



HEALTH LITERACY IN CANCER PREVENTION

A guide for European Cancer Leagues

This guide has been developed within the BUMPER project by Work Package 5 members Silvana Romero Saletti, PhD and Professor Stephan Van den Broucke with the input and aid of the BUMPER consortium.

For more information about the project, visit bumper.cancer.eu



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List of abbreviations

BUMPER: Boosting the Usability of the EU Mobile App for Cancer Prevention

ECAC: European Code Against Cancer

ECL: Association of European Cancer Leagues

EU: European Union

HL: Health Literacy

HLS-EU-Q: European Health Literacy Survey Questionnaire

HLSQ12: Short form of the European Health Literacy Survey Questionnaire

BUMPER IN A NUTSHELL

The **BUMPER Project** is an EU-funded initiative focused on boosting the usability of the first **EU Mobile App for Cancer Prevention**. The project, coordinated by the Association of European Cancer Leagues (ECL), along with 14 partners in 11 countries, aims to enhance the design, development, and promotion of this app, which will disseminate the **European Code Against Cancer (ECAC) recommendations** to a broad audience.

The ECAC recommendations are at the centre of this app which provides educational content and features for behaviour change. This app is a key part of Europe's Beating Cancer Plan, designed to reach a wide range of individuals and families, providing them with evidence-based information on cancer risk factors and prevention strategies.

The project's main objectives include supporting the development of the app, engaging with potential users to ensure its effectiveness and ease of use, **training health promoters in digital health literacy**, and conducting pilot measures to promote the app to specific target groups in various countries. By working closely with potential users, the project aims to identify and address barriers to using the app, ensuring it meets the needs of diverse populations and effectively helps them reduce their cancer risk. Some key numbers about the project are presented below:



Training health professionals like yourself about **health literacy and digital health literacy** and your role in cancer prevention is crucial within the **BUMPER project** because it will help you to use and eventually promote the app effectively. By building the skills to understand and address health literacy challenges, you will be better able to engage with patients and the general public, tailor the information to their needs, and promote the app as a valuable tool for cancer prevention.

The training consists of two short guides: one on health literacy and one on digital health literacy. These guides were developed carefully considering the interests and needs identified in a needs assessment led by UCLouvain WP5 members within the

BUMPER project in 2023 with different cancer leagues¹, as well as insights and findings from related studies throughout the project. Ultimately, equipping you with this knowledge, contributes to the overall success of the **BUMPER project** and its goal of improving cancer prevention efforts. Your engagement with these tailored guides will help strengthen our collective efforts to make a positive impact in the realm of cancer prevention.

UNDERSTANDING HEALTH LITERACY

Health literacy (HL), defined as *the capacity to obtain, process, and understand basic health information and services that are needed to make appropriate health decisions*², is a fundamental component in preventive actions, the effective delivery of health initiatives, and shaping health outcomes. HL has many implications for health care, health education, and health promotion³ and is strongly correlated with the social determinants of health, health behaviours, and health outcomes¹. Therefore, it is increasingly recognized as a key issue in health care and public health and is addressed in current health and social policies.

In the context of cancer prevention, addressing low HL can lead to a better understanding of risk factors, increased participation in screening programs, and adoption of healthier lifestyles⁴. Paired with effective communication and community engagement, it becomes a key component of empowering individuals to make informed decisions about their health⁵.

This guide aims to provide you with a deeper understanding of health literacy, its status in Europe, and evidence-based strategies for addressing HL, specifically in cancer prevention.

Health Literacy Dimensions and Skills

HL is a multidimensional concept¹ or a **constellation of skills** and it applies to the three domains of the health continuum (health care, disease prevention and health promotion) in clinical and community settings. Besides *functional literacy*, which includes the basic skills of processing written and verbally transmitted information that is necessary to engage in effective communication in everyday life², four types of competencies are essential to enable a person to navigate the health continuum²:

¹Romero, S. & Van den Broucke, S. (2023). Baseline needs assessment with the members of the Association of European Cancer Leagues (ECL) to identify barriers and opportunities for implementation of the EU Mobile App for Cancer Prevention. BUMPER internal report.

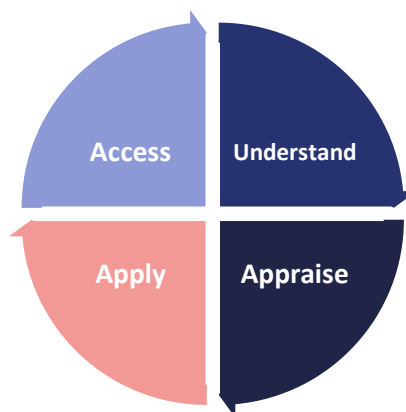
²Sørensen K, Van den Broucke S, Fullam J, et al. (HLS-EU) Consortium Health Literacy Project European. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health. 2012 25;12:80.

³Nutbeam D: Health literacy as a public goal: a challenge for contemporary health education and communication strategies into the 21st century. Health Promot Int. 2000, 15 (3): 259-267. Doi: 10.1093/heapro/15.3.259

⁴Ryman, C., Warnicke, C., Hugosson, S., Zakrisson, A. B., & Dahlberg, K. Health literacy in cancer care—A systematic review. European Journal of Oncology Nursing, 2024, 102582

⁵World Health Organization. *Community engagement: a health promotion guide for universal health coverage in the hands of the people*. World Health Organization. 2020.

1. **Access:** the ability to seek, find and obtain health information.
2. **Understand:** the ability to comprehend the health information that is accessed.
3. **Appraise:** the ability to interpret, filter, judge and evaluate the health information that has been accessed.
4. **Apply:** the ability to communicate and use information to make a decision to maintain and improve health.



Possessing these four types of skills enables people to acquire greater control of their health, different life events and challenging situations^{2,6}. As such, **HL goes beyond a set of functional capabilities such as reading or writing and entails a wide range of complementary skills and competencies that can be developed and built upon to empower individuals.**

While HL does not impact health directly, it impacts health promotion and health education constructs such as self-care, self-management, self-efficacy, problem-solving, decision-making, empowerment and specific health-related knowledge^{7,8}. Assessing these proxy measures of health-related outcomes is crucial when performing interventions, which can take many forms such as **education and disease management interventions, improving patient-provider communication, improving access to health information, and improving the usability of health-related systems and services**⁹.



BUMPER supports the development of the first EU App for Cancer Prevention and has made sure that It enables access to reliable evidence-based information, particularly the 12 ECAC4 messages.

Alongside educational content, it also allows the user to be aware on where they stand in their health journey and pursue personalized goals.

Therefore, this tool addresses health literacy and its multiple dimensions: access, understand, appraise and apply.

⁶Kickbusch I, Wait S, Maag D. Navigating health. The role of health literacy. London: Alliance for Health and the Future; 2005.

⁷Osborn CY, Paasche-Orlow MK, Bailey SC, Wolf MS. The mechanisms linking health literacy to behavior and health status. Am J Health Behav 2011; 35 (1):118–128.

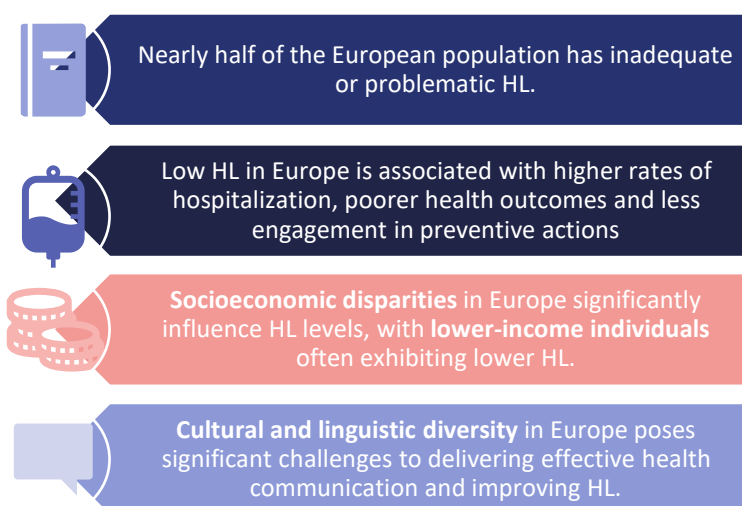
⁸Edwards M, Wood F, Davies M, Edwards A. The development of health literacy in patients with a long-term health condition: the health literacy pathway model. BMC Public Health 2012; 12:130.

⁹Stormacq, Coraline, et al. "Effects of health literacy interventions on health-related outcomes in socioeconomically disadvantaged adults living in the community: a systematic review." JBI evidence synthesis 18.7, 2020: 1389-1469.

Health Literacy in Europe: Key Challenges

Several studies at the European level^{1,10,11} have revealed that HL remains a public health challenge. Despite the efforts in the past decades in most countries to educate people on health-related issues and to promote health, a significant part of the population still has a limited or insufficient level of HL. Moreover, there is a substantial gap in HL across and between European countries.

One of the most pressing challenges is the **significant inequities** across diverse populations. Several factors including socioeconomic status, education levels, cultural differences and language barriers influence these inequities. Addressing them is crucial for ensuring equitable access to health information and improving health outcomes for all Europeans. The following figure shows the most pressing challenges for HL in Europe.



Applying clear communication strategies and techniques to promote health can help address the problem of low HL and reduce these disparities. Clear communication implies presenting familiar concepts, words, numbers, and images in ways that make sense for those needing the information, regardless of their HL level¹².

Health Literacy in Cancer Prevention

HL plays an important role in cancer prevention in various ways. For instance, it plays a role in **risk factor awareness, screening, early detection and making healthy lifestyle choices**.^{13,14} A high level of HL enables individuals to understand and act upon

¹⁰Sørensen, K., Pelikan, J. M., Röthlin, F., et al. Health literacy in Europe: comparative results of the European Health Literacy Survey (HLS-EU). *Eur J Public Health*, 2015; 25(6), 1053-1058.

¹¹Pelikan J, Link T, Straßmayr T. The European Health Literacy Survey 2019 of M-POHL: a summary of its main results, *European Journal of Public Health*, Volume 31, Issue Supplement_3, October 2021, ckab164.497, doi: 10.1093/eurpub/ckab164.497

¹²CDC. Talking points about health literacy. 2021. Retrieved from: <https://www.cdc.gov/healthliteracy/shareinteract/TellOthers.html>

¹³Morris NS, Field TS, Wagner JL, Cutrona SL, Roblin DW, Gaglio B, Williams AE, Han PJ, Costanza ME, Mazor KM. The association between health literacy and cancer-related attitudes, behaviors, and knowledge. *Journal of health communication*. 2013 Dec 4;18(sup1):223-41.

¹⁴Mazor KM, Rubin DL, Roblin DW, Williams AE, Han PK, Gaglio B, Cutrona SL, Costanza ME, Wagner JL. Health literacy—listening skill and patient questions following cancer prevention and screening discussions. *Health Expectations*. 2016 Aug;19(4):920-34.

information about lifestyle, environmental, and genetic factors that play a role in cancer. It is also associated with increased participation in cancer screening programs¹⁵, and it promotes the adoption of healthy behaviours that reduce cancer risk such as a balanced diet, regular exercise, avoiding tobacco, and limiting alcohol.

Within the **BUMPER project**, a recent survey led by the Foundation for the Promotion of Health and Biomedical Research of the Valencian Community (Fisabio) with the collaboration of all BUMPER consortium partners was performed with 2312 individuals above the age of 18 from 11 European countries¹⁶. Their **cancer prevention literacy** was measured using questions about cancer, based on the recommendations of the ECAC (4th Edition). The ECAC has been the main tool for cancer prevention plans and health promotion actions of the Cancer Leagues within the European Union (EU)¹⁷. One important result of the survey was that the majority of the sample did not know what the ECAC is. It is quite likely that many respondents know some of the ECAC messages separately, but do not know that they are part of a whole list of recommendations that belong to the ECAC. These results highlight the importance of continuing the work on promoting the ECAC as a whole and highlighting the less familiar recommendations. Along with the abovementioned challenges for HL, the survey results suggest that any actions to prevent cancer should focus on¹⁸:

1. Improving the quality of health communication that reaches diverse populations, especially by improving skills and providing support to health workers, cancer leagues, etc.
2. Enabling people to develop transferrable skills in accessing understanding, analysing, and applying health information.
3. Engaging with population groups that are disproportionately affected by low health literacy, ensuring priority is proportional to need.

The next section provides more insights on how this can be achieved within the Cancer Leagues.

ADDRESSING HEALTH LITERACY IN CANCER PREVENTION

As it has been argued throughout this guide, HL is an important aspect of cancer prevention and needs to be addressed. To take better account of HL in cancer prevention, preventative efforts should be focused on three aspects: organizational commitment, communication improvement, and community engagement.

¹⁵ Baccolini V, Isonne C, Salerno C, Giffi M, Migliara G, Mazzalai E, Turatto F, Sinopoli A, Rosso A, De Vito C, Marzuillo C. The association between adherence to cancer screening programs and health literacy: A systematic review and meta-analysis. *Preventive Medicine*. 2022 Feb 1;155:106927.

¹⁶ BUMPER WP4 Study on cancer prevention literacy. Non-published report.

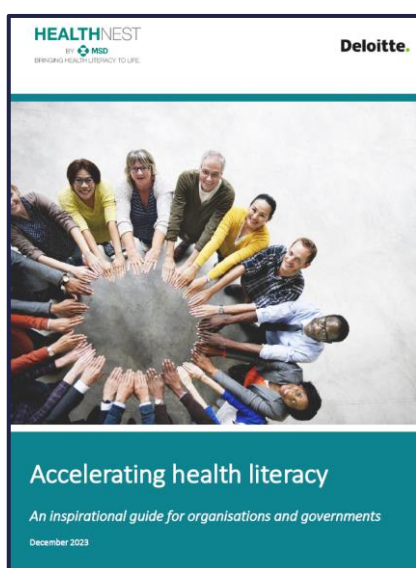
¹⁷ IARC (n.d) European Code Against Cancer, 12 ways to reduce your cancer risk – <https://cancer-code-europe.iarc.fr/index.php/en/>

¹⁸ Nutbeam D, Lloyd JE. Understanding and responding to health literacy as a social determinant of health. *Annu Rev Public Health*. 2021 Apr 1;42(1):159-73.

Organizational Commitment

Health literacy is not only the responsibility of individual citizens or patients but of the whole society. Organizations in health care and prevention can take a key role in this, **by committing to prioritizing HL in cancer prevention efforts.**

To that effect, leaders of organizations can allocate resources and establish measurable goals to better address HL and ensure sustained focus and accountability. This will help to develop and implement policies that integrate HL into the organization's cancer prevention strategies, including the provision of staff training on HL, focusing on improving their communication skills, cultural competence, and the use of plain language.



A good example of how organizations can include HL principles at their core is provided in the Health Nest guide *“Accelerating Health Literacy, an inspirational guide for organizations and governments”*. This guide includes information on the importance of on-record commitments to HL, raising awareness, measuring baseline HL, measuring impact, advocating for policies that prioritize health initiatives and equitable access to resources, and collaborating with other organizations to foster a healthier and more informed society.

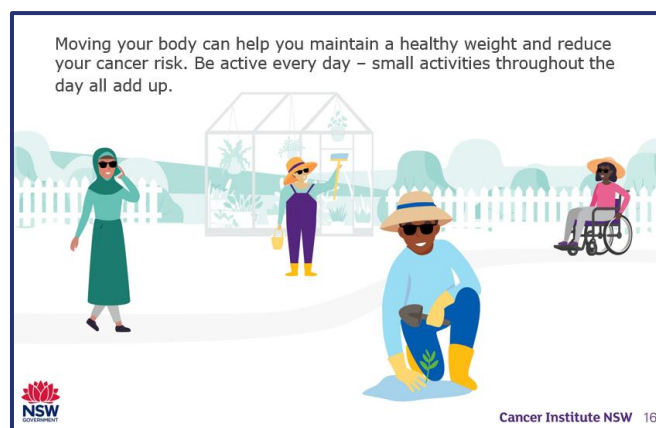
Source: <https://healthnest.be/en/>

Communication Improvement

Improving communication is a second strategy to address HL in cancer prevention. Some principles for effective communication in cancer prevention that incorporate attention to HL are the following¹⁹:

1. **Plain language:** Use clear, straightforward language in all communications with the community. Avoid medical jargon and complex terms that can confuse individuals, and make sure that written materials are at an appropriate reading level for the target audience. Using plain language is a recognized strategy for clearly communicating health information, both spoken and written, that addresses the HL needs of the general population and patients.

¹⁹ Simmons RA, Cosgrove SC, Romney MC, Plumb JD, Brawer RO, Gonzalez ET, Fleisher LG, Moore BS. Health literacy: cancer prevention strategies for early adults. *American Journal of Preventive Medicine*. 2017 Sep 1;53(3):S73-7.



Source: <https://rb.gy/544s83>

A good example of clear communication is provided by the Cancer Institute NSW, which developed the ***Staying Well and Preventing Cancer Flipchart*** to support health and/or community workers and educators. It addresses multicultural communities. Using simple text and illustrations to provide information on cancer prevention they target people with different HL levels.

2. **Use of visual aids:** Use visual aids such as diagrams, charts and videos to enhance understanding of cancer prevention information. Visual aids can make complex information more accessible and engaging. Videos and interactive tools also cater to different learning preferences. For instance, the abovementioned **BUMPER** study led by Fisabio found that the **preferred methods that individuals listed for receiving cancer-related information were: videos, FAQs, and infographics.**
3. **Use culturally relevant examples and images.** Being as inclusive as possible in the choice of images can help individuals identify with the content and feel included and motivated by the message.
4. **Teach-back method:** Studies have shown that between 40-80% of medical information shared by health professionals is forgotten immediately and that half of the retained information is incorrect²⁰. Implement the teach-back method to confirm understanding. Ask individuals to repeat information in their own words, which provides an opportunity to clarify any misunderstandings. For example: *"We covered a lot today and I want to make sure I explained things clearly. Could you please describe two things that you agreed to do to help you reduce your risk of cancer?"*.

²⁰ Kessels RP. Patients' memory for medical information. Journal of the Royal Society of Medicine. 2003 May;96(5):219-22.

Community engagement



Establishing partnerships is crucial for HL development. By collaborating with community organizations, it is possible to reach diverse populations. Engaging in community outreach programs to promote cancer prevention and health literacy can be very useful. As such, establishing channels for receiving feedback from the community and using such feedback to continually improve health literacy efforts and to ensure that communication strategies are effective and culturally appropriate is a powerful strategy.

PRACTICAL IMPLEMENTATION STEPS

The following steps can ensure that health literacy-based cancer prevention strategies within the Cancer Leagues render the expected results.



1. **Assessment:** Conduct a health literacy assessment within the communities you work with to identify areas needing improvement and at-risk populations. Use validated tools such as the European Health Literacy Survey Questionnaire (HLS-EU-Q) or its short form, the HLSQ12 to operationalize and collect data.
2. **Action Plan:** Develop a detailed action plan based on assessment findings. Set realistic and measurable objectives for addressing health literacy and enhancing cancer prevention awareness.
3. **Resource Allocation:** Allocate necessary resources, including budget, personnel and materials to support any initiatives to address health literacy within your cancer league. Ensure the sustainability of these initiatives through continuous funding and support.
4. **Staff Involvement:** Involve staff from all levels in planning and implementation to foster a sense of ownership and commitment. Encourage a culture of continuous improvement and learning within your cancer league.
5. **Monitoring and Evaluation:** Establish metrics to monitor progress and regularly evaluate the effectiveness of initiatives to address health literacy. Use both qualitative and quantitative data to assess impact and make necessary adjustments to enhance program effectiveness.

Although all this can seem difficult to achieve, sustained efforts to address health literacy will ultimately result in empowering individuals with the knowledge and skills they need to make informed decisions about how to prevent cancer. Introducing initiatives to address health literacy will allow us to bridge gaps in understanding, reduce health disparities and help individuals to take control of their health. These efforts will lead to a significant reduction in cancer rates and improve the quality of life for countless individuals.

FINAL THOUGHTS

Addressing health literacy is essential for effective cancer prevention. Cancer Leagues play a critical role in ensuring that communities understand cancer risks, screening guidelines and healthy lifestyle choices.

The ECAC is a valuable tool for cancer prevention and health promotion and the work done by cancer leagues to promote it is invaluable and is giving satisfactory results. Ensuring the knowledge and application of the ECAC recommendations is of vital importance, given that health literacy remains a challenge in Europe and has an impact on the health disparities that are still encountered within and between European countries.

By committing to the strategies outlined in this guide, health promoters and Cancer Leagues can address the challenge of low health literacy, reduce disparities, and ultimately improve cancer outcomes in their communities. **Let's take this opportunity to advance our mission and build a healthier future together!**