

Approaches to Promoting Patients' and Citizens' eHealth Literacy

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Abstract: eHealth Literacy (eHL) is of crucial importance in the increasingly digital landscape of healthcare. eHL is defined as the intersection of general health literacy and digital competencies, expanded to include new facets such as data literacy and privacy awareness. Current studies indicate that a significant portion of the German population has low eHL, leading to difficulties in evaluating online health information and challenges in accessing and utilizing digital health services, which correlate with lower health status. Various measures for enhancing citizens' eHL are proposed, including education, public awareness campaigns, and ensuring equal access to digital health services. Specific initiatives from the "MiHUBx" project are highlighted, such as developing a knowledge platform for patients and organizing information events focused on digital health topics. Fostering eHL is a societal responsibility that requires an inclusive and coordinated approach. Strategic efforts to this end are vital to ensure that all citizens can benefit from advancements in digital healthcare.

1 INTRODUCTION

In an increasingly digitalized world, access to healthcare information and services has changed tremendously. From online booking of medical appointments to the use of health apps and telemedicine, the digitalization of healthcare is rapidly progressing. These developments offer immense opportunities for improving healthcare, promoting a health-conscious lifestyle and thus increasing quality of life. However, the successful use of digital health solutions requires citizens to have the necessary digital health literacy (Dratva et al., 2024), also called eHealth Literacy (eHL). That means people have to possess a multifaceted set of skills that is fundamentally composed of general health literacy and digital competencies.

“people’s knowledge, motivation and competences 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” (Sørensen et al., 2012, p. 3). This definition takes into account not only the participation of individuals in healthcare but also their prevention and health promotion activities and considers HL to be a multidimensional concept (Pelikan et al., 2022; Sørensen et al., 2012).


2.2 Understanding Digital Competencies


There are various concepts that address the topic of digital competencies. One of the best known and most widely used is the European Reference Framework for Digital Competences (the so-called DigComp). According to its definition, “digital competence involves the confident, critical and responsible use of, and engagement with, digital technologies for learning, at work, and for participation in society. It includes information and data literacy,

2 E-HEALTH LITERACY

2.1 Defining Health Literacy

Relying on the European Health Literacy study (HLS-EU), Health Literacy (HL) can be defined as

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communication and collaboration, media literacy, digital content creation (including programming), safety (including digital well-being and competences related to cybersecurity), intellectual property related questions, problem solving and critical thinking” (Directorate-General for Education, 2019, p. 10). Sorko and Irsa (2019) define the term digital competence to include all the skills and abilities necessary to successfully meet the new demands brought about by digitalization. They refer less to an independent area of competence, but rather to a content-oriented classification. Accordingly, the term encompasses specific digital technical, methodological, social and personal competencies (Sorko & Irsa, 2019). This approach emphasizes the practical and contextual orientation in the application of the concept of competence.

2.3 The eHealth Literacy (eHL) Concept

eHL is a multidimensional concept that incorporates the two areas of competence described above. Put simply, eHL refers to the ability to find, understand, evaluate and use digital health-related information (Norman & Skinner, 2006).

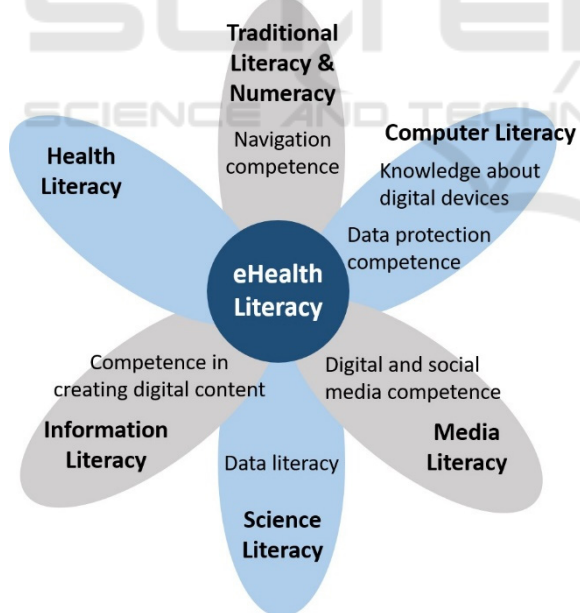


Figure 1: Lily model (adapted from Norman and Skinner, 2006) expanded with new facets according to Dratva (2024). Bold font: original Lily model competencies, regular font: conceptually additional digital skills; grey filling: analytic literacy skills, blue filling: context-specific literacy skills.

According to Norman and Skinner's Lily model (Norman & Skinner, 2006), as shown in Figure 1, eHL includes six core components that can be divided into analytic literacy skills, which are generically applicable to several sources and situations, and context-specific literacy skills, focused on specific issues, problem types, and contexts.

Since digital information is no longer just consumed but also produced, provided, and shared among individuals, more recent concepts also take this aspect into account (Dratva et al., 2024; Nutbeam & Muscat, 2021). They recognize additional important digital skills as part of eHL and have consequently expanded the original Lily model to include these facets. According to them, eHL also describes, for instance, the ability to decide what information you want to share with third parties and how you want to handle your own health data that is collected in an app (data literacy and data protection and information privacy literacy).

The systematic imparting of all the skills mentioned above is essential to enable patients and citizens to meet the new requirements of the digital age and to exploit the full potential for promoting and maintaining their own health in the context of the digitalization of the healthcare system.

2.4 Current State of eHL in Germany

Research reveals that eHL is often low at an international level and that large parts of the population have difficulties in dealing with digital health information (Schaeffer, 2021). Studies also show that a high level of eHL goes hand in hand with increased use of the internet and digital information services (Schaeffer, 2021). As one of the first comprehensive studies on eHL in Germany, the second Health Literacy Survey Germany (HLS-GER 2), which is part of the “Health Literacy Population Survey” (HLS19) of the “WHO Action Network on Measuring Population and Organizational Health Literacy” (M-POHL), examined this facet alongside general HL (Schaeffer, Berens, et al., 2021; The HLS19 Consortium of the WHO Action Network M-POHL, 2021). The survey was conducted using paper-assisted personal interviews with a nationally representative sample of over 2,000 participants. The results indicate that a very large proportion of the German citizens - over three quarters (75.8%) - has a low level of eHL (Schaeffer, Gille, et al., 2021). The eHL of the population in Germany is therefore significantly lower than general HL (58.8% have only low health literacy) (Schaeffer, Berens, et al., 2021). The most difficult aspect for respondents is, by far,

assessing the trustworthiness and neutrality of digital health information. The opaque coexistence of serious and dubious information in online information channels seems to make handling digital information extremely challenging nowadays (Dratva et al., 2024). This is not specific to Germany. The other 13 countries that surveyed eHL in the HLS19 reached the same conclusion (The HLS19 Consortium of the WHO Action Network M-POHL, 2021).

In another empirical study conducted as part of a panel survey with a population-representative sample of 8,500 adults living in Germany, 52.4% of the participants showed limited eHL (Zeeb et al., 2022). It should be noted that all participants in this study were recruited and surveyed online, so it is not representative in terms of internet use. Although both studies used the Digital Health Literacy Instrument DHLI (van der Vaart & Drossaert, 2017) to measure eHealth literacy, the version of the questionnaire used in this case contained twice as many items (21 items) as the HLS-GER 2 (ten items). The study authors attribute the difference from the results of the HLS-GER 2 study to the different participant groups and evaluation strategies, pointing to the limited comparability between the two studies. However, both studies concluded that users have great difficulty in evaluating the quality of the online information they encounter. Additionally, Zeeb et al. (2022) found that a poorer health status was statistically significantly associated with lower eHL.

2.5 The Importance of Enhancing eHL

The above-mentioned survey results underline that there is an urgent need for action to strengthen eHL in the general population. The consequences of a lack of eHL can be far-reaching: inadequate use of digital health services, misinformation and even adverse health outcomes are possible consequences. Without sufficient eHL, citizens cannot take full advantage of digital health services and are more vulnerable to health information of dubious quality. Improving eHL is of central importance for several reasons:

1. Improved access to health information and services and participation in health decisions: High eHL enables citizens to find and evaluate quality-assured health information on the internet, actively participate in medical decision-making processes, and better understand their own health decisions (German Federal Ministry of Health, 2022). This could increase self-efficacy and decision-making ability in health matters (Farley, 2020).

2. Reduction of health inequalities: eHL can help reduce health inequalities by enabling all population groups to access digital health information and services (Dratva et al., 2024). Digitally competent citizens can better utilize digital health services, which can contribute to improved healthcare, particularly in rural areas and underserved communities.

3. Promotion of a healthy lifestyle, prevention, and early detection: Competent use of health apps and wearables allows citizens to actively monitor and promote their health (German Federal Ministry of Health, 2022), contributing to disease prevention and early detection, and potentially leading to a long-term reduction in chronic diseases.

4. Increased efficiency in healthcare: Citizens with high eHL could relieve the healthcare system and contribute to cost efficiency by utilizing digital health services.

5. Promotion of medical research: According to a population-representative survey, more than 86 percent of Germans would agree to the use of health data for publicly funded medical research without individual consent (Richter et al., 2024), provided that data usage and access are legally regulated and adequately controlled. However, more than two thirds of respondents wanted a larger supply of information on medical research with health data in order to make an informed decision about whether to participate in data donation. An opt-out regulation (the omission of case-by-case consents) thus requires expanded information offerings to strengthen health data literacy and trust in medical research (Richter et al., 2024).

2.6 Possible Measures to Strengthen eHL

To generally strengthen eHL in the population, targeted measures are necessary. These should be implemented at various levels. The following exemplary list provides an initial overview of promising starting points and is intended to serve as a source of inspiration. How the recommended measures can be implemented in practice would have to be worked out in detail with the relevant social, political and medical players.

1. Education and training: Development and implementation of educational programs that train citizens in the use of digital health services and in dealing with digital health information. Media and health literacy should already be systematically linked and specifically promoted in the school setting (Bittlingmayer et al., 2020).

2. Enablement through healthcare providers: Healthcare providers should be actively involved in teaching digital health skills to their patients (Konstantinidis et al., 2022). This can be done through training, information events and the provision of easy-to-understand digital resources.

3. Low-threshold offers: Develop, promote and publicize low-threshold, easily accessible offers such as free online courses, tutorials and mobile apps that are specifically tailored to the needs of different target groups (e.g. adapted to age, occupational group, medical condition and/or skill level).

4. Public awareness: Implementation of multimedia education campaigns to raise awareness of the importance of eHL, promote the critical use of health information on the internet and social media and motivate citizens to upskill (German Federal Ministry of Health, 2022).

5. Research and evaluation: Promoting research on eHL, particularly on how people receive their health information and how they prefer to be informed or get access to information in the future, and continuously evaluating measures to strengthen eHL in order to assess and improve their effectiveness (Dratva et al., 2024).

6. Access to digital health services: Ensuring that all citizens have access to digital health services, regardless of their social or economic status (Dratva et al., 2024).

Taking the last point as an example for providing some insights into how the measures could be realistically implemented in practice, here are some more detailed ideas how to support equal access to digital health services:

Improving Infrastructure

- Ensure nationwide access to the internet by expanding broadband and mobile network infrastructure, particularly in rural and economically disadvantaged regions.
- Provide free internet access, for example, by offering complimentary Wi-Fi in public facilities such as libraries, schools, and hospitals.

Reducing Financial Barriers

- Offer subsidized digital devices through programs that provide low-income households with affordable or free tablets, smartphones, or computers.
- Ensure that essential digital health services and applications are free of charge or covered by the healthcare system.

Promoting Education and Training

- Enhance eHL by integrating training on the use of digital health services into programs offered by adult education centers, employment agencies, and social organizations.
- Provide individual support by establishing contact points where citizens can receive technical assistance and guidance, such as through "eHealth hotlines" or on-site services in community centers.

Ensuring User-Friendliness

- Develop accessible digital health solutions that are user-friendly and inclusive, ensuring they are easily usable for individuals with disabilities or limited digital skills.
- Offer multilingual health services and information to facilitate access for migrants and refugees.

Establishing Political Frameworks

- Create a legal framework that enshrines the right to access digital health services in the Social Code.

These measures can help to ensure that all citizens in Germany, regardless of their social or economic background, have access to digital health services, which is essential for systematically fostering eHL across the population.

2.7 Initial Approaches to Strengthen eHL in the German Population as Part of the Project "MiHUBx"

The digital progress hub "Medical Informatics Hub in Saxony" (MiHUBx), funded by the German Federal Ministry of Education and Research, aims to make healthcare data from routine care accessible for research purposes and strengthen collaboration in healthcare (MiHUBx, n.d.). To this end, the German medical informatics initiative is establishing a digital infrastructure with processes and tools that will enable healthcare facilities to make routine data available for research. To ensure the usability of this digital infrastructure, measures are being devised and implemented to promote the acceptance of the project's digital solutions developed and to enhance digital competencies. This includes enabling patients to gain a better understanding of digitality in healthcare and thereby increasing overall acceptance of digital applications in this context. To this end, various measures have been implemented or initiated to date, including the following:

2.7.1 Digital Knowledge Platform for Patients and Citizens

The aim of strengthening digital (health) competencies in the population is to be achieved, among other approaches, with the help of a knowledge platform embedded in the MiHUBx project website, which is currently being developed (Grummt et al., 2024). The information webpages for patients and citizens can be accessed at <https://mihubx.de/wissen-patienten/>. Patients are currently supported by the web subpages in strengthening digital competencies by providing them with information on topics such as health data, digital medicine, and corresponding applications. General information on digitalization in the healthcare sector is presented in layman's terms in the "Grundlagenwissen (Basic Knowledge)" section. In the "Digitale Kompetenz (Digital Competence)" section, users are informed about how they can assess the quality of health information on the internet and are provided with corresponding checklists and guidance. The HLS19 and HLS-GER 2 studies have shown that most people find it difficult to assess the content of digital health information (Schaeffer, Gille, et al., 2021; The HLS19 Consortium of the WHO Action Network M-POHL, 2021), which is why we want to support them in this important aspect. Additionally, the "Gesundheitsportale (Health Portals)" section offers a comprehensive compilation of valid health information sources and websites with information on topics such as digital health applications, data protection and security. The "Weiterbildungen (Education)" section refers to numerous free educational offerings for target groups such as patients and citizens with a focus on (digital) health, data (literacy), and artificial intelligence. Under "Podcasts", our podcast recommendations offer knowledge to listen to on current topics in healthcare, digitalization in medicine and general medical knowledge. A comprehensive "Glossar (Glossary)" explains technical terms from the fields of digital medicine, medical informatics, and digitalization. The knowledge webpages for patients provide a wide range of information and educational resources on digital health, all in one digital location. This is intended to increase acceptance of and participation in the digital transformation of the healthcare system. Incidentally, the next step will be implementing knowledge pages tailored specifically to the needs of physicians and medical staff.

2.7.2 (Online) Events for Patients and Citizens

To strengthen the eHL of patients and their relatives, (online) events are designed and conducted that provide an overview and education on digital health topics and offer opportunities for skill development. For example, MiHUBx took part in the 21st Dresden Science Night in June 2024, a format where scientific topics are introduced to the general public in a playful, accessible manner. Visitors to our stand were able to get an all-round view of the topics "digital medicine", "artificial intelligence", "use of patient data for medical research and broad consent" and "work of a data integration centre" using interactive offers and leave their opinions on an opinion board. The participants experienced a high level of openness and interest from visitors leading to insightful discussions.

In November 2024, we hosted an event on digitalization and data usage in healthcare for patients and interested parties in collaboration with the Complex Regional Pain Syndrome (CRPS) Patient Network. In meetings with board members of the network, we discussed which digital health topics are particularly relevant and interesting for CRPS patients, and developed a corresponding agenda. In an interactive online format, with a mix of lectures, discussions, and Q&A sessions, topics such as the electronic patient record (basics and access management), handling health data, as well as digital health applications and support options for CRPS have been addressed. The participants asked many questions and reported on their previous experiences in dealing with personal health data, which led to several interesting discussions. Unfortunately, we had to end the event after more than two and a half hours (two hours were originally planned), but based on the questions and the need for discussion, it could certainly have lasted even longer. Our aim is to continue organizing similar themed events for various patient organizations and networks.

2.7.3 Informational Flyers in Plain Language

In an analogue format, we provide patients and citizens with information about health data and its secondary use for medical research through informational flyers in plain language. These flyers are designed to help individuals understand complex topics, such as data donation, privacy protections, and the benefits of health data usage for medical research, in a straightforward and accessible way. By

addressing common questions and concerns, the flyers aim to build trust and promote transparency regarding the use of health data in research.

To further support digital health literacy, additional flyers are being planned on topics such as the electronic patient record or digital health applications.

With these resources, we aim to provide patients and the wider public with the knowledge they need to make informed decisions about their health data and the use of digital health services and applications.

3 DISCUSSION AND CONCLUSION

We are aware that our current offerings only reach a fraction of the population and are likely primarily targeted at those who already possess higher levels of eHL since digital competencies are a prerequisite for assessing online information and participating in online activities. Events on (digital) health are probably predominantly attended by individuals who already have a foundational level of HL and potentially some scientific knowledge. The major challenge is reaching those whose eHL is particularly low and who less frequently take advantage of digital health-related information opportunities. According to the findings of the HLS-GER 2 study, these individuals are primarily the ones with lower general HL, older adults (65+), individuals with lower literacy skills, lower educational levels, and/or lower social status (Schaeffer, Gille, et al., 2021). Strengthening eHL is thus a societal task that requires an inclusive and coordinated approach.

In their systematic literature review, Geukes et al. (2022) emphasize the urgent need for an evidence-based eHL concept to modify and implement digital technologies and health information in a target group-specific and resource-oriented manner. Digital technologies offer the possibility for individualized and needs-oriented design of health-related information. However, to be effective, this information must be understood by users and, within setting-based prevention, must be adequately utilized by organizations and integrated into structural development processes.

The measures outlined in section 2.6 are formulated in a rather broad or overarching manner and leave the stakeholders addressed – such as educational institutions, medical associations, political actors (e.g., the Ministry of Health), research sponsors, and social actors – leeway in their specific

design and implementation. Detailed proposals for concrete practical implementation would have been too extensive for this position paper and would have gone beyond its scope. We are aware of the fact that some of the proposed measures are very difficult to put into practice, such as the enablement of citizens through healthcare providers who usually only have a very limited amount of time per patient and in some cases also lack the appropriate eHL and educational skills. To overcome the absence of digital and educational skills, medical study curricula or medical training plans should pay more attention to these core competencies. The restricted time per patient is a major general problem for which we unfortunately cannot offer a quick solution. To overcome this problem, the entire German healthcare system would have to change.

Another important point to consider is the widespread use of social media platforms such as Instagram, Facebook, Tiktok, and X, which many people rely on as an additional source of (health) information (Suarez-Lledo & Alvarez-Galvez, 2021). Given the limited control over misinformation on these platforms, it is essential to address the social media aspect when teaching skills to distinguish between trustworthy and unreliable sources. Raising awareness about the ease with which anyone can use these platforms to disseminate (also unverified or false) opinions and share misinformation on health topics should ideally foster a healthy skepticism toward health-related claims made by private individuals, companies, and organizations.

Overall, eHL can be a critical competence and a key predictor for effective health prevention and promotion (Chang & Schulz, 2018). A meta-analysis from 2023 also found a positive correlation with health-related behaviors, suggesting eHL may act as a mediator between the consumption of health-related information and subsequent changes in health-related behaviors (Kim et al., 2023). It must therefore be fostered through targeted education and awareness-raising measures. Programs to promote eHL must be tailored to the specific needs of different user groups and life environments. Only if these programs are found, assessed, and adequately applied by users, they can have a positive impact on health by supporting effective health promotion and prevention.

Finally, it is crucial to ensure that all citizens can benefit from advances in healthcare made possible by digitalization. This will be essential for promoting the health and well-being of society in the digital age.

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