

**EUROPEAN
HEALTH PARLIAMENT**

EUROPE'S NEXT GENERATION OF HEALTH

COMMITTEE ON HEALTH LITERACY AND SELF-CARE

**MAKING EUROPE HEALTH LITERATE
BY 2025**

*Seven Actions to Promote Health Literacy and
Self-Care in the Digital Era*

#WeRun4Health

2018-2019

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DISCLAIMER

The views and opinions expressed in this book are those of the respective European Health Parliament Committees. They do not reflect the views of the individual EHP committee members, nor the views of their respective employers or of the partner organisations supporting the project. Their contributions do not imply endorsement of the specific policy recommendations.

ENDORSEMENTS

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A big thank you to: Ms Bhasuri Ariyathilaka; Ms Nicola Bedlington; Dr Andrew Bottomley; Ms Jacqueline Bowman-Busato; Ms Karin Kadenbach; Ms Eva Kaili; Dr Heidi Maurer; Dr Jany Rademakers; Dr Kristine Sorensen; Ms Valentina Stramiello; Ms Susanna Van Tonder.

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Last but not least, thanks to all the participants who responded to our online survey.

Kristine Sørensen

Director of the Global Health Literacy Academy, Executive Chair of Health Literacy Europe and President of the International Health Literacy Association.



"Health literacy is on the European health agenda. I am convinced that the efforts and recommendations of the Committee on Health Literacy and Self-Care of European Health Parliament will help us embrace the health literacy divide and to ensure we leave no one behind. A proper response from professionals and organisations in the healthcare field considers people's functional, interactive and critical health literacy. We shall meet people where they are and build on their capabilities by making health accessible, understandable, appraisable, and applicable for all. Yes, let us together make Europe health-literate by 2025!"

Jacqueline Bowman-Busato

Policy-Impact Lead, Self-Care Initiative Europe
Principal, Third-i



"The Policy-Impact arm of the Self-Care Initiative Europe is delighted to have collaborated on this year's European Health Parliament Health Literacy and Self-Care Recommendations. Digital health literacy is an important enabler for the embedding and uptake of self-care, particularly in upcoming digital native generations. The very thorough work of the European Health Parliament Committee on Health Literacy and Self-Care has not only usefully contributed to the policy dialogue, but most importantly proposed some concrete actions which will help realise tangible results across policy sectors as well as geographic scope in the EU Member States. We very much look forward to continuing our joint efforts to make self-care a reality along the continuum in Europe and a measurement of resilient health ecosystems, with digital health literacy as a core element for sustainable uptake of self-care."

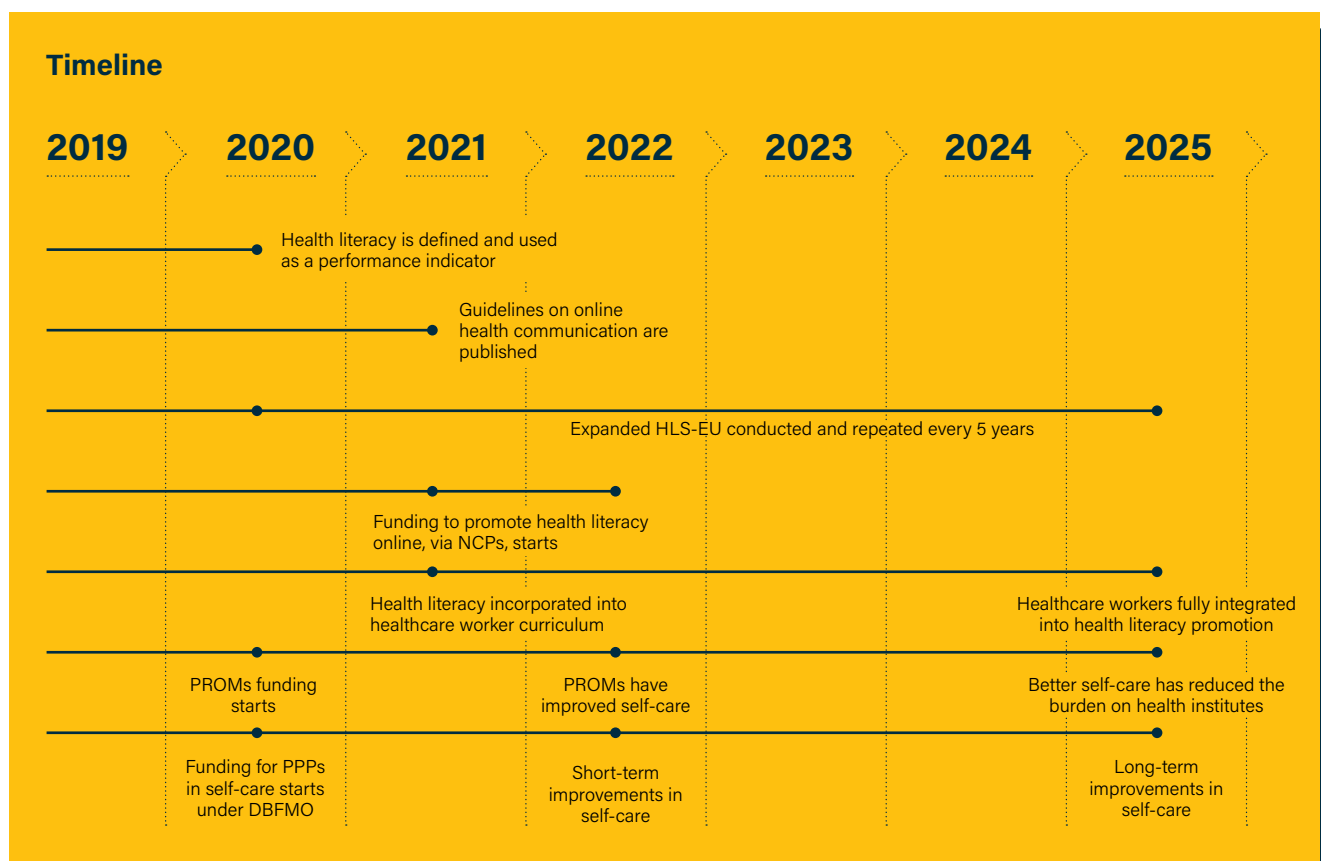
EXECUTIVE SUMMARY

Online health information is available almost anywhere, at any time, and is shared faster than ever. As consumers of health information in an increasingly digital world, we are faced with many challenges – where do we find reliable information and how do we appraise and apply it to prevent illness and promote self-care? How do we become more health literate and navigate the digital healthcare landscape?

In order to promote health literacy and self-care, the EU and its Member States need to work together to establish best practices for the accessible and reliable online communication of health information. This means implementing novel policies to improve:

- » **The availability of reliable health information via digital sources**
- » **Education of health professionals on health literacy, including digital aspects**
- » **Meaningful patient involvement in developing health literacy tools and methods**

Our seven policy recommendations are actionable, bring health policy into the digital sphere, and promote patient inclusiveness in their self-care.



INTRODUCTION

Citizens across Europe are continuously challenged to make healthy life choices, learn about their treatment options and understand their journey as patients. In order to do so, they need to be health literate. Health literacy is generally defined as people's knowledge, motivation and competency to access, understand, appraise, and apply health information in everyday life concerning healthcare, disease prevention and health promotion.¹ It is a key determinant of health, and lays the foundation for patient-centricity by enabling patients to play an active role in their own health and to consider their own self-care. Yet, close to 50% of the EU population reports below optimal levels of health literacy¹, with large discrepancies between countries assessed.²

An underexplored avenue to promote health literacy across the EU is digital media. In Europe, there are more smartphones than there are doctors per capita^{3,4} and a significant number of European citizens regularly consume health-related information via digital sources.⁵ However, the plethora of healthcare information freely available online may present complex and conflicting messages, making it hard to interpret, judge, and apply for self-care.⁶ A key example of this is the spread of vaccine hesitancy through social media.⁷

Some EU initiatives such as: IC-Health⁸ (Horizon 2020-funded initiative to improve digital health literacy of EU citizens); Eurobarometer survey (2014) on European's digital health literacy⁵; and the 2016 expert report on "Accelerating the Health Literacy Agenda in Europe"⁹ aim at addressing issues related to low health literacy. However, there are no existing EU-wide policies that focus on health literacy promotion via media and digital health.¹⁰

To align with the EU strategic health goals including the Europe 2020 strategy¹¹ and the eHealth Action Plan 2012–2020¹², to in turn promote good health among its citizens, an overarching EU strategy for health literacy is needed, with a specific focus on digital media.

"Health literacy is defined as people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in everyday life concerning healthcare, disease prevention and health promotion."¹¹



OUR APPROACH



In addition to expert consultation and a comprehensive review of the literature identifying the barriers to improving health literacy within the EU, the Committee on Health Literacy and Self-Care conducted an online survey asking European citizens about their understanding of health literacy; where they obtain relevant health information; whether they wish they could be more involved in the management of their health care; and what they think the EU could do to improve health literacy and promote self-care across its Member States.

The literature, consultation and survey results provided the framework upon which the Committee based our policy recommendations, which focus on three areas: (1) quality of information; (2) education and uptake of health literacy practices; and (3) patient-centred self-care.

"We developed an online survey and distributed it via social media channels. A total of 169 citizens (average age 28, range 18-64 years), from across 23 European countries responded. The results guided and informed this policy brief."

RECOMMENDATIONS



I. PRIORITISE HEALTH LITERACY AND SELF-CARE UNDER THE NEXT EUROPEAN COMMISSION

Adopt common definitions and include health literacy and self-care among the European Core Health Indicators (ECHI)

As Europe enters a new legislative term, it is paramount that all sectors employ the same definition of health literacy and self-care, as a continuum to enabling the sustainable embedding and uptake through all channels, including digital. We call on the European institutions to fulfil the following by the end of 2019:

- › Agree on common EU definitions of health literacy and self-care before the adoption of the next EU Strategic Plan.
- › Include health literacy and self-care as performance indicators in the list of ECHI.

II. QUALITY OF INFORMATION

As the volume and availability of health-related information is increasing, the poor reliability of this information makes it challenging to navigate. Improving the quality of this information and citizens' ability to critically assess it is therefore key. The Committee recommends the following policy actions to address this issue:

Establish guidelines for accessible and reliable online communication of health information

The Committee recommends the creation of a standardised set of best practice guidelines for effective health communication to the public. Conforming to these standards will be an easy indication to the public as to the reliability of a source's healthcare information as well as an appraisal method for expert reviewers.

The key components of these guidelines should check for accurate, evidence-based, up-to-date information, as well as language and format adapted for the lay audience. A similar self-certification method has been developed to promote best practices in the reporting of clinical research (CONSORT¹³), and epidemiology research (STROBE¹⁴).

The Committee recommends that the European Commission convenes an expert panel in early 2020 to develop these guidelines, which should be released and communicated by 2021.

European Core Health Indicators (ECHI) are a list of indicators that account for health and health systems overview across the EU. Some examples of ECHI are vaccination coverage in children, drug-related deaths, or hospital beds.²⁵

Promote and build on the European Health Literacy Survey

The European Health Literacy Survey (HLS-EU), first conducted in 2011 across eight Member States, revealed low health literacy and large discrepancies between countries. This is particularly evident in groups with a higher age and lower socioeconomic status¹⁵, which presents a public health challenge. An immediate and actionable solution is to expand the pivotal HLS-EU, in line with the following guidelines:

- › Expand the survey into all Member States;
- › Conduct the HLS-EU every five years to evaluate the effect of policy measurements;
- › Include questions on how citizens gather and assess health information;
- › Expand and adapt the survey for children and adolescents;
- › Adapt a digital version of the survey to cover a broader audience;
- › Add a section focusing specifically on digital health literacy;
- › Foster closer cooperation between the EU and WHO to strengthen health literacy measurement.

By supporting current efforts (e.g. Action Network on Measuring Population and Organisational Health Literacy (M-POHL Network¹⁶)), this initiative can have immediate impact by 2020.

III. EDUCATION AND UPTAKE OF HEALTH LITERACY PRACTICES

Although citizens are willing to actively improve their digital health literacy, the discussion remains largely within industry and expert circles¹⁷ and uptake across health professionals, doctors and the population remains a challenge. The Committee therefore recommends the following:

National Contact Points (NCPs) are independent organisations of different types (such as Universities, Ministries, etc.) based in all Member and Associated States. They provide multilingual support to citizens and aim to raise awareness on cross-border health care.²⁶

Leverage existing National Contact Points (NCPs) to promote health literacy online

The NCPs established in every Member State under the Cross-Border Healthcare Directive 2011/24/EU¹⁸, should be leveraged to support the uptake of health literacy via digital media by:

- › Training staff on the promotion of accessible and reliable healthcare information online as a means to increase health literacy and self-care, building on the guidelines referred to in recommendation #1 and local experience of the NCPs;
- › Strengthening cooperation and sharing of best practices on health literacy.

Funding to promote the above initiatives should be made available under Horizon Europe, Digital Europe and the European Social Fund+, as part of the upcoming Multiannual Financial Framework (2021-2027). An investment today would result in a sustainable output from 2021 onwards.

Develop health literacy as a professional skill in the health workforce

As new technologies are fast developing, providing adequate training and enhancing digital awareness for health professionals is crucial. Long-term investment in systemic changes such as educational programs for the health workforce will allow healthcare professionals to sustainably promote health literacy in their patients, across healthcare departments, for years to come. The Committee recommends that:

- › In collaboration with educational institutions and organisations within Member States, the European Agency for Health & Safety at Work develops and facilitates health literacy training for health professionals;
- › Healthcare professionals' curricula foster and incorporate evidence-based health literacy measurements and interventions;
- › The European institutions, in collaboration with national health literacy networks and Health Literacy Europe¹⁹, provide and facilitate digital platforms for knowledge exchange and knowledge transfer among the health workforce;

- › A centralised EU platform for sharing of existing and new health literacy tools, innovations and technologies among health professionals is established and funded by the European Commission.

IV. PATIENT-CENTRED SELF-CARE

Patient centricity lies at the core of health-related policies. The successful implementation and promotion of health literacy will empower patients and encourage the meaningful participation of citizens in health-promoting behaviour, resulting in the increased uptake of self-care and improved quality of care overall.

Create EU-wide standards in patient-reported outcome measures (PROMs)

Meaningful patient participation in health care improves health literacy and in turn, self-care. Digital health solutions using standardised PROMs will further promote self-care by monitoring of subjective outcomes (e.g. pain or depression). Achieving PROMs uniformity, together with advances in digital health, would promote the development of new health care models. These will translate into health benefits to EU citizens and greater economic efficiency and sustainability of EU health care systems

To reach PROM uniformity and avoid PROM-related data fragmentation, the Committee calls on the European Commission to form a “European Consensus Group on

Patient-reported outcome measures (PROMs) are self-reported questionnaires about health or quality of life. They can be used to monitor patients’ progress and allow for meaningful engagement in one’s self-care.²⁷

Patient-Reported Outcome Measures for Health Literacy and Self-Care”, a multinational, multi-stakeholder effort to include representatives from healthcare professionals, academics, patients, and industry.

This recommendation will immediately support the long-term initiatives to optimise PROM use. The expected long-term improvement in self-care will tangibly reduce the burden on healthcare institutes.²⁰

Establish public-private partnerships (PPPs) to facilitate a personalised approach to self-care using digital technologies

Co-creation of a personalised self-care plan using digital technologies for monitoring progress and care will become the norm in the years to come. Medical and technological advancements increasingly require people to manage complex medical tasks at home. Telemedicine (e.g. RENEWING HeALTH²¹) can reduce the burden on the health care system while simultaneously improving individuals’ health literacy and promoting self-care.

The Committee recommends that continuous funding under Digital Europe and Europe 2020 Strategy is made for PPPs, under the “Design-Build-Finance-Maintain-Operate” (DBFMO) contract²², for projects that will facilitate and promote the uptake of reliable digital health information by addressing patients’ individual needs.

Such PPPs allow the implementation of ambitious and highly impactful projects, by matching the resources of one stakeholder to the needs of another. This recommendation could therefore greatly improve self-care in Europe by 2025.



Our recommendations are actionable, bring health policies into the digital sphere, and put the patient in the driving seat by:

- › Securing access to reliable health information;
- › Promoting the education of health workforce;
- › And increasing meaningful patient participation.

CONCLUSIONS

A woman with dark hair and glasses is speaking into a microphone. She is wearing a dark jacket over a light-colored shirt. The background is a blurred indoor setting with vertical lines, possibly a stage or a conference room. The entire image has a blue tint.

Increasing health literacy improves citizens' health and wellbeing, decreases the burden on healthcare systems and reduces health inequalities.²³ Health-literate societies will therefore be healthier, prosperous, and more equitable.

Given that a vast majority of European citizens use the internet at least once per week,²⁴ digital health and media should become complementary tools to empower citizens and democratise healthcare across Europe. These policy recommendations set out to engage citizens, policymakers, healthcare professionals and other stakeholders in taking active steps to achieve the ambitious goal of making Europe health literate by 2025.

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