DIGITAL HEALTH LITERACY IN CANCER PREVENTION

A guide for European Cancer Leagues

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

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List of abbreviations

BUMPER: **B**oosting the **U**sability of the EU **M**obile A**P**p for Canc**E**r P**R**evention

DHL: Digital Health Literacy

ECAC: European Code Against Cancer

E-health: Electronic Health

HL: Health Literacy

HLS19-DIGI: Health Literacy Scale 19 Digital

M-POHL: Measuring Population and Organizational Health Literacy

mHealth: Mobile Health

WHO: World Health Organization

The Health Literacy (HL) guide, provided a foundational understanding of HL, emphasizing its significance in cancer prevention and outlining strategies for cancer leagues to enhance HL in their organizations and the population. It also touched upon the **BUMPER project**, highlighting how health literacy is a central theme in its efforts to support the development and boost the usability of the first **EU Mobile App for Cancer Prevention**. This guide delves deeper, focusing specifically on **digital health literacy (DHL)**.

In today's technology-driven world, information about health, health management, treatment and disease management is increasingly available digitally. This requires people to have the necessary digital skills to access and process this information. As a result, **digital health literacy** has become a key competence and an essential element of cancer prevention and treatment. This comprehensive guide will help you understand this concept, how digital tools and technologies can be leveraged to promote cancer prevention, the pros and cons of using mobile health apps, and the ways to adopt the app in your work.

UNDERSTANDING DIGITAL HEALTH LITERACY

Definition and Scope

Digital Health Literacy (DHL) refers to the ability to seek, understand, evaluate, and apply health information from digital sources to address health-related problems[1,2]. It involves a combination of multiple skills or "literacies"[2]:

Traditional Literacy

It refers to the basic (or prose) literacy skills such as the ability to read text, understand written passages, and speak and write a language coherently.

Information Literacy

Skills to identify, locate, evaluate, and effectively use information.

Media Literacy

Understanding how to interpret and critically evaluate health information presented in various digital formats such as videos, blogs, and social media.

[1] TNS Political and Social. Flash Eurobarometer 404 European Citizens' Digital Health Literacy. Brussels, Belgium: European Union; 2014.
[2] Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. J Med Internet Res 2006 Jun;8(2):e9

Computer Literacy

Proficiency in using computers and digital tools such as smartphones, tablets, and apps.

Scientific Literacy

This refers to the understanding of the nature, aims, methods, application, limitations, and politics of creating knowledge systematically, and placing scientific knowledge in context.

Health Literacy

The ability to comprehend health information and make informed decisions based on that information

While DHL shares core aspects of general health literacy, it also includes additional skills[3], such as the ability to use computers and smartphones to access information and interact with health providers, media literacy to use search engines such as *Google*, and information literacy to assess a variety of sources, as well as analytical and critical thinking to assess the credibility and relevance of the information that is accessed.

Why is DHL important in cancer prevention?

The digital age is changing how we approach healthcare in numerous ways. Smartphones and other mobile devices have made accessing information easy for people worldwide. Digital health services such as wearables, medical devices, and health apps have advanced and transformed the delivery of health information.

However, **using these technologies requires DHL skills to enable individuals to be empowered and to manage their health with autonomy**[4]. Regarding cancer, individuals with high levels of DHL are more able to access and understand relevant research findings, guidelines on preventing or managing cancer, and online support services, which can facilitate better communication between healthcare providers, cancer leagues, and the general public.

However, while digital transformations have an enormous potential to benefit population health, they can also exacerbate existing inequalities[5]. One of the challenges that must be addressed is **the digital divide that exists within and between European countries**[6]. Not only does access to digital infrastructure differ between

[3] Smith B, Magnani JW. New technologies, new disparities: The intersection of electronic health and digital health literacy. Int J Cardiol. 2019 Oct 1;292:280-282. doi: 10.1016/j.ijcard.2019.05.066. Epub 2019 May 28. PMID: 31171391; PMCID: PMC6660987.

[4] Robbins D, Dunn P. Digital health literacy in a person-centric world. International journal of cardiology. 2019 Sep 1;290:154-5.

[5] van Kessel R, Hrzic R, O'Nuallain E, Weir E, Wong BL, Anderson M, Baron-Cohen S, Mossialos E. Digital health paradox: international policy perspectives to address increased health inequalities for people living with disabilities. Journal of medical Internet research. 2022 Feb 22;24(2):e33819.

[6] Scheerder A, van Deursen A, van Dijk J. Determinants of Internet skills, uses and outcomes. A systematic review of the second- and third-level digital divide. Telematics Informatics 2017 Dec;34(8):1607-1624.

groups by age, sex, socio-economic status, education, place of residence and disability[7], but there are also significant discrepancies in digital health literacy.

In the context of the WHO-founded Action Network on Measuring Population and Organizational Health Literacy (M-POHL), the digital health literacy of 29,000 participants in 13 countries was measured using the HLS_{19}-DIGI[8]. A significant part of respondents, between 22% and 58%, found it difficult to find, understand, evaluate, and apply digitally available health information. On average, 8% of respondents (with percentages ranging from 2% to 18% for the different countries) found it **very difficult**, and another 25% found it **difficult** (with results ranging from 20% to 40%). **In terms of the determinants of DHL, the strongest predictors found were health literacy levels, financial deprivation, age and social status in society**, but this was not the case for all countries. **Older people, people who perceived their health as bad, and people with low education levels were the most vulnerable to having low DHL, confirming the findings of other studies**.

It is also worth noticing that **people with low DHL are more at risk of being excluded from health communication and information services**, are less informed about preventive services and how to access them, are more at risk of making decisions based on incorrect information and are less able to understand complex information[9]. Therefore conceptualizing, measuring and enhancing DHL is necessary, both at the professional level (i.e., among cancer league members) and the public level (i.e., among individuals).

Addressing DHL within the population can support you and other health providers and workers in three ways:

- **Efficient Workflow:** Increased DHL among patients and individuals can reduce the time that you spend on answering basic health questions, thus allowing for more focused or targeted interactions.
- **Enhanced Patient Engagement:** Engaged and informed patients are more likely to adhere to treatment plans or prevention recommendations, resulting in better health outcomes and patient satisfaction.
- **Data-Driven Insights:** Digital tools and apps can collect data that provide valuable insights into individuals' and patients' health evolution, aiding in personalized preventive and care planning.

M-HEALTH IN FOCUS

Digital health is a broad, interdisciplinary field that leverages technology to improve health outcomes, healthcare delivery, and wellness. It encompasses a wide range of

[7] van Kessel R, Wong BLH, Rubinić I, Czabanowska K. Is Europe prepared to go digital? Making the case for developing digital capacity: an exploratory analysis of Eurostat survey data. PLOS Digital Health (in press) 2022:1

[8] M-POHL - WHO Action Network on Measuring Population and Organizational Health Literacy. Digital Health Literacy. In: HLS19 International Report on the methodology, results and recommendations. 2021

[9] Busse TS, Nitsche J, Kernebeck S, Jux C, Weitz J, Ehlers JP, Bork U. Approaches to Improvement of Digital Health Literacy (eHL) in the Context of Person-Centered Care. International Journal of Environmental Research and Public Health. 2022; 19(14):8309.

tools, platforms, and systems designed to enhance the efficiency, effectiveness and accessibility of healthcare[10]. **E-health** falls under digital health and specifically refers to the use of Internet and related digital technologies to support healthcare delivery. This includes online health records, telemedicine, online health education, and patient portals. E-Health is a key component of digital health but focuses primarily on its delivery through the Internet.

M-health (mobile health) is a subset of e-health and digital health. **mHealth apps**, are applications designed for smartphones, tablets, and other mobile devices to deliver health-related services and information[11]. These apps cover a wide range of functionalities, including: tracking physical activity, monitoring symptoms, managing medications, providing educational information, facilitating communication with healthcare providers and promoting healthy lifestyles.

A recent review within the **BUMPER project** led by the Leibniz-Institut Fur Praventionsforschung Und Epidemiologie – BIPS[12], mapped interventions to enhance digital health literacy across diverse populations. Several interventions **targetting DHL via mobile apps or online platforms** carried out in America and Europe with varied populations (e.g. people with diabetes, HIV, cardiovascular disease, etc.), and different methodologies were found. Most of the interventions had positive and promising outcomes, including increases in DHL, self-management skills, and health-related behaviors. However, methodological limitations such as small sample sizes and a lack of control groups call the findings into question, and more rigorous study designs are needed. One important conclusion of this study was that future research should address gaps in sustainability, scalability, and the impact of DHL on health inequalities considering cultural sensitivities.

Ultimately, this review sheds light on the promising role of mobile apps in enhancing digital health literacy and supporting self-management skills across various populations, which could significantly contribute to cancer prevention efforts. They can play a significant role in empowering users to take charge of their health, making healthcare resources more accessible and personalized. By leveraging mHealth apps, individuals can stay informed, motivated, and engaged in their health management, contributing significantly to disease prevention and overall well-being.

However, for mHealth apps to be truly effective and equitable, they must account for the varying levels of health literacy and digital health literacy among users. These applications should be designed to be user-friendly, offering intuitive interfaces and clear, comprehensible information tailored to diverse populations. Ensuring wide accessibility is crucial, as it helps prevent the exacerbation of the digital divide, making sure that all individuals, can benefit from these health innovations.

[10] Smits, M. et al. "From digital health to digital well-being: systematic scoping review." Journal of medical Internet research 24.4 (2022): e33787.
[11] Pires IM, Marques G, Garcia NM, Flórez-Revuelta F, Ponciano V, Oniani S. A research on the classification and applicability of the mobile health applications. Journal of personalized medicine. 2020 Feb 27;10(1):11.
[12] Ahmed, F., Barrera, B., Christianson, L. … & Brand, T. Mapping Interventions to Enhance Digital Health Literacy Across Diverse Populations: Scoping Review. Manuscript under review.

In the BUMPER project we have been committed to making the EU App for Cancer Prevention as accessible as possible. The App will be made free for everyone, and people will be able to choose to use it in their local language, addressing some of the challenges that produce disparities in access to health information and resources.

Within the two pilots that we conducted to test the usability and functionality of the app, we strived to include people with varying levels of HL, DHL, age and educational levels.

mHealth apps are varied: some are broader in scope, others more focused, with different functionalities that tackle different individuals' and patients' needs. Some apps that are relevant to cancer prevention are:

Educational Apps

- These apps offer extensive information on cancer types, prevention strategies, treatment options, and recent research findings. Cancer.Net Mobile is a good example.

Symptom Tracking Apps:

- These allow users to log symptoms, track changes over time, and share data with healthcare providers. Apps like My Cancer Coach and CancerAid fall into this category.

Lifestyle management Apps

- Apps that monitor and promote healthy behaviors, crucial for cancer prevention are abundant, and normally focus on one behavior. Some examples, are QuitGuide (for smoking cessation), MyFitnessPal (for diet and exercise tracking), and Sleep Cycle (for sleep monitoring).

Screening and reminder Apps

- These apps remind users about regular screenings (e.g., mammograms, colonoscopies) and follow-up appointments.

Support and Community Apps

- Apps providing access to cancer support groups, patient communities, and counseling services. Examples include Cancer Support Community and CaringBridge

Pros, cons and applications of mHealth apps

In the following section, we will explore the pros, cons, and practical applications of mHealth apps, to provide a balanced view of these innovative tools, highlighting their potential to enhance healthcare delivery while also addressing the challenges they pose.

Some of the benefits of using and promoting a mHealth app among individuals and patients are[13]:

- **Accessibility:** Mobile health apps provide on-demand access to reliable health information, reducing barriers related to time, costs and location, especially for underserved communities.
- **Cost-Effectiveness:** mHealth solutions can potentially reduce healthcare costs by minimizing unnecessary hospital visits, streamlining administrative processes and improving disease prevention efforts.
- **Enhanced Chronic Disease Management:** mHealth applications are particularly effective in supporting the management of chronic conditions[14]. They can facilitate medication reminders, provide personalized health education, and allow for remote monitoring of vital signs.
- **Personalized Feedback:** mHealth apps can tailor health information and interventions based on individual needs, preferences and health data. This can lead to more effective and efficient healthcare delivery, making the advice more relevant and actionable.
- **Community Support**: Apps with community features allow users to connect with others who have similar health concerns, providing emotional support and shared experiences.

BUMPER supports the development of the first EU App for cancer prevention based on the European Code Against Cancer (ECAC). After collecting some information from the user, it will suggest tailored recommendations to reduce their cancer risk. The App is educational, it allows tracking lifestyle choices, reminders for screenings can be set, and information on support groups and local resources is offered.

mHealth holds great promise for revolutionising healthcare delivery, particularly in terms of accessibility and personalised care. However, some disadvantages of mHealth apps are[15]:

- **Privacy and Security Concerns:** mHealth apps require the collection and storage of sensitive personal health data, raising concerns about privacy breaches and unauthorized access.
- **Digital Divide and Access to Technology:** Not everyone has equal access to smartphones, internet connectivity, and digital health literacy skills, creating a digital divide that can limit the reach and effectiveness of mHealth solutions.
- **Usability:** Challenges related to the design and complexity of apps, which can be particularly problematic for elderly or less tech-savvy users.

[13] Messner, E., et al. "mHealth applications: potentials, limitations, current quality and future directions." Digital phenotyping and mobile sensing: New developments in psychoinformatics (2019): 235-248.
[14] Debon, R., et al. "Mobile health applications for chronic diseases: A systematic review of features for lifestyle improvement." Diabetes & Metabolic Syndrome: Clinical Research & Reviews 13.4 (2019): 2507-2512.
[15] Giebel, Godwin Denk, et al. "Problems and barriers related to the use of digital health applications: scoping review." Journal of Medical Internet Research 25 (2023): e43808.

- **Data Accuracy and Reliability:** The accuracy and reliability of data collected through mHealth applications can be influenced by user behaviour, sensor limitations (e.g. the app relies on sensors that do not measure the data accurately), and the quality of the app itself.
- **Lack of Standardization and Interoperability:** The absence of common protocols and systems that can work together makes it difficult to integrate mHealth data with other healthcare systems, leading to separate and disconnected data silos.
- **Regulatory and Ethical Challenges:** The use of mHealth raises complex legal and ethical questions about data ownership, informed consent, and the role of healthcare providers in the digital health ecosystem.
- **Limited Evidence of User Engagement and Effectiveness:** Sustained engagement can be challenging, with many users abandoning apps after initial interest declines. While promising, the long-term impact of mHealth on health outcomes and cost-effectiveness is still under investigation. For instance, a recent review within the **BUMPER project** led by the Centro di Riferimento per l'Epidemiologia e la Prevenzione Oncologica in Piemonte, CPO[16] looking into the effectiveness of mobile apps for promoting healthier lifestyles and cancer prevention, found that the evidence is inconsistent. While mobile health apps show potential in promoting health behaviors, their effectiveness can vary greatly depending on the specific health topic, user demographics, and app features. Further research is needed to consolidate findings, establish best practices, and develop tailored interventions.

These challenges need to be addressed through effective regulation, robust security measures, and thoughtful design focused on user engagement and equity for mHealth apps to be effective.

Why is having a mHealth app based on the ECAC an asset?

Having a mHealth app based on the European Code Against Cancer (ECAC) such as **the EU Mobile App for Cancer Prevention**, is a significant asset for several reasons:

- **Evidence-Based Information:** The ECAC is the gold standard for cancer prevention as it provides scientifically backed guidelines, ensuring that users receive accurate and reliable advice.
- **Comprehensive Approach:** The code covers a wide range of preventive measures, including recommendations on lifestyle, screening, and vaccinations, making the app a one-stop resource for cancer prevention.
- **Consistency with European Standards:** As the app follows European health standards, it aligns with public health policies, facilitating easier integration into existing health frameworks.

[16] BUMPER Work Package 3. Deliverable No D3.1. Scoping review report. Non-published report.

- **Trust and Credibility:** An app based on the ECAC has inherent credibility, making it easier to gain user trust and engagement.

HOW CAN WE ADOPT THIS APP?

As health professionals, staying updated with the latest technological advancements in healthcare can enhance your professional skills and knowledge. Familiarising yourself with mHealth apps, such as the EU Mobile App for Cancer Prevention, and including them in your daily work, can be beneficial. Some ways to implement this include:

Recommendations for the Cancer Leagues

- **Assess DHL**: Implement an assessment of DHL among cancer league workers to identify areas of improvement and train workers accordingly.
- **Integration into Programs:** Integrate this app or similar tools into current cancer prevention and patient education programs.
- **Hands-On Workshops:** Organise workshops focused on the hands-on use of the EU Mobile App for Cancer Prevention. Provide step-by-step guidance on setting up and navigating through the different app features.
- **Demo Sessions:** Arrange sessions where experienced users, such as tech-savvy healthcare professionals or patients, can demonstrate how they effectively use the app.
- **Technical Support:** Establish a support infrastructure to assist workers facing technical difficulties, and to answer their queries related to app usage.
- **Regular Updates:** Keep workers informed about the latest updates and changes to the app. Regular information sessions or newsletters can be effective.
- **Feedback Loop:** Encourage workers to provide feedback on the EU Mobile App for Cancer Prevention and any other mHealth apps they use. Regularly review and discuss this feedback to identify issues and areas for improvement.
- **Overcoming barriers:** Discuss the long-term benefits of using the app and provide success stories of health professionals and people who have used it.

Addressing low Digital Health Literacy

Low digital health literacy is a widespread problem as stated above. While addressing DHL should involve many stakeholders, such as governments, policymakers, educational institutions, and community organizations, tech companies and app developers are responsible for creating user-friendly interfaces and ensuring their tools are accessible to individuals with varying levels of digital literacy.

As cancer league members, you will likely encounter individuals with low digital health literacy in your daily work. You may encounter that these people have issues with

navigating webpages with cancer-related information, digital medical records, and using mHealth apps. In the case of eHealth resources, assuming that the web pages and tools are user-friendly and well-designed, a good approach could be to designate people within the organization who feel at ease with technology and to train them in the use of these tools. We call them *digihelpers*[17].

Digistarters, on the other hand, are people who need help, and might have some digital knowledge but need help to overcome some challenges when using applications. Some helpful advice on how *digihelpers* can approach *digistarters* are:

1. **Remember that many people are systematically excluded from digitalization:** When discussing the use of mHealth apps, it is important not to assume that everybody has the same digital background. There are many reasons why people have not developed DHL competencies regardless of their educational background or their age:

   - They never learnt digital skills at home, school or work
   - They resist due to fear of services not being safe
   - Technological developments go too fast and they can't keep the pace
   - Some of them have trouble in their daily life (e.g.with understanding governement communications, filling in forms, understanding public transport timelines)
   - Their environment is not digital. So they do not have internet at home, or a working computer

2. **Assess their current skills:** Ask some questions regarding their current app use (e.g. How frequently do you watch a video on YouTube?) and validate what they already know and are capable of doing. If the person does not use apps, ask why. Some of the most common reasons mentioned are:

   - They are afraid of technology and making mistakes
   - They do not dare to do it alone, have low confidence, or need constant reassurance that they are doing it well.
   - They have other people taking care of their digital challenges for them, so they do not learn to use it themselves.
   - They refuse to admit to themselves that they need help.

3. **Remember that this is a process:** Helping a *digistarter* requires patience, understanding and a positive environment, so it is important to establish a good rapport and a climate of trust, equality and respect. There are different

[17] Mediawijs. Débuter en tant que digihelper. Conseils pratiques pour accompagner les digistarters. 2022

ways to support someone so, adapt your behaviour according to the person in front of you. Transmit some of these messages accordingly:

"Many people are taking up this challenge and are not comfortable with the digital world".

"It makes sense that people who grew up in a non-digital age have more difficulty familiarizing themselves with digital technology".

"It is normal for people who have difficulty reading and writing to also have difficulties with digital aspects (since language plays an important role)".

"Developments in the field of technology are incredibly fast and it is difficult for everyone to follow the pace".

"Some applications and websites are not user-friendly, so it is normal to find them difficult to use".

"I will do everything in my power to help you and I myself don't know everything".

4. **Build Confidence:** Start with basic tasks (e.g., downloading the app and answering the questions after the welcome page) and gradually introduce more complex features (e.g., turning on notifications, setting goals) to build users' confidence in using technology. Celebrate each accomplishment. Every little step can mean a lot for a *digistarter*.
5. **Simplify the Learning Process:** Use simple language, clear instructions, and visual aids (such as screenshots of the app or videos) to guide them through the app functionalities. Pay attention to your language and your speed and be patient if the *digistarter* asks you to repeat a step. Adapt the speed to their skills. Introduce them to any words that they do not know gently (e.g., user account, badges).
6. **Take your time:** Let the *digistarter* express themselves and explain the issues they encounter, validate their feelings and let them know that if they have any questions, they can come back to you.
7. **Let the *digistarter* do recurring tasks by themselves:** You can give instructions, but it is essential that they perform the tasks on their device by themselves.
8. **Utilize Peer Support:** Pair digitally savvy individuals with those less familiar with technology for peer-to-peer learning and support.

FINAL THOUGHTS

As cancer league workers, enhancing digital health literacy and leveraging mobile health apps such as the **EU Mobile App for Cancer Prevention** can significantly contribute to your cancer prevention efforts. This guide has provided an in-depth understanding of digital health literacy, its importance, the utility of mobile health

apps, and strategies to motivate your organization and yourself to adopt these tools and engage other individuals. Embracing these technologies will transform how you support and approach the public, resulting in better health outcomes and empowered individuals and patients.

By incorporating digital health literacy into your daily practice, you can foster a culture of continuous learning and adaptation. Working together, we can bring the best possible resources and support to those we serve in the fight against cancer.

Remember, integrating digital health literacy into cancer prevention programs is not just about adopting new technologies, but also about creating an environment where healthcare workers, cancer league members, individuals, and patients are continuously learning and adapting. **Let's embrace this journey toward technological empowerment in healthcare!**