems. This plan is now being implemented under the title "eHealth Action Plan 2012-2020 Innovative healthcare for the 21st century"³.
- 2.5 The goals of this eHealth Action Plan were complemented in April 2018 by a "Communication on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society"⁴.
- 2.6 This communication cites the report on the State of Health in the EU⁵, concluding that only by fundamentally rethinking our health and care systems can we ensure that they remain fit for purpose. One of the pillars is the introduction of digital solutions for health and care. These digital tools can translate scientific knowledge into helping citizens remain in good health.

² https://ichealth.eu/wp-content/uploads/2018/10/ICH-FC_Final-Presentation_allDay.pdf.

³ COM(2012) 736 final.

⁴ COM(2018) 233 final.

⁵ State of Health in the EU "Companion Report 2017", <u>https://ec.europa.eu/health/state/summary_en</u>.

- 2.7 EU funding supports research and innovation in digital health and care solutions through the Horizon 2020 programme⁶ and public-private partnerships. In its mid-term review on the implementation of the Digital Single Market strategy⁷, the Commission set out its intention to take further action in three areas:
 - citizens' secure access to their own data and the sharing of health data across borders;
 - better data to advance research, disease prevention and personalised health and care;
 - digital tools for citizen empowerment and person-centred care.

In addition, Member States must be encouraged to develop mechanisms to identify and, as far as possible, remove websites with misinformation or to position trusted websites in searches so that they are displayed first.

- 2.8 The European WHO office published⁸ a very comprehensive overview of ongoing projects and their outcome in its WHO-HEN-Report-57. In their conclusion the authors state that central to health literacy is the development of skills through the life-course, including pre-school activities, formal instruction in schools and adult learning. They recommend policy considerations that could promote the development of holistic health literacy policies in Member States and the development, implementation and rigorous evaluation of policy-related activities to demonstrate the benefits of health literacy policies to citizens and society.
- 2.9 The European Commission has included programmes for enhanced digital health literacy in its research strategies and has also funded important projects under FP 7 and Horizon 2020⁹.
- 2.10 It is acknowledged that people with higher age and/or lower education have a lower digital health literacy. This impacts their involvement in their own health care and the ability to get access to health information. The IROHLA project provides solutions for the older generations¹⁰. The EESC¹¹ has already covered many aspects of e-inclusion (according to the Riga Declaration¹²).
- 2.11 The IC-Health project¹³ provides a huge amount of analyses and resources about digital health literacy. IC Health is a project to develop a series of Massive Open Online Courses (MOOCs) to help improve the digital health literacy of European citizens and to advance understanding of digital health literacy and how it can be used to improve health outcomes. The project results are currently being summarised.

⁶ COM(2011) 808 final.

⁷ COM(2017) 228 final.

^{8 &}lt;u>http://www.euro.who.int/___data/assets/pdf_file/0006/373614/Health-evidence-network-synthesis-WHO-HEN-Report-57.pdf?ua=1.</u>

^{9 &}lt;u>OJ L 347, 20.12.2013, p. 104</u>.

^{10 &}lt;u>https://www.age-platform.eu/project/irohla</u>.

¹¹ <u>OJ C 318, 29.10.2011, p. 9</u>.

¹² EU Ministerial Declaration on ICT for an inclusive society, Riga, Latvia, 11 June 2006, point 4.

^{13 &}lt;u>https://ichealth.eu</u>/.

3. **General comments**

- 3.1 The question of literacy and skills promotion becomes all the more prevalent against the background of the recognised societal challenge of demographic change. In order to maintain the sustainability of health and care systems, our rapidly ageing society requires extra-training of health and care staff, to ensure that their skills correspond to new needs, and optimal management of health expenditure, in addition to the advancement of digital literacy among the population at large.
- 3.2 The EESC supports the European Commission's activities to promote citizens' empowerment that concentrate on the transformation of the health system. However, the EESC is of the view that concurrently citizens need to be enabled to use these digital tools; an action plan for the improvement of both health literacy and digital health literacy needs to be implemented across the Member States.
- 3.3 Some European countries concerned about the results of the OECD¹⁴ comparative study have carried out their own studies. France (2004-2005) found about 3.1 million adults who were classified as functionally illiterate (9% of the working-age population). A study carried out in the UK in 2011 found that 14.9% (over 5 million) of British people are functionally illiterate. A study in Germany showed that 4.5% of German society in the age group from 18 to 64 are completely illiterate (no literacy skills). Functional illiteracy affects 10% of people in this age group. The total population of complete and functional illiterates is 7.5 million¹⁵. This fact must be taken into account when discussing digital health literacy.
- 3.4 The EESC emphasises that all professions in education, research and health need to collaborate. EESC members should promote this collaboration through their organisations. The goal of all efforts must be the increased, informed and relevant use of digital tools in all sections of society.
- 3.5 The EESC recommends referring to IC-Health results for further implementation of the EU Commission's E-health priorities for increased awareness of e-health solutions published in the April 2018 communication¹⁶. Horizon 2020 Europe¹⁷ should follow up actions and conclusions to be drawn from the project and use experience gained from the MOOCs.
- 3.6 It is important that citizens of all age groups, cultures and impairments be part of any process related to digital health literacy. In order to also gain the acceptance of health and home workers for changes in their work environment and to address their needs, the EESC advises including these groups too in the development of new digital tools. This includes the training and further education of nurses as well.

^{14 &}lt;u>http://www.oecd.org/skills/piaac/newcountryspecificmaterial.htm</u>.

^{15 &}lt;u>https://ec.europa.eu/epale/fr/blog/analfabetyzm-funkcjonalny-doroslych-w-krajach-bogatego-zachodu.</u>

¹⁶ COM(2018) 233 final.

¹⁷ COM(2018) 435 final.

- 3.7 The EESC acknowledges the Friends of Europe initiative to rethink the health system in Europe and develop ideas for "Smart (dis)investment choices in healthcare"¹⁸. The aim is to work towards the identification and discontinuation of ineffective measures in the health care system, thus ensuring that the extra funds available go towards making a difference in health outcomes.
- 3.8 The EESC supports the Friends of Europe concept of an empowering task force for healthy citizens across all age groups, with reference to the recommendations of the 2018 European Council on key competences for lifelong learning¹⁹. Individuals need to know about the "components of a healthy mind, body and lifestyle". This is a good basis on which to engage and activate citizens. Member States should regard this as a cross-cutting priority across education, health, social and employment policies, as well as a key mechanism to reduce healthcare costs and improve health outcomes. For instance, while closing down a hospital always leads to some backlash, it can sometimes be necessary if the institution is no longer cost-effective or fails to deliver promised care. Bringing in automation can streamline the process of organising care. For example, in a recent pilot at three UK-based hospitals, virtual assistants operated with artificial intelligence were eight times more productive in managing routine referrals and test results than medical secretaries.
- 3.9 Informed citizens take action to improve their own health. This leads to healthier lifestyle choices, higher vaccination uptakes, healthy ageing, increased adherence to treatments, and greater use of prevention of risky behaviours. Digital tools could therefore be useful in the area of therapeutic education, making people with chronic conditions more aware of their treatment.
- 3.10 The EESC²⁰ has already emphasised the importance of digital health literacy in the context of vaccination to enable access to and the processing of digital information on vaccines.
- 3.11 Digital services can in particular support low-skilled people (e.g. with reading problems and illiteracy), as well as visually impaired people if the information is provided via videos or podcasts. Also programmes for migrants with limited host-country language skills could be supported in this way. Appropriate measures and resources should be envisaged to enable these groups to have access to digital health tools.
- 3.12 People, regardless of their age and condition, need to be empowered to use these digital resources (websites, apps) to find the answers to their questions and manage their own health data (e.g. prescriptions supervised by health professionals, digital health data, digital information about their medicines etc.). For example, health funds should systematically educate their insured persons. Further action with regard to health insurance is covered in an EESC initiative²¹.

^{18 &}lt;u>https://www.friendsofeurope.org/event/smart-disinvestment-choices-healthcare.</u>

¹⁹ https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32018H0604(01)&rid=7.

^{20 &}lt;u>OJ C 440, 6.12.2018, p. 150</u>.

^{21 &}lt;u>OJ C 434, 15.12.2017, p. 1</u>.

- 3.13 School programmes and other educational efforts for children and adolescents should also be used to stimulate dialogue between generations. Projects such as the German Reading Foundation²² and others shall be identified in the course of this discussion.
- 3.14 The EESC suggests discussing whether general health information could be disseminated via employers. People often use digital tools at work. Training on the prevention of accidents in the workplace has become routine. This might be widened to health information.
- 3.15 The EESC reiterates its opinion that it is very important to train patients in how to access and use their own data, which currently in many cases is "locked away" in health information systems, as reinforced by the General Data Protection Regulation (GDPR)²³, and it is vital to include knowledge of eHealth in training programmes for health professionals²⁴.

4. Specific comments

4.1 Infrastructure

- 4.1.1 The EU Commission has launched several programmes to enhance technical infrastructure and allow cross-border interaction.
- 4.1.2 The survey results during the IC-Health project show in some cases, for example, that young people and other people with lower literacy levels may prefer mobile devices to web-based sources on the computer. The EESC proposes that these aspects be further explored and included in the considerations underlying future programmes.
- 4.2 The European Commission, EMA and HMA have initiated a process to establish key principles for electronic product information (ePI) about medicines²⁵. In many Member States databases with patient-friendly, regulator-approved ePI already exist. The importance of reliable ePI about medicines was already set out in detail by the EESC in "Towards digital health electronic information for safe use of medicinal products"²⁶. This approach and priority centred on the reliability of digital information should also include medical devices.
- 4.3 The EESC believes that this information may be used for the improvement of health literacy in addition to the sources discussed so far. Regulator-approved information about medicines should be considered, for example. These are needed to ensure continuously provided up-to-date information about medicines and treatments. The EESC believes that in this way the safe and effective use of medicines could be ensured, adherence to medication could be enhanced and the outcome of treatment optimised.

^{22 &}lt;u>https://www.stiftunglesen.de/</u>

^{23 &}lt;u>OJ L 119, 4.5.2016, p. 1</u>.

^{24 &}lt;u>OJ C 271, 19.9.2013, p. 122</u>.

^{25 &}lt;u>https://www.ema.europa.eu/en/events/european-medicines-agency-ema-heads-medicines-agencies-hma-european-commission-ec-workshop.</u>

^{26 &}lt;u>OJ C 13, 15.1.2016, p. 14</u>.

4.4 Need for further research

4.4.1 Technical research and technical development

4.4.1.1 The EESC recommends that synergies be explored through additional public-private partnerships involving people of all ages and backgrounds in order to design attractive digital information sources and other digital tools that keep pace with commercial digital information sources, social media and digital entertainment and can be used, for example, when measures proposed by the European Commission are implemented. These partnerships must work according to a charter on the reliability of data and the absence of conflicts of interest.

4.4.2 Educational aspects

- 4.4.2.1 Internet usage varies greatly between different social and age groups. Many use social networks but do not make use of the information available. A small group never uses the internet at all. In line with previous EESC initiatives²⁷, research should be launched to answer the following questions:
 - How can we encourage continuous active learning, on both how to access information and how to differentiate between reliable and unreliable digital sources, e.g. promoting IC-Health MOOCs? Mass support and training measures are needed to tackle this issue since 47 % of the EU workforce lack sufficient e-skills²⁸.
 - How can we make resources (e.g. entertainment methods) available that raise people's interest in making use of reliable digital sources of information?
 - How can we support the transfer of successful programmes? For example, see "Sophia"²⁹, an innovative health insurance tool in France for patients with diabetes or COPD (chronic obstructive lung disease), based on health coaching. The Sophia programme is inspired by foreign disease management experimentation in the US, Germany and the UK³⁰.
 - What role can the various educational institutions (universities, adult education centres, etc.) play in strengthening the many skills involved e.g., working with new technologies, getting involved and managing one's health in a socially beneficial way, and imparting social and technical expertise?
 - How can existing materials (e.g. regulator-approved information on medicines) be used?
 - How can we stimulate the exchange of knowledge and experience about health literacy and digital skills between the generations?
- 4.4.2.2 The IC Health project identified a new approach to learning, educational entertainment (EE):"In order to understand the process of attitude and behavioural changes, there is clearly a need for more controlled experiments to uncover the cognitive and/or affective factors that mediate

^{27 &}lt;u>OJ C 13, 15.1.2016, p. 14</u>.

²⁸ <u>OJ C 13, 15.1.2016, p. 161</u>.

²⁹ Name of the Joint Sickness Insurance Supervisory Service.

^{30 &}lt;u>https://www.oecd.org/governance/observatory-public-sector-innovation/innovations/page/sophia.htm.</u>

EE's effects" and for identifying the conditions under which EE narratives may or may not work.

- 4.4.3 Need for a broader health literacy strategy:
 - Health literacy is context- and content-specific. A Health Literacy strategy in Europe is recommended for supporting citizens' rights in health, including a focus on digital health literacy across a person's entire lifespan.
 - Digital health literacy combines digital abilities with health. Both capabilities require specific education and training.
 - A strategy and implementation plan is needed.
- 4.4.4 Need for equal access to the internet:
 - The digital world is only accessible to those with access to the internet. How can we close the digital divide in Europe, which excludes regions, islands and rural areas from access to the Internet, meaning that people in future will be excluded from access to digital healthcare? Europe and the Member States must make significant investments to guarantee Internet access to all if we want everyone to reap the advantages of these developments.
 - Many public services are web-based and require specific skills and resources to make use of them. A digital divide may enhance inequalities in European welfare societies.
 - Environments, settings, communities and cities can help facilitate open and free access to the internet for citizens to actively participate in society.
 - Public-private partnership can support the facilitation of free access to the internet for everyone in Europe.
 - Access to the internet is a human right when governments rely so heavily on digital services.

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