

Challenges in digital health literacy

The challenges in digital health literacy are varied. The concept means more than merely health literacy preceded by the adjective *digital*; rather, it relates to autonomous patients as citizens exercising their right to self-determination in healthcare as well as their political voting rights. Digital health literacy is a prerequisite to being a legally capable patient, and in today's information society, it is indispensable. Those, who lack it might suffer health policy-based digital exclusion. Not only can the state promote digital health literacy, but bottom-up initiatives can do so as well. Digital health literacy is tied to a number of human rights, such as the right to education and healthcare, which are considered second-generation human rights, while political voting rights are deemed first-generation rights.

Keywords: *digital health literacy, health data literacy, data altruism, digital abuse, legal literacy, political literacy.*

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Introduction

The following article is a narrative review. The keywords “digital health literacy,” “health data literacy,” “data altruism,” “digital abuse,” “legal literacy,” and “political literacy” were applied when selecting the literature to review from the Web of Science. (Google Scholar was also used when necessary.) Abstracts were first reviewed, followed by the body of the articles, which were analyzed in order to find the literature best corresponding to the topic of digital health literacy. Recency was a relevant criterion. Ultimately, the findings were summarized and synthesized.

Digital health is conceived as “the integration of technologies into health, healthcare, daily life, and society to improve the effectiveness of healthcare delivery and personalize treatments” (Al Meslamani 2024, 167). It forwards the treatment of illnesses and the management of health risks as well as well-being, prevention, and healthy lifestyles. eHealth is a cost-effective and safe use of information and communication technologies in order to promote health and related domains, such as, healthcare services, health literature, health education, etc. As claimed by WHO (2019, 1), digital health is “...a term encompassing eHealth (which includes mHealth [mobile health]), as well as emerging areas, such as the use of advanced computing sciences in ‘big data’, genomics and artificial intelligence.”

According to the WHO Regional Office for Europe (2023, 25), “Digital health literacy is the ability to search, find, understand and evaluate health information from electronic resources and to use the knowledge gained to solve health-related problems.” Digital health literacy is of growing importance in today’s societies. It is still problematic in developing countries; however, the EU and the US also suffer inadequacies. The related international literature is ample, although the situation is swiftly changing, and fresh information is quickly becoming outdated.

The concept of health literacy was coined by Scott Simonds in the US as a social policy issue in 1974 (Simonds 1974). Ploomipuu et al. (2020, 1211) note that “the definition of health literacy is arguably still in its infancy, especially in non-English speaking countries.” Sørensen and Brand (2014, 642) contend that the various translations of *health literacy* in EU documents have led to notional confusion.

The term *health literacy* has been integrated into the language of scholarship in the English-speaking world, and serious attempts have been made to include it in other nations’ terminology as well. A uniform grasp of the notion could advance the concept of adequate terms in various languages. The EU and especially Hungary promote the realization of this goal.

Health Data Literacy

The Functional, Communicative and Critical Health Literacy Scale distinguishes between the patient’s ability to read and understand the doctor’s instructions (functional health literacy); the patient’s capacity to discuss the information related to their disease with a doctor and family members (communicative health literacy);

and the patient's skills to decide on the validity of health information retrieved from various sources (critical health literacy) (Ishikawa et al. 2008, 874–879). Heijmans et al. (2015, 41) argue that “Health care professionals should tailor their information and support to the health literacy skills and personal context of their patients.” Heijmans et al. (2015, 41) find it important to note that the patient-provider relationship necessitates both health literacy on the part of the patient and communicative skills on the part of the provider. This connection is based on a consensual agreement between patient and provider and not solely in the legal sense (i.e., treatment contract), but also from an ethical, medical, and financial perspective.

The level of health literacy in today's societies is correlated with an increasing number of highly educated patients (see also Szabó 2019, 109), the quality of the human right to healthcare (see also Lee 2024, 697), recent advancement in medical science, and the improvement of health data literacy (see also Koltay 2023, 73). As a result, health literacy has progressed immensely since the previous century. Of course, differences can be distinguished between countries.

Arriaga et al. (2022, 1) state, “Health literacy entails the knowledge, motivation and competencies to access, understand, appraise and apply health information in order to make judgements and decisions in everyday life.” I believe health literacy may be conceived even more broadly, as it also implies health data literacy. Understanding health information necessitates equal access to health information through education and culture. Dunn and Hazzard (2019, 294) contend, “Digital health literacy is an extension of health literacy and uses the same operational definition, but in the context of technology.”

Koltay (2023, 72) argues that data literacy serves to manage and critically share and reuse research, business, and population data, among other things. Koltay (2023, 73) underlines that information literacy is also important in healthcare. I further argue that the human right to self-determination in healthcare could not function with low health data literacy among patients. Patients should be able to access and understand their health data to accept or decline a healthcare service. Those living with neither technical access nor sufficient knowledge of their health data find themselves excluded from informed decision-making. The human right to self-determination in healthcare derives from the human right to dignity. Patient autonomy requires a certain level of health data literacy. It cannot be quantified; however, it can be determined at a national level when comparing citizens' health data literacy. This varies from country to country, with disparities potentially being detected even within the same society.

Menyhárd stresses that health data may be used for public purposes. In the latter case, other people's right to health prevails over the individual's right to the protection of personal data (Menyhárd 2022, 37–38). Regarding COVID-19 vaccines, the genetic and other data retrieved from blood tests served to develop the vaccines. This was underpinned by *publica commoda* (Menyhárd 2022, 34). The Charter of Fundamental Rights of the European Union, Art. 8, para. 2, declares that personal data may be processed for specified aims if consented to by the person concerned or otherwise authorized by law.

Based on legal dogmatics, the right to health data protection is a personal right for everyone. It is of an absolute character; everyone should respect it. In the EU, the right to health data protection may be legally limited if allowed by supranational law and permitted by national law. For example, according to the General Data Protection Regulation (GDPR), Art. 9, para. 2(a), patients may autonomously waive this protection, an act which requires health data literacy on the part of the patient. Patients should clearly understand that this is either in their best interest or based on data altruism. However, the data subject is not always identical to the person exercising this right. For instance, in the case of a minor or a legally incapable adult, a guardian (e.g., a close relative) is entitled to waive this protection (see also Weiczner 2023, 18). In today's information society, only people with sufficient health data literacy and digital health literacy should be granted the right to make legally sensitive decisions both in their case and in that of others. Those without adequate health data literacy and digital health literacy are not only incapable from a sociological perspective, but their legal capacity might also be questioned. Considering the Hungarian jurisdiction over legal capacity (National Office for the Judiciary 2024), this might be enforced in the future.

The Promotion of eHealth and eLaw

The digitalization of healthcare and legal procedures is sorely needed in the twenty-first century. Indeed, digital health literacy is instrumental in fostering eHealth and eLaw. For example, in Denmark, since 2009, the *sundhed.dk* health portal has ensured access to health-related information as well as communication with healthcare providers. Holt et al. (2019, 9) arrived at the conclusion that “skills, motivation, and experience of health and digital services are related to the adoption and usage of technology.”

Telehealth was boosted by the COVID-19 pandemic. It was essential, especially in less advanced digital countries. However, according to Tiwari et al. (2023, 5), technological illiteracy in low- and middle-income countries hampers the efficacy of telehealth. Eliza et al. (2024, 1–2) argue that an android healthcare app called *Shastho-sheba* was devised to supply patients in Bangladesh with online healthcare during the COVID-19 lockdown. Shortly afterward, it was further developed to help orphans access telemedicine. It turned out to be useful for resource-constrained communities.

The COVID-19 pandemic had a positive impact on telemedicine in many countries, including some Central and Eastern European EU Member States (Julesz 2020; Kovács 2022). The pandemic triggered the digitalization of healthcare (e.g., by widening the scope of telemedicine) and the digitalization in various domains of public administration (e.g., the EU digital COVID certificate).

Digitalization and digitization go hand in hand. In Hungary, the digitalization of public administration and the justice system is currently underway. In many areas, digitalization has already become a reality (Csáki-Hatalovics 2021, 56; Bojtor and

Bozsó 2023); nevertheless, there is still much to do. For example, the electronic death certificate (eHVB) is widespread throughout the world. In Hungary, at the time of writing this article, this method will soon be fully introduced. The form should be completed by the physician digitally in the eHVB system and forwarded to the civil registrar (Electronic Civil Status System) through the National eHealth Infrastructure. Owing to the introduction of the electronic death certificate, only health data on the deceased person that truly concerns a civil registrar or undertaker would be available to those parties. Thus, health data protection would be digitally ameliorated (Julesz 2022; Julesz 2023). Additionally, this is largely dependent on the physicians' digital competencies. Many primary care physicians in Hungary are elderly and have insufficient digital literacy. In contrast, relatively young specialists (e.g., pathologists) in Hungary are familiar with eHealth. Bak and Kelemen-Erdős (2023, 9) hold that using and developing information and communication technology (ICT) tools call for continuous learning on the part of employees and put pressure on individuals to create competitive situations.

Digital Health Literacy and Digital Inclusion

Norman and Skinner (2006, 1) contend, "Engaging with eHealth requires a skill set, or *literacy*, of its own." The authors differentiate between six components of eHealth literacy: traditional literacy, information literacy, media literacy, health literacy, computer literacy, and scientific literacy (Norman and Skinner 2006, 5–6). Although I concur that these six kinds of literacy are at the core of digital health literacy, I add legal literacy to the list, because digital health literacy is inconceivable without an awareness of health law. Patients should know their rights and duties with respect to the provider and vice versa. Without legal literacy, not only would telemedicine fail, but also other areas of patient-provider communication and health data use in general would collapse. This does not necessitate the expertise of a lawyer specialized in the field. However, only legally literate patients are equipped with digital health literacy. An understanding of health law is a must in today's societies. The mysticism of legislated norms and practice of law remains upheld; however, patients with digital health literacy should be cognizant of the substantive and procedural norms directing the patient-provider relationship.

Yang et al. (2022, 2) state, "The concept of digital health literacy grew from eHealth literacy and was honed thereafter." Van der Vaart and Drossaert (2017, 1) identify digital health literacy with eHealth literacy. Yang et al. (2022, 2) further assert, "Only the channel of accessing and processing health information has changed, evolving from the earlier electronic channel to the digital technology channel." In general, these terms are seen as synonymous in the professional literature.

Based on a study conducted in Ankara, Turkey, Kizilcik (2024, 1819) maintains, "A group with high media literacy behaves more cautiously in health." Kizilcik (2024, 1819) further indicates that medical students' media literacy is better than

average. According to a recent study, media literacy is significantly correlated with health literacy in Iran (Afshar et al. 2022, 195), a developing country. Patients with strong competencies in media literacy are more likely to find valid health-related information. These patients can search for information properly, e.g., on the internet, and find valid answers to their health problems. Media literacy cannot replace medical skills, though it may be a filter before addressing a physician. Health literacy, *inter alia*, may help patients understand medical advice based on professional knowledge. Van Kessel et al. (2022, 1) posit that digital media also has a negative effect as demonstrated by the spread of factually incorrect information. I argue that, on the whole, the possible negative effects of digital media are counterbalanced by its advantages for digital patients.

The UN International Covenant on Civil and Political Rights, Art. 19, para. 2, declares, “Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds.” Lee (2024, 697) argues that media literacy contributes to this human right. Patients are not only receivers, but also imparters of health-related information. This reciprocity is contingent on media literacy, which is a component of digital health literacy. Health-related and healthcare-related information that is communicated can help patients navigate through the healthcare infrastructure. For instance, they can make informed decisions when choosing a health facility or a treating physician. Communication on social platforms always conceals inherent dangers to society and especially to healthcare consumers. A sociological risk/benefit ratio should be considered in every information society to prevent digital abuse and maintain patient safety.

The term *digital literacy* first appeared in 1997 in the book *Digital Literacy* by Paul Gilster (Gilster 1997). Campanozzi et al. (2023, 1) maintain that a person is digitally literate if they possess “the skills necessary to be able to live within a society in which communication is increasingly based on new technologies.” Szabó et al. (2023, 109–111) contend that most children imitate their parents’ digital practices. If their parents are university-educated and live in large cities, they typically have the most satisfying level of digital literacy. Digital health literacy is also supported by human rights institutions. Certainly, the human right to health and healthcare and the human right to education are enshrined in most constitutions in the world – even in countries that are weak in those areas.

Szabó (2019, 109) states, “The availability of reading devices and materials naturally improved teaching reading, thus people’s literacy skills.” Digital competencies are required in school curricula in both developed and developing countries. Due to a greater proportion of young people in developing countries, digital literacy might be more popular there than in aging societies. As a consequence, based on demographic data (UN ESA 2024, 1), it is possible that digital health literacy in developing countries might surpass that in the US and the EU in the long run.

The WHO Regional Office for Europe (2023, 29) argues that less than half of the Member States of WHO European Region have “implemented comprehensive digital inclusion initiatives, particularly for disadvantaged populations.” For instance,

Rab and Török (2022, 94) note that, in Hungary, “Digital culture and tools are widespread, but many people are missing out.”

It is not only international organizations that should point out incongruencies in digital health literacy worldwide. National lawmakers should also undertake to introduce legislative measures for digital inclusion nationwide. The 2030 UN Agenda for Sustainable Development, Art. 15, declares, “The spread of information and communications technology and global interconnectedness has great potential to accelerate human progress, to bridge the digital divide and to develop knowledge societies.” In the US, *Healthy People 2030* is an initiative of the US Office of Disease Prevention and Health Promotion. Among its main goals are “eliminating health disparities, achieving health equity, and attaining health literacy” (Jackson et al. 2021, 1155). Jackson et al. (2021, 1156) contend that “equity in health literacy and digital health” should be ensured.

The results of a survey among German university students during the COVID-19 pandemic concluded that it was both the reliability of digital health information and the recognition of commercial purposes that caused problems for students (Dadaczynski et al. 2021, 1). It is evident that people using web-based information might encounter difficulties. Digital health literacy has its limitations even in populations with high cultural and digital abilities.

Smit et al. (2024, 2) maintain that one in six citizens in the Netherlands aged between sixteen and sixty-five is socially and digitally low-literate to a certain extent. However, the authors argue that Dutch citizens with low digital literacy are still capable of digital participation and digital inclusion (Smit et al. 2024, 2). A recent study among middle-aged and elderly Portuguese (fifty-five years and older) demonstrates that women have lower digital literacy than men and that the level of education is also salient (Quialheiro et al. 2023, 10). In developing countries, the need for digital inclusion raises slightly different problems from those in the developed world. For example, Aydinlar et al. (2024, 11) point out the fact that female students in health-related education at a university in Turkey have “less computer knowledge and previous coding education than male students.” The situation is worse among female students in nursing studies than among those in medical or biomedical engineering studies (Aydinlar et al. 2024, 11). The disadvantaged situation of women is often emphasized in the professional literature on digital inclusion in less well-off countries. Nonetheless, wealthier countries also show great effort in promoting the digital and social inclusion of women. It is critical to foster digital health literacy among not only female students in health-related subjects, but also women in general.

Aslan et al. (2024, 1) indicated that many older people’s negative experiences of communicative eHealth services derive from low digital literacy, limited support networks, and complicated application interfaces. According to Kim et al. (2023, 1033), older people’s technology-related anxiety and technophobia are barriers to digital inclusion. The fear of technological determinism is also an important factor (see also Héder 2021; Héder et al. 2022; Héder et al. 2023). Tsatsou (2022, 1488) argues that vulnerable people in the United Kingdom, such as those with disabilities,

are often socially stigmatized, thus hampering their digital inclusion. Ethnic minorities and older people are also exposed to the “forces of established cultural frameworks.” Age, sex, ethnicity, educational level, and physical and mental disabilities are keystones of digital inclusion and digital health literacy. Related problems arise in both developing and developed countries. However, digital inclusion serves social justice and both are instrumental in forwarding digital health literacy. Further, age-related digital health illiteracy is a relevant issue throughout the world. The age factor should be taken into serious consideration because we live in aging societies. The increasing number of elderly patients in national healthcare systems highlights the still existing defects of digital health literacy. This social policy issue impacts both the US and the EU. The efficacy of healthcare provision is proportional to healthcare consumers’ level of digital health literacy, *inter alia*.

The Various Facets of Digital Health Literacy

Based on the professional literature retrieved from the Web of Science and cited previously in this article, the results show that digital health literacy is multifaceted, involving legal, economic, and social facets. Furthermore, the literature indicates that legal certainty and patient safety are interrelated. Patient safety widely depends on digital health literacy, and it can only become a reality if legal certainty prevails. In addition to a moral approach, a legislative solution to the problem of digital health illiteracy and inequality should also be considered. The value systems in the EU, the US, and the developing world differ largely from each other. Further disparities can be discerned within those groups of states; however, digital health literacy is a common value in all of them. Thus, the quality of the rule of law has a large impact on the quality of digital health literacy.

Digital health literacy is also an economic question and rests on the national as well as the individual’s economic status. Access to digital resources hinges on the allocation of digital tools among citizens as well as on the monetization of health information. However, the allocation cannot be equal, because it is based on numerous country-specific factors. Indeed, top-down measures are not sufficient to bridge the gap between the poor and the wealthy. Striving for equality within society may be the most that can be expected at present.

The concept of digital health literacy is dealt with extensively in sociology and covered in other fields as well. Sieck et al. (2021, 1) and van Kessel et al. (2022, 2) argue that digital health literacy and internet connectivity are “super social determinants of health,” because they correlate with every other social determinant of health.

Digital health literacy is, indeed, a sociological question. The interaction between society and the economy leads to the development of digital society as a whole (*Figure 1*).

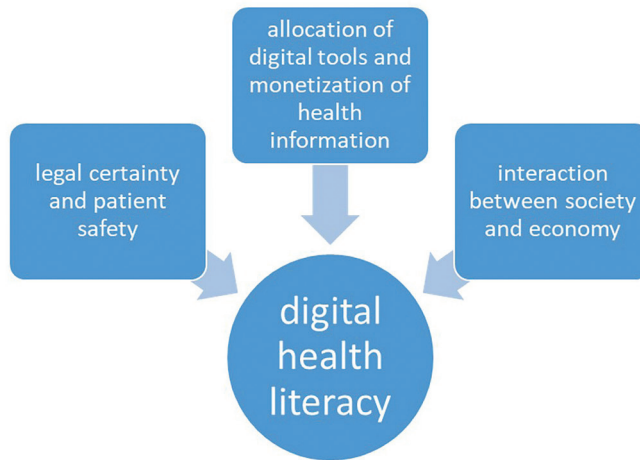


Figure 1: The multi-faceted digital health literacy (own edition)

With time, marginalized groups will catch up with the majority because those living at an acceptable level of digital health literacy need marginalized people in the marketplace. A market economy demands citizens with a similar level of digital health literacy. Otherwise, medicine and other health products as well as expensive health services could not be commercialized. It is not just European societies that are gradually being transformed by the rules of the marketplace. This phenomenon gives rise to minimizing socio-cultural discrepancies within societies.

Actors in a society are not merely those entitled to participate in political elections, but, more broadly, it includes those impacting the socio-economic functioning of the state. In developed democracies, a certain degree of voting rights are granted to all people residing in the state. However, in many states, the political rights of non-national inhabitants are reduced, while their economic, social, and cultural rights are close to those of nationals. All social actors should be provided with digital health literacy, regardless of their political rights. Moreover, the right to digital health literacy should be categorized as second-generation human right.

Nevertheless, changes to second-generation human rights are inevitable. Recently, many health-related rights have arisen. Some might fall outside the scope of second-generation human rights, while others simply change already existing health-related and educational human rights (e.g., the right to digital health literacy, the right to vaccination justice, etc.).

The Relevance of Digital Health Literacy

The rebirth of technological determinism and the spread of autonomous agents have rekindled old fears within the information society. Szabó (2019, 109) contends,

“If we agree with McLuhan’s theory of technological determinism, every medium shift changes culture since mediums are human perceptions, thus mediums have more power on society than the message itself.” Phenomena such as technophobia and computer anxiety are detrimental to institutional trust, especially in the healthcare infrastructure currently under digital development. Related digital health literacy is a fairly new notion at the heart of the digitalization of the healthcare system.

Digital health illiteracy consists of several factors, such as traditional illiteracy, health data illiteracy, digital incompetency, and functional, critical, and communicative health illiteracy. The digitalization of today’s healthcare system comprises both the healthcare infrastructure and making healthcare services digitally available for all. These two main factors are interrelated.

First, digital health literacy is essential to enjoying digital healthcare services, so it primarily concerns healthcare consumers and providers. Second, digital health literacy is important in understanding the motives behind health policy from the aspect of a non-professional user.

Today, the doctor-patient relationship widely rests on digital competencies on both sides. First, digital health literacy enables patients to reflect on medical advice. Healthcare workers offer options to the patient, and, as a rule, the patient is free to make an informed decision. The options are to “accept” or “decline” a healthcare service. This binarity is overwhelming in medical practice, though there should be other options as well. If several alternative treatments exist, the physician must inform the patient about them and leave the informed choice up to the patient. Emphasis should be placed on the orientation of patients when communicating with a doctor, who represents the healthcare system *in loco*.

Second, digital health literacy enables autonomous citizens to understand the functioning of the healthcare infrastructure and to put health policy issues in perspective. Political literacy impacts digital health literacy. In order to make a political decision, citizens should discern between health policies made by the government and those offered by opposition parties. Only those who understand the possible benefits and inherent disadvantages presented by the political actors can make responsible decisions. Thus, digital health literacy is a tool in the hands of political actors. Those who possess this type of literacy can be politically active, while others remain, more or less, outsiders. The latter phenomenon can be viewed as health policy-based digital exclusion.

Conclusions

The major deductions of my article are as follows:

Digital health literacy has numerous components: traditional literacy, information literacy, media literacy, health literacy, computer literacy, scientific literacy, health data literacy, political literacy, and legal literacy (*Figure 2*).

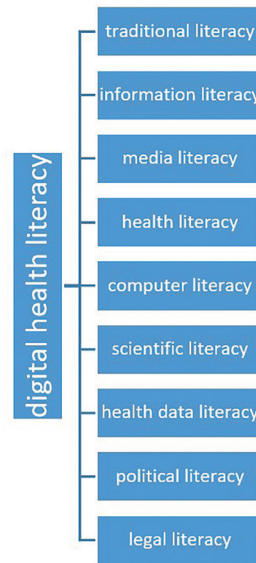


Figure 2: The components of digital health literacy (own edition)

Some of these literacies have already been generally acknowledged by the scientific community, while others are still disputed. As a new result of this article, I argue that legal literacy, health data literacy, and political literacy form an integral part of digital health literacy.

Another new result from this study is that a certain degree of digital health literacy should be expected of legally capable patients. It should be required so as to make informed healthcare decisions. Nevertheless, it might become a reality in the future. Digital health literacy should also be required to understand health policy and thus vote responsibly.

The next conclusion is that health data altruism is a recurring topic in the literature. However, digital abuse can corrupt this originally proactive inclination among digital citizens. Health data are sensitive, and there is no health data altruism if owners of data are not truly free to share them. Indeed, abuse of health data is a global problem that should be surmounted at the national level.

The legal, economic, and social facets of digital health literacy are equally important, even if the sociological aspect seems to be overemphasized. The relevance of digital health literacy is twofold. Patients need it so that they can communicate with healthcare workers, and, as citizens, they also need it to clearly comprehend health policy issues made by state authorities and their political alternatives.

Digital health literacy is a special kind of health literacy – and not solely because of the adjective preceding the term *health literacy*. It is more than an enhanced form of health literacy. In today's information society, social capital rests on citizens' ability to express themselves in the language of the digital society and to internalize reliable digital information.

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