



## **HELPE**

**Health Literacy in Physiotherapy Education** 

# Health Literacy and Digital Health Literacy: concepts and recent advances

















#### **Authors**

Monica Christova <sup>1</sup> Hannes Aftenberger <sup>1</sup> Christian Grüneberg <sup>2</sup> Angela Arntz <sup>2</sup>

#### Consortium HELPE

Hannes Aftenberger <sup>1</sup>
Angela Arntz <sup>2</sup>
Monica Christova <sup>1</sup>
Carles Fernández Jané <sup>3</sup>
Christian Grüneberg <sup>2</sup>
Angelique Hagen <sup>5</sup>
Marietta Handgraaf <sup>2</sup>
Birgit Jocham <sup>1</sup>
Pirjo Mäki-Natunen <sup>4</sup>
Janke Oosterhaven <sup>5</sup>
Sanna Paasu Hynynen <sup>4</sup>

- 1. University of Applied Sciences FH JOANNEUM, Austria
- 2. University of Applied Science, Hochschule für Gesundheit, Germany
- 3. Blanquerna School of Health Sciences, Ramon Llull University, Spain
- 4. JAMK University of Applied Sciences, Finland
- 5. University of Applied Sciences Utrecht, Netherlands





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A major goal of the HELPE project is to develop new learning contents related to HL in order to improve the HL competences primarily in the PT students, but also in other health- related education fields. As a basis for these educational materials in the following report general concepts and recent developments and recommendations in HL and the digital HL with their relevance to physiotherapy are summarized and discussed.

#### Health Literacy: concepts and models

Health literacy (HL) was first introduced about 50 years ago in response to the increasing importance of health care and the need of adequate health education of people which enables them to meet the complex demands of public health in the circumstances of rapid development of new technologies (Simonds, 1974).

Health literacy was linked formerly to the general literacy and initially was limited mostly to the ability to read medical contents to enable the individual to communicate adequately with the health care provider. Later the concept of HL was broadened to a more complex set of abilities including understanding and acting upon written health information, understanding health instructions, communication with health professionals and self-management (Peerson & Saunders, 2009) and was recognized as an important public health issue internationally (Briggs & Jordan, 2010). A large number of definitions of HL exist leading to debate as to what health literacy represents and how it is measured. Some definitions focus on literacy and numeracy skills, while others encompass broader attributes such as conceptual and cultural knowledge, and social skills. In the literature more than 25 definitions of HL are found most of which emphasized on the individual skills to obtain, process and understand health information in order to take adequate decisions about health. Since the individual HL emerges from the interaction with the social environment, it is necessary to consider also the importance of the health professionals as part of the public health literacy. Namely, the health care organizations and professionals are the ones having the responsibility to adapt their services to the clients' needs in order to reduce the negative impact of limited HL. Recently, also Santana et al. (2021) pointed out that the concept of HL was not solely reliant on individual capabilities but also on organizations' ability to make health-related information and services equitably accessible and comprehensible. In "Healthy People 2030" it was clearly distinguished between the personal and the organizational HL, providing the following definitions:

"Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others. Organizational health literacy is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others."

Both personal and organizational HL may exert a significant impact on an individual's health. They are able to contribute for better understanding of a diagnosis, treatment, or recommended lifestyle changes which are supposed to lead active and healthy lives.

For the purposes of the HELPE project we refer to the comprehensive definition of Sørensen et al. (2012) which incorporates both the individual and the public health perspectives of HL as entailing "peoples' 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". Importantly in this definition three health domains can be





identified: health care (in the case of disease), disease prevention (being in risk for disease), and health promotion (keeping sufficient health). These three health domains have a relevance for the physiotherapists and other healthcare practitioners who are actively involved in patient treatment but also in disease prevention and health promotion. Further, all definitions of HL refer to certain "skills" and "competencies". These can be summarized as: access (the ability to seek, find and obtain health information), understand (the ability to comprehend the accessed health information), appraise (the ability to interpret, filter, judge and evaluate the health information, and apply (the ability to communicate and use the information to make decision to maintain and improve health. It should be noted that these should be informed decisions and actions, which can be used to promote not only one's own health, but also the health of others. Health-related actions for example selecting health care provider, service or preventive measures, or assisting family members with individual health needs can be executed at various places such as at the health care provider's office, in social media, at home, workplace, or in a public institution.

The concept of Health literacy in general is increasingly recognized for its complexity and multidimensional face and thus is comprehensively divided into three categories: reflecting the interaction between individual skills and the health system's demands (Nutbeam, 2000, 2008).

<u>Functional HL</u> refers to "sufficient basic skills in reading and writing to be able to function effectively in everyday situations". These basic skills appear to be sufficient for individuals to obtain the necessary health information (for example, related to risks of disease) and to enable to apply the obtained knowledge for certain activities. It can be expected that people with such basic health literacy skills are responding well to education and communication concerning information on health risks, or general using of health services.

Communicative or interactive HL is defined as "more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances". Individuals with these advanced skills show good responsiveness to education and communication activities targeting improved personal capacity to act independently, motivated and confidently.

<u>Critical HL</u> comprises "most advanced cognitive skills which, together with social skills, can be applied to critically analyze information and to use this information to exert greater control over life events and situations". The critical HL along with the information on personal health includes also information on the social, economic and environmental determinants of health.

The Health Literacy Instructional Model (Conard, 2019) combines 5 domains of HL to build health literacy skills (Fig 1). To acquire knowledge is the first domain in building comprehension and skills, followed by the numeracy skills. Numeracy skills can be improved by calculation tasks in association to daily behaviours (fitness and activity monitoring, BMI and calories calculations). Navigations skills can be enhanced by providing more information on access, costs, usability and quality of the healthcare systems. Communication is the most crucial part in the interaction between client and provider, in which the provider plays the main role once for adapting to the patient level/situation and secondly as a part of the patient education aiming to build up better communication skills. Finally, the client should be an active participant in the health providing-accepting process being able to take independent and motivated decisions.







Figure 1: Health Literacy Instructional Model, based on Conard, 2019

The conceptual framework of Sørensen et al. (2012)(Fig. 2) provides the most comprehensive dimensions of health literacy, showing different factors which impact on health literacy as well as the pathways linking health literacy to health outcomes. In addition, it supports the practice of healthcare, disease prevention and health promotion by serving as a conceptual basis to develop health literacy enhancing interventions (Sørensen et al., 2012).

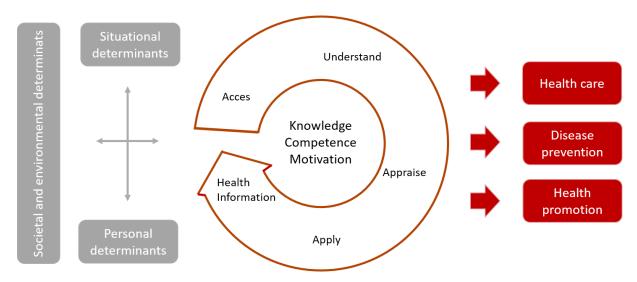


Figure 2: Framework of Health Literacy, based on Sørensen et al. 2012

#### Health Literacy in Europe

Beside the national importance of Health Literacy, it has gained growing attention on the European health agenda, too. Sørensen et al. (2015) conducted a European health literacy survey in eight European countries with a total number of 8000 participants. Large numbers of the European population show difficulties in handling health issues due to limited health literacy skills. Individuals with limited health literacy have difficulties to comprehend health information, to navigate healthcare organization, to interact with health care providers and to participate in self-management of their health (Berkman et al., 2011; Groene & Rudd, 2011; Pires et al., 2015). The results of the study showed that almost 1 in 2 (47%) had insufficient or problematic health literacy. However, the distribution of levels differed substantially across countries (29–62%). Subgroups within the population, defined by financial deprivation, low social status, low education or old age, had higher proportions of people with limited health literacy, suggesting the presence of a social gradient (Sørensen et al., 2015). Limited health literacy represents an important challenge for health policies and practices across Europe, but to a different degree for different countries. While actions on HL have been identified in 16 EU member states, only in six countries national-level policies have been implemented, however not associated





with adequate HL programs and activities. The social gradient in health literacy appears an important consideration when developing public health strategies aiming improvement of health equity in Europe. Still better monitoring and evaluation at European level are needed in order to ensure more successful coordination of efforts to improve HL.

In conclusion and alignment to many other studies, the authors emphasise on efforts to strengthen citizens' health literacy by redesigning user-friendly and user-involving systems, adjusting curricula and training health professionals to better meet the challenge of the health literacy deficit, and increasing patients' expectations of being active partners in their care (Sørensen et al., 2015). In this relation the HELPE project will develop a shared HL curriculum for the physiotherapy (PT) bachelor degree program with the possibility for implementation in other health profession-related educations as well.

#### Factors influencing the individual Health Literacy level

In order to provide adequate to the individual HL health care services, it is important to identify first which factors contribute to decreased HL level. In summary, following risk factors may influence the HL (Speros, 2005; von Wagner et al., 2007, 2009; Pandit et al., 2009; Sørensen et al., 2012; Wångdahl et al., 2014; Sørensen et al., 2015; Quenzel et al., 2016; Mantwill & Schulz, 2017; Stormacq et al., 2019).

- education level
- financial status
- social and socioeconomic conditions
- demographic and socio-political factors
- age
- language skills
- reading and arithmetic skills
- cultural and religious specificity
- chronic disease
- disease severity
- physical and cognitive abilities
- access to health education materials
- health-related experience
- parental influences

Significant cross-country variations of these factors and their magnitude of influence on HL have been reported in the different countries (Sørensen et al., 2015) whereby in Europe the financial status, education and the age were identified as the strongest prediction factors. Recognizing vulnerable groups and risk factors from lower levels of HL is an important step for the development of effective approaches in the communication between health care provider and client which should be integrated in the knowledge of HL in the PT education programs.

Respectively, the HELPE project targets the following client groups: older people, patients with chronic diseases, patients with low economic status, education and migration background.





#### Impact of Health Literacy on health and disease

Health literacy improves patients' responsibility for their own health and supports them in the decision-making process for individual treatment. Higher HL is associated with increased health and disease knowledge, with better self-reported health status, problem-solving and motivation, with more adequate use of health services, shorter hospitalization, consequently leading to lower healthcare costs (Speros, 2005; Manganello, 2007; Paasche-Orlow & Wolf, 2007; Mancuso, 2008). It was demonstrated that individuals with higher HL show better health and longer life-expectancy (Ratzan, 2001). In turn, physical and cognitively healthier population tend to be more productive and require less health care services and costs.

Several lines of evidence highlighted the relationship between low health literacy and poorer health behaviours and outcomes (DeWalt et al., 2004; Paasche-Orlow & Wolf, 2007) independently of other sociodemographic factors. Clients with limited HL may face the following obstacles (Magnani et al., 2018):

- difficulties in accessing health care and insurance services
- difficulties in reading and comprehension of health-related information (instructions, informed consent documents, patient education materials)
- unsuccessful comprehension in communication with the health care provider, due to inadequately delivered information
- problems to use spoken and written communication (language proficiency) and to use numeracy and quantitative skills

These barriers lead to limited use of health insurance (Levitt, 2015) and less utilization of preventive healthcare services, to less adherence to the therapy and medication, to lack of motivation and active participation, to inability of taking adequate health decision, which finally increase the risk to acquire a wide range of medical conditions. For example, Magnani et al. (2018) summarized that low HL expressed with insufficient disease knowledge, limited self-efficacy, activation, attitudes and self-care (diet, physical activity, medication and treatment adherence, problem solving) was associated with increased cardiovascular risks and conditions for example: hypertension, diabetes, stroke, coronary heart disease, obesity. Impact of HL on low back pain (Edward et al., 2018) reproductive health (Kilfoyle et al., 2016) psychological disturbances and quality of life (Rababah et al., 2020) have been described, too. Consequently, intermediate- and long-term healthcare outcomes may occur such as raised healthcare costs (Palumbo, 2017) increased hospitality and mortality rates (Berkman et al., 2011).

Collectively, these evidences reveal the crucial importance of providing relevant health information in a feasible and comprehensive way in order to shape the individual health understanding and behaviors and consequently improve health outcomes. The main responsibility for the effective delivery of health-related information have health professionals from different healthcare sectors.





#### Health Literacy in physiotherapy practice and patient education

Physiotherapy gained an increasing importance and expanding responsibility in the large family of the healthcare sectors. Physiotherapists work in an inter-professional team and are actively present in almost all health- and disease-related conditions across the entire life spam of their clients. In addition, in comparison to the other health professionals, they spend a substantial amount of time with the client. They are not simply involved in disease prevention, treatment and rehabilitation, but also in providing health information, in educating patient how to understand and manage his/her health status and at the same time in finding the most optimal approach for that.

Nowadays, physiotherapists work with increasing number of individuals with chronic and multiple disease, with aging population, with people of diverse cultural, language sociodemographic, physical and cognitive status. All these vulnerable groups show respectively diverse levels of HL and require appropriate patient education strategies. In order to ensure educational strategies that match the individual learning capacities, needs and HL levels of the clients, physiotherapists should possess appropriate HL knowledge and competencies.

First of all, physiotherapists need to recognize the **signs of compromised HL** (Weiss, 2007; Ennis et al., 2012) such as:

- Incompletely or inadequately completed forms
- Frequently missed therapy appointments
- Inability/difficulty to name and take correctly medications
- Inability to follow instructions referred by other health professionals
- Inability to comprehend/complete their home exercise program, or disease management tasks
- Refusing to read written instructions or asking the therapist to read to them

Secondly, physiotherapists are supposed to screen clients in order to evaluate the level of HL. Various assessment instruments have been developed to measure HL, focusing for example on different cognitive tasks (reading fluency, memory span and understanding sentences, etc.). Identifying the HL level will help the physiotherapist to develop and apply respective intervention strategies which is an important initial step in facilitating the client to participate actively in the therapist-patient interaction process. Generally, such **strategies** include: simplifying forms, improving the readability of printed information, absence of specific medical terminology through patient-centered language and feedback conversations that assure that the therapist has been understood by the patient. Further, appropriate communication strategies (use plain language and clear sentences, ask questions, give feedback, use "teach back" method) should be utilized in order to optimize the patient education process (Hironaka & Paasche-Orlow, 2008; Ennis et al., 2012).

**Evidence-based patient education** implies the joint use of current medical best evidence to inform patients about their **health and management options** (Bunge et al., 2010). It means that the patient is informed about his/her health condition, aims of the therapy program and about the prognosis. Particularly, this may include (Lopez-Olivo & Suarez-Almazor, 2019):

- clarifying diagnostic uncertainties
- providing possible therapy options
- explaining the purpose and possible success of treatment
- clarifying associated risks and burdens





- informing about the patient's rights to refuse one treatment or choose alternative one
- support by developing problem-solving strategies

Important part of the patient education is the access and usage of health information. It was reported that different age groups use very different sources of information. Older adults used to receive health information more from the health care provider, radio, TV, books and magazines and less from Internet. The tendency of using Internet sources also by older adults is rapidly increasing. The choice of health information source depends also on the specific cultural, sociodemographic and cognitive characteristics of the individual. It is important for the physiotherapist first to identify the preferred and the optimal source of health information for the individual client and secondly, to provide accurate and reliable health information resources in a compatible form.

#### Digital Health Literacy

The rapid growth of Internet, along with the progress in the electronic and mobile technologies shows a global impact on health and health care. The **electronic health** (eHealth) is defined by WHO as the cost-effective and secure use of information and communications technologies in support of health and health-related fields (WHO, 2021). It includes health-care services, health surveillance, health literature, and health education, knowledge and research and aims to provide secure and cost-effective care to underserved populations. In order to benefit from the developed eHealth resources the consumers should be capable to access and read text, use information technology, and appraise the content of these (Norman & Skinner, 2006). Thus, the same authors defined the term **electronic health literacy** (eHL) as "the ability to seek, find, understand, or appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem", also known as **Digital Health Hiteracy** (DHL). On one site, the DHL shares core aspects of health literacy. On the other side it incorporates additional knowledge and skills: **computer literacy** to computers and related technology efficiently to accomplish tasks; **media literacy** to use search engines; **information literacy** to evaluate a wide variety of sources (Norman & Skinner, 2006).

Advantages of the digital health technologies include convenience of accessibility, availability of information and solving problems outside of the clinical settings, time efficiency, reduction of travel expenses. E-technologies offer variety and flexibility for using health information (websites, interactive applications, games, augmented and virtual reality, combinations of text, images, audio and video, social networking tools, animations, risk calculators) that can assist clients matching to their individual needs and preferences. Further, technology solutions have the potential to improve the communication between the client and the healthcare professional, because they enable clientcentered and personalized way of providing information and treatment (Dunn & Hazzard, 2019). Some digital tools (for example apps, portable devices with augmented reality) are rather appealing with entertaining and interactive elements, which capture clients' attention, engage them cognitively and emotionally (Lam et al., 2017). This leads to increased participation and adherence to the therapy process. The implementation of digital technologies facilitates also the healthcare provider, for example to monitor patient's behavior, compliance, nutrition, medication adherence, symptom management, or to undertake quick adaptations of the treatment. In addition, using e-tools enables individuals to exert more control over one's health and to have better access to own data, while remaining connected to the healthcare team (Conard, 2019), which finally improves one's HL and DHL.





Digital technology solutions can promote the HL and DHL by extending the existing forms of information transfer (for instance books, clinical settings). On the other hand, to be a barrier because of insufficient capabilities of clients to deal with digital instruments (Dunn & Hazzard, 2019).

The individual level of digital HL is predetermined and influenced by several factors. Individuals with limited DHL for instance, tend to be significantly older and suffer more often chronic diseases (Neter & Brainin, 2012). Lower educational attainment is another limitation in understanding eHealth contents and technical instructions. Individuals with lower socio-economic status are limited in accessing eHealth information due to the lack of computers, personal mobile and wearable devices, internet access. Great amount of evidence-based health information is provided exclusively in English or in German, which creates barriers for users using other languages. DHL encompasses a set of skills necessary for informed usage of electronic applications, not just limited to browsing for topics of interest, but also dealing with interactive digital health platforms, using health apps and wearables or communicating with health care providers. Despite access to the Internet via smartphones has become the most common way for obtaining information, technology-unfriendly individuals, such as the elderly for instance are still unwilling and unable to use technology. Thus, insufficient competency and specific skills to navigate "smart" devices are major burden of data entry or confusion with app usage (Krebs & Duncan, 2015) leading finally to confusion, discomfort and consequently decreased use of eHealth resources.

In this context, the question arises whether digital media should be used to break down DHL barriers or whether analogue means should be used instead.

To involve clients in eHealth-related activities, it is crucial first to evaluate the individual level of DHL in clients. The measurement tool eHealth Literacy Scale (eHEALS) (developed in English and translated in few other languages) by Norman & Skinner (2006) has been used in different settings. It consists of eight items for self-report of ease and skills when navigating the Internet for valid health-related information. The instrument has been widely used, however a lack of correlation between eHEALS scores and actual task performance in online health information seeking (Quinn et al., 2017; van der Vaart & Drossaert, 2017) was found. Another concern was the fact that it could not sufficiently address critical and interactive health literacy skills (Norman, 2011; van der Vaart & Drossaert, 2017). The Digital Health Literacy Instrument (DHLI) screening tool was developed to evaluate not only the operational, but also navigational skills, quality of information search, reliability assessment, relevance determination, adding self-generated content and privacy protection (van der Vaart & Drossaert, 2017). The importance of assessing digital health competencies of health workers was also stressed (Jimenez et al., 2020).

Digital health literacy (DHL) includes the provision (the medium) of information (APP's, homepages, tools), the ability to use these medias (support tools), and the learning to understand this information (learning platforms) (Fig. 3). This requires an appropriate selection and high quality of the digitally provided materials that meet well established criteria. Eysenbach et al. (2002) proposed seven quality assessment criteria for client health information on the Internet:

- Accuracy of provided information, which should be based on current guidelines or standards of care
- Completeness/comprehensiveness, which can be achieved by addressing the main concepts of the topic and thematically subdivided





- Technical elements, consisting for example informational sources, sponsorship, target groups
- Good readability of information
- Design and aesthetic elements
- · Accessibility that ensures usage of information also by people living with disabilities
- Usability in order to facilitate navigation

Although there are no standards for digital decision aids, various quality evaluation criteria were developed for decision aids in general (International Patient Decision Aid Standards Collaboration assessment checklist; Workbook on Developing and Evaluating Patient Decision Aids to evaluate the development and evaluation processes of decision aids; Ensuring Quality Information for Patients, to evaluate information quality (O'Connor & Jacobsen, 2003; Moult et al., 2004; Lenz & Kasper, 2007; International Patient Decision Aid Standards (IPDAS), 2019).

DHL can be successfully promoted by using eHealth tools. To reduce barriers for clients when dealing with digital information in inpatient settings, Smith & Magnani (2019) recommend for instance the formation of interdisciplinary teams. These include not only health workers but also App designers and programmers. These teams are supposed to work with clients in order to identify and resolve DHL barriers, providing systematically technical and medical support. Through close cooperation and interactive tools, DHL education can be delivered in an individual and client-friendly way. It is important to define the health care aspects that can be facilitated by digital technologies. Applications, instructions and materials that are actual, standardized, comprehensive, readable concise, and easy to navigate should be provided to ensure easy and friendly usage. To enhance communication, materials should be available in video and audio format suitable also for persons with limited general literacy. Linking main contents to related additional materials enables deeper understanding and independency in acquiring new knowledge. Using patient personal experience and characteristics when transmitting messages engages actively the client into the process. Considering the client's characteristics (age, sociodemographic status, cultural background, beliefs and behaviors, education and language level) are critical when designing eHealth tools intended to promote DHL. This can determine to a certain extend the availability for access and the preferred means of communication. Clients with limited HL and DHL should be explicitly informed about the available digital services, should be supported technically, and encouraged to use novel evidence-based applications (for example fitness trackers). Importantly client's feedback should be considered to evaluate the efficacy and to improve patient experience and care.

Implementing eHealth tools on clients is related to **ethical challenges**, namely data collection and data sovereignty. Data sovereignty, meaning responsible informational freedom appropriate to the opportunities and risks of Big Data, should be the central ethical and legal goal when dealing with Big Data, as defined by the German Ethics Council (Deutscher Ethikrat, 2018). It is also necessary for the use of telerehabilitation and for the inclusion of the "data sovereign" patient in treatment and research processes (keyword: data donation) (Strotbaum et al., 2019).





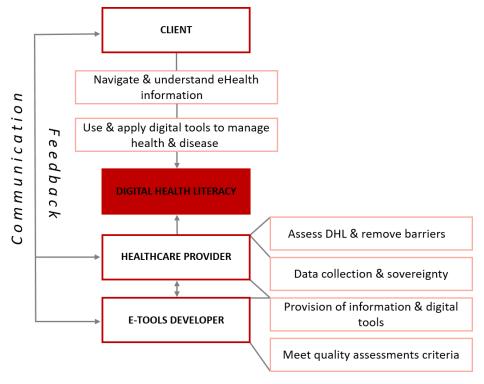


Figure 3: Digital Health Literacy – an overview

#### Digital Health Literacy in the physiotherapy practice and education

Physiotherapy practice confronts with increasing number of elderly individuals and patients with chronic conditions, which is one reason for the limited personal and time resources. This requires an optimization of the health care process and involves among others implication of digital technologies. In this relation, the digital patient education is the core feature for achieving better DHL level and thus improving the therapy effectiveness. This is especially important for the physiotherapists who work increasingly in digital environment, in the field of prevention, pre-and postoperative rehabilitation, therapy of acute and chronic disease and patients' self-management. For example, telerehabilitation such as video counselling or instructions are suitable both for therapeutic interventions and for prevention. Banbury et al. (2018) showed that video group settings lead to the same results as face-toface interventions, whereby the quality of the counselling session and the technical equipment are of importance. Remote patient monitoring systems can help the physiotherapist to observe and control biometrical (fitness activity, blood pressure), behavioral data (rest and activity time, activities of daily life, self-management of symptoms), and risk factors. The most common technology solutions to build corresponding HL skills are apps and wearable devices, which enable unique way of personalizing information and its use in an interactive way. Most recent advances including Artificial Intelligence, Machine Learning, Virtual Reality can build HL skills by incorporating the learning and behavioral preferences in the physiotherapy process. Navigating electronic prosthetic and other supportive devices (wheelchairs, robotic hands, walking devices) in daily life also requires a certain level of skills, which finally reflects the DHL. In turn, collection and evaluation of client's data enables computer, electronical and software specialists to improve the product's quality and develop novel devices.

In the physiotherapy education the digital solutions enable the delivery of multimedia education, such as videos, speech and print, at different reading levels, in multiple languages and using formal and





informal teaching methods (Conard, 2019). In the HELPE project, the courses address the linguistic component in particular. The communication of health information in a simple client-oriented language is attempted for example in the form of simulation interviews and educational videos.

Physiotherapists working with non-native speaking client groups for digital solutions. Lopez-Olivo & Suarez-Almazor (2019) described that digital learning tools are often only available in English or in the local language. For clients with insufficient general education and little knowledge of the local language, there are only limited opportunities to use this form of education. In HELPE we create courses in non-native speaker groups in the frames of community interventions with the possibility to develop digital offers for this setting.

The HELPE project addresses physiotherapy students, providing them with competences in HL and DHL and ideas on how they themselves could implement innovative learning tools for digital patient education. In this context, digital solutions will be considered for all developed courses.





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