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Advancing health literacy for equitable access to healthcare

Towards a guide to health literacy policy, strategy and service design

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CONTENT

EXECUTIVE SUMMARY

This technical report informs decision-makers about health literacy and its role in facilitating equitable access to healthcare in order to guide policy, strategy and service design. Health literacy is an urgent public health priority as European health systems face a range of challenges. Access to health information and healthcare plays a crucial role for the fulfilment of personal and societal expectations and for enabling citizens to make healthy choices. However, health systems are complex and health organisations may be structured and operate in ways that make it difficult for people to access information and engage in healthcare. The report focuses on health literacy as a foundation for empowerment and access to healthcare based on the interaction and fit between healthcare systems and individuals, households, and communities. In the introduction the concept of health literacy is introduced and defined. Subsequently, part one highlight *what* the key challenges are for making healthcare valid, timely, and actionable to achieve appropriate quality and *why* health literacy can help to mitigate those challenges. Part two introduces *how* health literacy tools and approaches can be applied in practice. The concluding remarks summarise the content and its implications for the future.

INTRODUCTION

Health literacy is an urgent public health priority as European health systems face a range of challenges including reduction in healthcare funding, an ageing population, increased immigration, cultural diversity, personnel shortages, waiting lists for patients, managed care, home care, long-term care, growing use of technology and digital health services and tools, and emergent health threats such as the COVID-19 pandemic[1,2]. Low health literacy is closely related to adverse health outcomes whereby health literacy becomes a critical social determinant of health[2].

According to Article 3 on equitable access to healthcare of the *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine:*

> *"Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to healthcare of appropriate quality"* [3]

This technical report aims to inform decision-makers on the mitigating role of health literacy in the provision of equitable access to healthcare in order to guide policy, strategy and service design. In the introduction the concept of health literacy is introduced and defined. Subsequently, part one highlight's what the key challenges are for making healthcare available and actionable to achieve appropriate quality, and why health literacy can help mitigate those challenges. Part two introduces how health literacy tools and approaches can be applied in practice. The concluding remarks summarise the content and its implications for the future.

HEALTH LITERACY AND ACCESS TO HEALTHCARE

Health literacy represents the knowledge and competencies which accumulate through daily activities, social interactions and across generations[4]. Personal knowledge and competencies are mediated by the organisational structures and availability of resources which enable people to access, understand, appraise, and use information and services in ways which promote and maintain good health and wellbeing for themselves and those around them. [5]. Health literacy is critical to public health because it can empower people to actively, confidently, and fully participate in multiple life roles (e.g., parent, employee, patient, consumer, citizen, and so on) so that they can "continually learn new information and unlearn outdated information in order to maintain good health and act as informed patients". [6]

The **comprehensive conceptual model of health literacy** derived from the European health literacy project explains how personal, situational, and contextual factors influence health literacy and the consequences for healthcare use and costs, health behaviour and health outcomes, participation and empowerment, equity and sustainability[7].

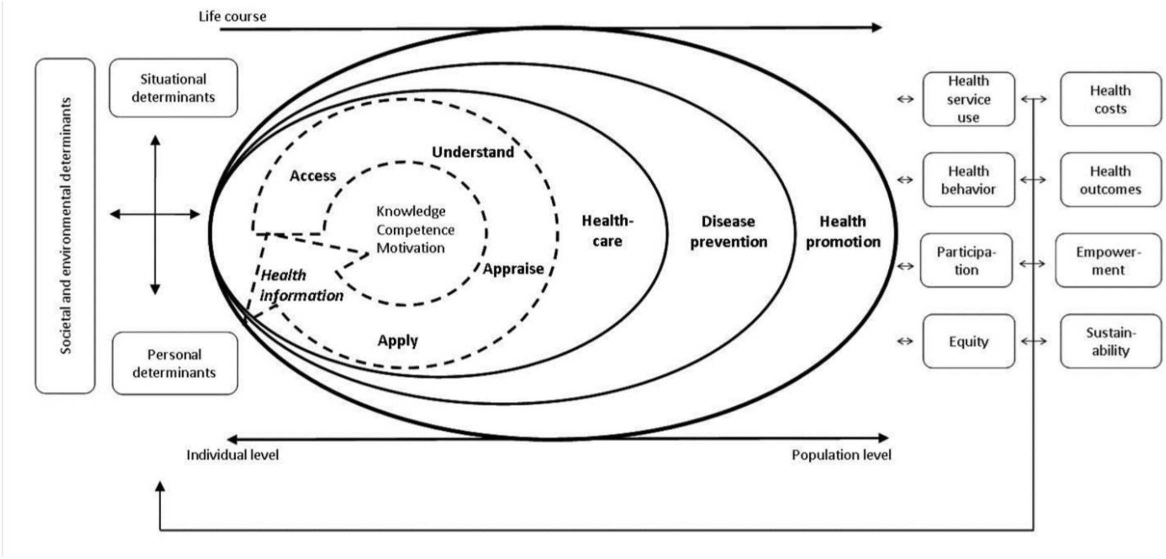

Figure 1: Health literacy conceptual model[7]

The concept referring to **access to healthcare** can be understood as the empowerment and opportunities of an individual to use healthcare and as multidimensional concept based on the interaction (or degree of fit) between healthcare systems and individuals, households, and communities. It is closely associated with availability, affordability, and acceptability[8]. Access to health information and the utilisation of health knowledge play a crucial role for the fulfilment of personal and societal expectations and for enabling citizens to make healthy choices[6].

However, health systems are complex and health services may be structured and operate in ways that make it difficult for people to engage. Thus, access to healthcare "reflects an individual's capacity to benefit from services given the individual's circumstances and experiences in relation to the healthcare system"[8]. In turn, health literacy enhances people´s skills to meet the complex demands of the systems as well as health systems´ capacity to meet the complex needs and demands of people they serve[2].

Developing the health literacy of both people and systems strengthens the equality of opportunities in accessing healthcare[9]. The vulnerability in terms of accessing quality healthcare is determined by the same dynamic interplay: thus, to be seen as vulnerable is being impacted by the competencies and needs of the individuals and the organization of the health services[10]. Due to the social gradient in health literacy and access to health care, the development of health literacy should be guaranteed to all, in particular to people in vulnerable situations due to their health literacy[11].

Essentially, the development of health literacy and the **health literacy responsiveness** of the systems are keys to support the development of the opportunities and capacities to reach and use healthcare of appropriate quality on an equitable basis. Health literacy responsiveness can be defined as "the provision of services, programs and information in ways that promote equitable access and engagement, that meet the diverse health literacy needs and preferences of individuals, families and communities, and that support people to participate in decisions regarding their health and social wellbeing"[12].

For the purpose of this guide health literacy will be viewed particularly from the perspectives of:

1. **Health knowledge.** The overall information related to, for instance, health and disease, and patients' rights.
2. **Practical skills.** The various health-related or health-supportive skills, such as basic digital skills, communication skills and abilities to seek health information and navigate in health care settings.
3. **Critical thinking and self-reflective skills.** The abilities to compare and assess the credibility of health information, abilities to reflect the usefulness of the information from one's personal perspective, and abilities to become aware of and identify the symptoms of various diseases.
4. **Participatory skills**. The abilities to participate in suggesting alternatives and in making shared decisions on the issues that impact one's life.

KEY CHALLENGES IN ACCESSING HEALTHCARE OF APPROPRIATE QUALITY

This part provides an overview of key challenges that may hinder people's access to health information and quality healthcare. It presents and discusses access to digital spaces, valid health information and appropriate care as well as interaction between patients and professionals and shared decision-making.

ACCESS TO DIGITAL SPACES

Having relevant digital competencies, equipment and internet access have been recognised as digital determinants of health[13]. This includes digital skills as 'the backbone of the digital society' and 'a precondition for participating effectively in today's society'[14]. Digital spaces have become a central environment for communication and engagement, learning and work, but also health prevention and promotion, healthcare interventions and self-management. 'Health 4.0' is a term used to describe the digital transformation of health and medical care, and to highlight that 'digital' is part of all spheres of life[15], including health and its prevention, promotion and care. Digital health could be described as "the field of knowledge and practice associated with the development and use of digital technologies to improve health" [13].

The COVID-19 pandemic clearly showed the importance of being able to have access, on an equal basis, to opportunities to access digital spaces. Digital technologies, such as mobile phones, have made it possible for rapid contact tracing, symptom checking, advice seeking and receiving of online healthcare (e.g., tele-medicine, online prescriptions), and public communication and education. Furthermore, with billions of people being isolated, digital environments may have been the only or most important way to access updated and valid information, to reach self-care guidelines and various health-care services, and to be connected with other people[16]. Clearly, access to digital spaces has provided many important solutions while minimising the possibilities of being exposed to agents causing infectious diseases[17].

Together with telehealth (i.e., individuals managing "their care with remote support from health-care professionals", different digital technologies like wearable devices and smart phones can form a constant connection between patients at homes and clinicians, and to raise the alarm in the event of probable emergency situations[18]. Importantly, remote support can foster the development of health literacy[18]. Access to digital spaces is particularly important when mobility is restricted[14] or when people live in rural or remote areas. As compared to traditional communication strategies, digital spaces support "accessibility and widening access of health information to various population groups, regardless of age, education, race or ethnicity, and locality" [19].

CHALLENGE

Although in 2020, 91 % of European households had internet access, still one tenth do not. The country differences are clear[20] as are the differences between urban and rural areas[20]. Before the COVID-19 pandemic, nearly 40 % lacked basic digital skills[20] needed to access digital spaces and services. Many new online health services and technologies may only be available for those with sufficient knowledge, skills and financial resources[21], whereas for "people suffering from rare diseases, elderly or homeless, digital health services might not be offered or even developed"[22]. Digital inequalities are evident and may increase vulnerability in reaching timely and appropriate health care as well as exposure to various unfavourable health indicators, such as depression and loneliness among older adults[23]. However, the development of digital health services and tools has the potential to increase equality in accessing healthcare of appropriate quality and to decrease health disparities.

During the pandemic, digital inequalities increased vulnerability to the COVID-19 pandemic[24]. Especially among elderly people, digital illiteracy may result in inequalities in vaccine access even in developed countries[25]. Though the digital transformation of health and medical care may bring along many benefits, disparities in skills and resources may "reproduce and reinforce existing equalities related to restricted mobility"[24], as might the unpreparedness of the health providers to take into account digital health inequity and individuals' experiences about online health technologies[17].

FOCUS: HEALTH LITERACY IN THE DIGITAL ERA

To overcome the challenges and barriers that might hinder access to digital spaces, individuals need sufficient knowledge on available digital health services, and practical digital health literacy skills that empower them to find, navigate and practice in online health services. They also need skills to communicate with healthcare personnel in eHealth[26] and to interpret and critically appraise the findings of various health apps. On the other hand, systems should be developed to help individuals with varying needs and to provide various services and tools that secure all people's access to digital spaces. "Health systems need to [...] exploit more fully the potential of new digital technologies to strengthen prevention and care"[27].

Table 1 provides a summary of the health literacy competencies and the elements of the responsiveness of the systems that support people´s health literacy to access digital spaces.

Table 1: Health literacy and access to digital spaces

People's health literacy	**Systems' health literacy responsiveness**
Health knowledge ● Having knowledge on available digital	● To secure easily accessible internet access for all people (incl. homeless people) ● To develop digital health communications

healthcare services (sites and applications) - "Being familiar with health concepts to enter and extract appropriate information in [online medical] record" (Chan & Kaufman, 2011) Practical skills - General digital skills to use devices and applications, for all age groups - Skills in finding and navigating relevant digital healthcare sites - Skills to use digital healthcare services - Skills to interpret the results of various health apps - (Online) communicating skills Critical thinking - To develop critical appraisal skills to interpret the results of health apps	and healthcare services (sites and applications) that are easy to use and adaptable for individuals with different needs, together with the key stakeholders in the digital field as long-time partners in developing digital technologies and related (pandemic) preparedness - To offer easily accessible support to use information technologies - To develop healthcare providers competencies in using online health services - To develop healthcare providers competencies/training to take into account individuals' experiences in using digital technologies and services, and to provide equitable healthcare with needed adaptations

ACCESS TO VALID HEALTH INFORMATION

> *"Every individual has the right to access to all kind of information regarding their state of health, the health services and how to use them, and all that scientific research and technological innovation makes available" - Article 3, European Charter for Patients' Rights*[28]

Access to accurate, reliable, sufficient and transparent information is a human right. All people should have equal opportunities to receive updated and valid information that is easy for them to understand. Access to health information contributes to the knowledge base of the individuals including improved awareness of the health condition and choices for care. Thereby, it secures equitable access to health services[29] and supports self-management of health. During health crises like Covid-19 pandemic, access to valid health information is an important protective measure, but it has been also seen as "the most effective prevention against the disease panic" [30].

Individuals' abilities to extract, compare and analyse health information from different sources form an essential element of the access. These abilities support patients' understanding of a given care and to apply the information to achieve greater control over life in general[31]. Furthermore, opportunities to reach digital health information has possibilities to complement health information provided by health professionals [32,33] and hence, to support patients' understanding of their health condition and the way to promote their health[33].

CHALLENGE

The pandemic crisis has underlined the need for health literacy that enhances access to timely, accurate and applicable health information. The need has been challenged by the rapid spread of misinformation and disinformation especially via social media and other internet tools and services[34]. Together with low health literacy, this phenomenon known as an 'infodemic' has challenged individuals' possibilities to find reliable information from trusted sources, and has increased the risks of noncompliance with protective measures and late access to relevant care[34]. People with lower health literacy are more likely to trust information from social media, friends or, for instance, pharmaceutical companies than information from health authorities such as doctors[35]. For individuals, the validity of information may not only relate to the accuracy of information but also its applicability to one's life and current needs[33].

Abilities to think critically and to find and appraise information on coronavirus secure genuine access to trusted knowledge and to handle the infodemic. However, the COVID-19 pandemic has confirmed that the health literacy of a population is an underestimated problem[36]. For instance, in Europe every fourth adolescent has difficulties in assessing the credibility of health information and comparing information from different sources, and every fifth adolescent has difficulties in finding health related information that is easy for them to understand (Health Behaviour in School-aged Children study 20217/18, unpublished findings). Among the adult population, the proportion who report having difficulties in judging whether health information is reliable, is close to 47 %[1]. Limited health literacy to find, understand, appraise and use information hinders genuine access to information leading to a situation where individuals may lack relevant understanding of their health, the way to promote and sustain it, and when and how to seek help. Health literacy to access information depends also on the availability, complexity and comprehensiveness of valid information of different kinds (e.g., text, figure, voice) that is scientifically and culturally secure[27] and available in relevant languages[24].

> *"The health services have the duty to make all information easily accessible, removing bureaucratic obstacles, educating healthcare providers, preparing and distributing informational materials." - European Charter for Patients' Rights*[28]

FOCUS: HEALTH LITERACY IN THE INFORMATION AGE

Along with access to digital spaces, good health literacy (e.g., information seeking skills, information appraisal skills, internet navigation skills) enables access to valid information and understanding of complex communication. It also supports individuals to draw information from multiple sources and hence to receive sufficient and relevant information, and to develop a comprehensive understanding[37]. Possessing good health literacy enables people to judge the validity of the information sources and select the ones that can be trusted. Clear communication helps all and especially those with cognitive impairments or language difficulties. Furthermore, available information should be shared by trusted sources.

Table 2 provides a summary of the health literacy competencies and the elements of responsiveness of the systems that support people´s health literacy to access valid health information.

Table 2: People´s and systems´ health literacy and access to valid health information

People's health literacy	**Systems' health literacy responsiveness**
Practical skills: ● Ability to seek and find health information from different sources Critical thinking and self-reflective skills: ● Ability to compare and synthesize health information from different sources and ● Ability to appraise health information ● Ability to relate health information to one's own life ● Ability to reflect the usefulness and applicability of information from one's personal perspective	● To offer health information in all relevant languages ● To offer easily available health information ● To offer information that is easy to understand, culturally sensitive and empathetic, by using different communication strategies ● To offer updated and valid health information from trusted sources ● To offer information that is adaptable to the daily lives of individuals and which is "relevant to people of different sexes, ages, ethnic or migration status, sexual orientation, or gender identity, or with a disability or a specific illness, etc."

ACCESS TO APPROPRIATE CARE

> *"Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services." - Article 2, European Charter for Patients' Rights*[28]

Access to appropriate care is a central factor in discussions on healthcare disparities and related health outcomes[38]. In considering the appropriateness of care several elements should be considered: care should be based on clear evidence of effectiveness to improve health, and it should be delivered by healthcare professionals specialising in medicine and with adequate expertise to work in a culturally sensitive manner; appropriate care takes into account the use of resources according to the needs of regions and population groups and with the principle of cost-effectiveness; it is offered in a way that secures equity in care delivery, and; it is patient-centred thus taking into account context, culture, and autonomy, needs and preferences of patients as well as their involvement in care and empowerment in seeking care and self-management[38].

A precondition for being able to receive appropriate care is that for citizens the information about the available health services and the way to use these services should be made easily available[39]. "Access to primary care might be of considerable importance in terms of delivering preventive medical interventions and providing a gateway to a health-care system that delivers effective interventions for the major causes of mortality, including cancer and cardiovascular disease". [40]

CHALLENGE

Awareness of one's rights as a patient is a key element. Nevertheless, people with low health are more likely to experience difficulties in figuring out and finding the available health services and care they need, and hence experience delays in receiving care[41] or even miss appointments[42,43]. Especially people with several long-term mental health conditions[44], elderly people and those with high levels of socioeconomic deprivation are more likely to miss appointments, which is of special concern "if these appointments would have included preventive activities such as screening or chronic disease monitoring"[45]. Limited health literacy is also linked with unnecessary and improper use of health services and resources[46]. Low health literacy is a significant problem in Europe as one in four people report having difficulties in finding information on the treatments of illnesses that concern them and one in five people report in knowing what to do in case of emergency, and one in six people not knowing how to find relevant health care[47–49].

Complex and fragmented healthcare systems hinder the fulfilment of patients' rights to access care they need, and may for its part contribute to the development of health disparities[50]. Complex systems cause unnecessary challenges for individuals in their attempts to find and receive care and hence impair their abilities to navigate the healthcare environment[51]. "In fact, healthcare settings are usually designed assuming limitless health literacy skills by the side of patients", which causes the situation that they are not able to understand and react on the needs of those with low levels of health literacy[51]. Furthermore, unavailability of culturally sensitive care is a clear barrier to access appropriate care[52].

FOCUS: DEALING WITH THE COMPLEXITY OF HEALTHCARE SYSTEMS TO FIND APPROPRIATE CARE

"Health literacy matters for access to care"[41]. All people should know their rights as patients. Having relevant information about one's health condition and the ability to interpret the symptoms of various diseases, in addition to knowing when to seek help is crucial to ensuring timely access to healthcare. People also need sufficient skills to seek, demand and find appropriate care, and to navigate healthcare systems in general. Healthcare systems should be developed in a way that meet the needs of various population groups. Information on the services available with cultural sensitivity should be made easily accessible. “Enhanced health literacy paves the way for both patient empowerment and patient engagement, which are crucial requirements to enhance the functioning of healthcare organizations”[51].

Table 3 provides a summary of health literacy competencies and elements of responsiveness of the systems that support people´s health literacy to access appropriate care

Table 3: People´s and systems´ responsiveness to health literacy and access to valid health information

People’s health literacy	**Systems’ health literacy responsiveness**
Health knowledge ● Having information about one’s rights as a patient ● Having information about the symptoms of disease ● Having information about various choices for health care Practical skills ● Ability to seek ● Ability to demand appropriate care ● Ability to navigate in healthcare systems Self-reflective skills ● Ability to identify and interpret the symptoms of various diseases	● To promote cultural sensitivity and understanding of care ● To offer options for various types of care ● To ensure the availability of easy access information on various options for care, in all relevant languages ● To develop coherent and simple healthcare environments for people to navigate ● To involve people in developing user- and health literacy friendly systems

COMMUNICATION BETWEEN INDIVIDUALS, HEALTH PROFESSIONALS AND HEALTH AUTHORITIES

> *‘Information must be communicated to the patient in a way appropriate to the latter's capacity for understanding, minimizing the use of unfamiliar technical terminology. If the patient does not speak the common language, some form of interpreting should be available’*[39]

"Adequate communication between patients and health professionals is a core principle of medicine"[53]. Improving communication is likely to improve equity through fostering access to information, initiating two-way communication between individuals or communities and health systems, and by taking into account the experiences of the communities as a starting point for the development of systems[54]. Furthermore, the creation of spaces for equal communication and genuine dialogue between patients and healthcare professionals is key to ensuring that options for available care and care provided are understood, relevant and applicable to patients' lives. Clear and participatory communication has the potential to empower people to choose, which is essential for making choices accessible[54]. This requires a shared language including the use of words, concepts and opportunities to ask clarifying questions and to obtain responses at the same level[33] which, together, secure access to information provided and shared decision-making during appointments. The communication style of the care provider is linked with better patient self-management and empowerment[55]. On the other hand, patients' understanding of care and confidence in self-care abilities have the potential to enhance the impact of the provider's communication on self-management[55]. Good communication between patients and healthcare providers forms the basis for patient-centred and shared decision making.

Clear, understandable and well-developed health communication is especially important during health crises like pandemics, and may save lives by, for instance, promoting and accomplishing adherence to required behaviour change[56]. Health professionals and health authorities should find the best ways to reach all people, especially those in vulnerable situations and who are difficult to reach, such as homeless people and digitally disadvantaged with mobility restrictions. Furthermore, communication from trusted sources should be open and honest in what is known and unknown, and it should be consistent, simple and understandable, as well as empathetic[56].

CHALLENGE

Complexity of communication and lack of common language, either due to different spoken languages or the use of words that both do not understand, are obstacles for effective patient-provider communication. Medical terms and medical jargon used either by healthcare professionals or expressed in printed materials offered to patients are likely to result in the misunderstanding of information by patients[33]. Also, limited time allocated for appointments may lead to an instruction that does not allow space for questions and dialogue. Longer appointments which can 'be bought' using private health care have the potential to increase disparities in healthcare access. This is a particular concern in situations when extra time would be necessary due to complex communication needs (Finset et al., 2020), or when people lack sufficient skills in communicating with healthcare professionals, in general.

On average in Europe, 15 % of adults report difficulties in understanding what the doctor is saying, 18 % in reflecting and assessing if the information provided by the doctor is applicable to one’s life, and 28 % in understanding the leaflets that come with the prescribed medicine[48]. These, together with doctors over-estimating their communication skills[57], echo a clear mismatch between an individuals’ competencies and the communication styles of healthcare providers and health authorities. Communication challenges are evident especially when a patient has complex communication needs that should be taken into account carefully[58]. The planning of different ways of communicating, in addition to oral communication, will become paramount[58].

FOCUS: ENHANCING EFFECTIVE TWO-WAY COMMUNICATION WITH HEALTH LITERACY

For communication to be effective and accurate, ”both the nurse [or other health professional] and the patient need to possess the skills and knowledge required for participation within the communicative interaction”, both in cases with or without complex communication needs of the patient[58]. Individuals need sufficient knowledge about their health condition and relevant concepts to be able to understand what health professionals are saying and what is communicated in printed materials. They also need abilities to reflect and assess the issues from their personal perspectives and skills to apply the instructions and decisions in practice to ensure the effectiveness of the communication.

Table 4 provides a summary of the health literacy competencies and the elements of the responsiveness of systems that support the sufficiency of individuals’ health literacy to communicate with healthcare providers

Table 4: People´s and system´s responsiveness to health literacy concerning communication between individuals and health professionals and health authorities

People’s health literacy	**Systems’ health literacy responsiveness**
Health knowledge ● Having adequate health information to be able to communicate clearly ● Having information about one’s right to communication that is appropriate to one’s capacity for understanding Practical skills ● Ability to communicate clearly and seek clarifications ● Ability to communicate in digital health sites and services Critical thinking and self-reflective skills	● To create spaces for communication that take into account the special communication needs of patients ● To offer training for healthcare professionals about various ways of communicating with patients with or without complex communication needs ● To avoid medical jargon and difficult words (shared language) ● To develop cultural understanding and sensitivity ● To allow time for questions, clarifications and two-way discourse ● To develop the availability of digital eHealth

- Ability to assess the appropriateness of the care and applicability of the instructions from one's personal perspective	sites and services for people with different communication needs, and to complement face-to-face appointments - To train healthcare providers skills to provide care and communicate in digital environments in a way that takes into account patients "non-verbal cues, emotional states and understanding"

POSSIBILITIES FOR SHARED DECISION-MAKING REGARDING CARE AND PREVENTION

> *"An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks." (Convention on Human Rights and Biomedicine)*
>
> *"Each individual has the right to freely choose from among different treatment procedures and providers on the basis of adequate information"* [39]

Shared decision making, where healthcare professionals and patients discuss the best possible options for care and make decisions together using best available information[59], is key to patient empowerment. It fosters patients' genuine possibilities to freely choose and make informed decisions about medical alternatives and self-care management. In a patient-centred process for informed consent, information about various options for treatments and their risks, benefits and costs is communicated in a biased-free, transparent and clear way[60]. Shared decision making enhances the respect for patient autonomy, weighing the benefits of treatment against probable risks from the perspective of individuals and their preferences and experiences, and avoiding decisions that would have not been made if patients would have been well informed and involved[59]. It has been linked with improved decision quality, and better patient knowledge and risk perception[61], and it has a potential to decrease the disparities in health between less and more disadvantaged patients in terms of their literacy skills[62]. Furthermore, "well-informed preference-based patient decisions might lead to safer, more cost-effective healthcare, which in turn might result in reduced utilization rates and improved health outcomes"[63].

CHALLENGE

The lack of awareness about involvement being an option and hierarchical healthcare systems hinder shared decision-making processes from evolving. Different studies on adult health literacy in Europe have shown that difficulties in engagement with healthcare providers are clear[47,64]. For instance in Britain, 23 % of people report having concerns about being able to discuss their health concerns with a healthcare provider, 35 % of people report difficulties in making sure that the healthcare provider understands them properly, 25 % of people report difficulties in discussing with the provider until they understand all they need to know, and 23 % of people experience difficulties in asking questions to providers in order to obtain health information[61]. Though some of the difficulties mentioned above are rooted in patients’ low health literacy, some may relate to the difficulties of health authorities to redistribute power and agency[65].

FOCUS: AGENCY AND INFLUENCE THROUGH HEALTH LITERACY

Health literacy addresses the understanding of a person´s rights as a patient and as a human. For instance, for children and adolescents this would mean understanding that they have the right to be heard and involved in making decisions that influence their lives - in accordance with their age and maturity. Health literacy fosters possibilities to participate in decision-making processes, and to share power over knowledge, knowing and making the decisions. A sufficient amount of information on one’s health condition and information on available options for treatment and the associated risks and benefits are prerequisites for being able to participate equally in decision-making about one’s care in the first place and to provide informed consent. The ability to ask for clarifications is needed as is the ability to consider personal preferences, possibilities and values will be taken into account while deciding how to proceed with the care. Healthcare providers should “adapt their procedures to different health literacy states by giving patients a voice, acknowledging their social realities and collaborate with them as equals”[66]. Providers should be aware of the diverse backgrounds and individual needs to facilitate shared-decision making and individualised care [38]. A sufficient amount of information about various treatment options and their risks, benefits and costs, should be given in an understandable way and also in written format to support patients’ abilities to make informed decisions and to communicate that “the decisions are truly owned by the patients”[67].

Table 5 provides a summary of the health literacy competencies and the elements of the responsiveness of the systems that support people´s health literacy to participate in shared-decision making regarding care and prevention.

Table 5: People´s and systems´ responsiveness to health literacy concerning shared decision-making

People’s health literacy	**Systems’ health literacy responsiveness**
Health knowledge ● Having health information about one’s health condition and available options for care ● Having information about one’s rights	● Allowing time and opportunities for shared decision-making (patient-centred practices) ● Offering sufficient amount of information for patients, in different formats ● Supporting patient’s reflective thinking

(including the right to be heard and to participate in making the decision that influences one’s health and health care) Critical thinking and self-reflective skills ● Ability to identify and describe one’s own expectations, preferences, wishes and needs ● Ability to reflect the instructions from one’s personal perspective and to assess what fits with one’s own life (opportunities, preferences) ● Ability to ask for clarifications when necessary Participatory skills ● Ability to participate in making care plans, to discuss about alternative options and to make joint decisions	(supportive communication strategies) ● Valuing patients (their knowledge, experiences etc.) ● Distribution of power, creation of mutual understanding and trust, and respect of patients’ views, expectations and values ● Being aware of diversity of patients and their unique needs

IMPLEMENTATION OF HEALTH LITERACY POLICY, STRATEGY AND DESIGN IN PRACTICE

This part provides insights into the practical approaches and tools to advance health literacy responsiveness and access to quality healthcare in practice. It includes focus on the implementation of health literacy policy and strategy, health literacy interventions and service design, building health literacy capacity as well as partnerships and knowledge-sharing.

IMPLEMENTATION OF HEALTH LITERACY POLICY AND STRATEGY

The WHO Framework on integrated people-centred health services calls for a fundamental shift in the way that health services are funded, managed, and delivered to ensure equitable access to healthcare. The focus is first and foremost on how to develop meaningful, people-centred solutions[68]. Creating a culture of health becomes a priority for policy-makers and decision-makers involved in shaping health services in the 21st Century[69]. By applying the health literacy lens to systems and services it is possible to bridge the inequality gaps and lower barriers to facilitate timely and appropriate healthcare[70].

The **Shanghai Declaration on promoting health in the 2030 Sustainable Development Agenda** provides a global mandate for the prioritization of health literacy within public policy[71]. The Declaration emphasizes the role of good governance and integration of health literacy policies and strategies.

Other examples of countries with **national health literacy policy initiatives** include Australia where improving health literacy is a national priority[72], Austria that has adopted the advancement of health literacy as one of ten national health goals[73], and Portugal that is driving interventions and programmes nation-wide to enhance population health literacy[74].

BUILDING HEALTH LITERACY CAPACITY

Building health literacy capacity entails the development of sustainable skills, organisational structures, resources and commitment to prolonging and multiplying health gains [75]. This means ensuring that conditions are in place to achieve health improvement and that systemic efforts can be multiplied and sustained over time, independent of external events[76].

HEALTH LITERATE WORKFORCE

The growing awareness of health literacy is creating job opportunities and requirements to enhance the workforce with the development of health literacy as a professional skill. A review of American job adverts indicated that health literacy is increasingly mentioned as a skill in demand and even as part of new functions in healthcare, for instance, as a *health literacy coordinator*[77]. Based on the growth related to health literacy research and policy-making in general, it is most likely that the same pattern will show in European countries.

In response, it is encouraged to include health literacy in educational curricula in higher education and post-graduate trainings within a wide range of disciplines[77]. Training in health literacy, plain language, culture and communication are essential for anyone working with health services[78]. Moreover, it is beneficial to take into account the healthcare experiences of patients with low health literacy by inviting patient advocates or adult literacy students to share their experiences and testimonials. It is critical to focus on the user experience as well as on the needs and demands in order to develop the necessary skills for an appropriate health literacy response.

Health literacy curricula can be built on the knowledge, skills and attitudes that health professionals need in order to effectively address low health literacy among consumers of health care services and health information as part of effective health literacy practices [79,80]. The U.S. Institute of Medicine recommends that "professional schools and professional continuing education programs in health and related fields, including medicine, dentistry, pharmacy, social work, anthropology, nursing, public health, and journalism, should incorporate health literacy into their curricula and areas of competence"[81]. In turn, the review of job adverts revealed more than 20 professional disciplines where health literacy is relevant[77].

HEALTH LITERATE ORGANISATIONS, SETTINGS AND COMMUNITIES

Health literacy capacity is needed to develop health literate organizations. According to Brach et al.[82], organisational health literacy capacity can be based on ten attributes: 1) leadership that makes health literacy integral to its mission, structure, and operations; 2) integration of health literacy into planning, evaluation measures, patient safety, and quality improvement; 3) training of workforce to be health literate and monitor progress; 4) involvement of populations served in the design, implementation, and evaluation of health information and services; 5) meeting the needs of populations with a range of health literacy skills while avoiding stigmatisation; 6) applying health literacy strategies in interpersonal communications and confirm understanding at all points of contact; 7) provision of easy access to health information and services and navigation assistance; 8) designing and distributing print, audio-visual, and social media content that is easy to understand and act upon; 9) addressing health literacy in high-risk situations, including care transitions and communication about medicines; and 10) clear communication of what health plans cover and what individuals will have to pay for services[82].

Other resources include the Australian Ophelia toolkit to optimise health literacy in organisations and communities[12,83]; the American Health Literacy Universal Precaution toolkit presented by the Agency for Health Literacy Research and Quality[84]; and the Vienna model for health literate hospitals[85]. In recent years, health literacy is being implemented beyond the health sector through efforts in, for example, schools[86,87] and at work[69,88]. According to the Shanghai Declaration[71], health literacy should be developed first and foremost through the school curriculum, and its role as part of Health Promoting Schools has been widely acknowledged[89,90].

HEALTH LITERACY COMMUNICATION AND SERVICE DESIGN

Limited health literacy is a pervasive and independent risk factor for poor health outcomes. Often health systems are overly complex. For those with limited health literacy, the complexity may be a barrier and hamper the quality of care. In order to bridge this fundamental injustice, it is recommended to integrate universal precautions that presume limited health literacy for all healthcare users, expanded use of technology supported communication, and clinical incentives that account for limited health literacy[91]. According to the *Review of Public Health Capacity in the EU*, health literacy strategies enhance the inclusion of people in vulnerable situations, for instance, in relation to ethnicity[92,93]. A number of resources are presented to enhance health literate interaction and communication as well as service design.

INTERACTION AND COMMUNICATION TO ENHANCE HEALTH LITERACY

Clear communication is the basis for patients to be able to understand and act on health information. Regardless of a patient’s health literacy level, it is important that staff ensure that patients understand the information they have been given. Common tools to improve interaction and communication include *Ask Me 3, Teach-Back* and *Three Steps for better health literacy.*

Ask Me 3 is an approach developed by the Partnership for Clear Health Communication[94]. It is a quick, effective tool designed to improve health communication between patients and providers. Ask Me 3 promotes three simple but essential questions that patients should ask their providers in every health care interaction and providers should always encourage their patients to understand the answers to:

1) *What is my main problem?*
2) *What do I need to do?*
3) *Why is it important for me to do this?*

Three steps for better health literacy – a guide for health professionals[95] is an approach developed by the Ministry of Health in New Zealand and it is recommended for health professionals to lower barriers for healthcare and reduce complexity. It includes three steps:

1) *Find out what people know*
2) *Build health literacy skills and knowledge*
3) *Check you were clear (and, if not, go back to step 2)*

Teach-Back is an activity in which learners teach each other what they have learned, for instance, by using verbal explanations, demonstrations, and skits[84]. The Teach-Back method is a way of checking understanding by asking patients to state in their own words what they need to know or do about their health and to confirm that things have been explained in a manner that patients understand. Teach-back can be applied whenever explaining important and complex concepts to patients about their health care such as a new diagnosis, medication, home care instructions, treatment plans, behavioural change recommendations, the use of new devices, treatment options and follow-up instructions.

HEALTH LITERATE SERVICE DESIGN

Health literate service design focuses on how patients become health literate regarding their condition, how they experience healthcare communication (including information exchange and informed/shared decision-making), how health literacy affects patients' experiences of using healthcare services in various contexts, and what the facilitators and barriers to the development and use of health literacy skills are. The following examples demonstrate how to increase health literacy responsiveness as for better service design.

The (supported) **Health Literacy Pathway Model** is an example that describes how health literacy develops along a trajectory that enables individuals, supported by others, to seek, engage with and act on health information to manage their health and become more actively involved in healthcare consultations and informed decision-making[96].

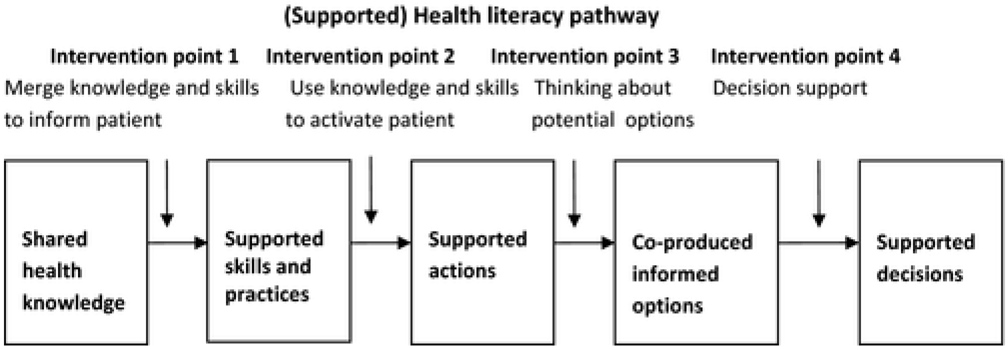

Figure 3: The supported health literacy pathway

Patient journey mapping is a way to visualise and obtain an overview of patient experience during their entire care journey. A patient journey map (also known as healthcare customer journey map) is an outline of all the touchpoints a patient goes through in their care journey in a healthcare facility. This includes all the touchpoints pre-, during, and post-visit. This method provides insights into the patient experiences during their care journey in a healthcare facility and the patient flow in general to create strategies to improve the quality of care, increase efficiency, and improve patient satisfaction[97].

Mapping linguistic landscapes is a method to study visible semiotic signs in public spaces to study how language includes or excludes people from communication and full participation in social and societal contexts. It is used to gain insights in how people navigate healthcare systems and to improve healthcare environments[98].

Given that clinical research communications can be very technical and complex, using **plain language**[99] can help clearly explain information so that the target audience has a better chance of understanding. Plain language helps the reader to:

1) *Find what they need*
2) *Understand what they find*
3) *Use what they find to meet their needs*

Data visualisation, such as the use of infographics and graphs, has become a meaningful way to present medical data that impacts decision-making on a collective and individual level to enhance health literacy[100]. Data visualisation involves breaking down the data points in terms of time, place, and elements of which people are familiar with, or personalising/localising numbers to make them more digestible and meaningful. Storytelling with data through simple graphs, comparative charts and representational icons often helps to make the implicit explicit as a means to enhance individual and population health.

Applying visual elements and plain language help bring an individual with lower health literacy and numeracy skills to an outcome that equates to better health behaviours and practices[99].

PARTNERSHIPS AND KNOWLEDGE SHARING

A vibrant worldwide community is driving the rise of a global health literacy movement for social change building on empowerment and health equity. The movement is based on formal and informal health literacy interest groups, coalitions, alliances, networks, platforms as well as institutes, organisations and associations where health literacy is being developed, discussed and assessed to strengthen capacities[101]. Some European and international examples include:

- **International Health Literacy Association (IHLA)** which was inaugurated in 2017. The aim of IHLA is to unite people around the world working to promote health literacy with the purpose of creating health literacy for all and a world where people and societies can act to improve health and quality of life. The backbone of the organization is based on the interest groups which develop and implement health literacy within a wide range of topics [https://i-hla.org/].
- **Health Literacy Europe** was launched in 2010 as a spin-off of the European Health Literacy Project (2009-2012). The network hosts the European Health Literacy Conferences and supports the development of health literacy in a European context [https://www.healthliteracyeurope.net/].
- The **Asian Health Literacy Association (AHLA)** was launched in 2013. It hosts the Asian Health Literacy Conferences and supports the development of health literacy in Asia [https://www.ahla-asia.org/].
- The **WHO Action Network on Measuring Health Literacy in Populations and Organizations (M-POHL)** was established in 2017 with the purpose of measuring health literacy in Europe at population and organisational levels. The International Coordination Centre is based in Austria. The network is in charge of the HLS19 European health literacy survey which was conducted in 2019/2020. The initiative is an amplification of the first European Health Literacy Survey from 2011 [https://m-pohl.net/].

National initiatives have developed in several countries such as in the United Kingdom and the Netherlands:

- The **UK Health Literacy Network** represents a multi-disciplinary group. The aim of the network is to advance research, theory, education and practice on health literacy with special attention to its personal, social, economic and political implications [https://www.healthliteracy.org.uk/].
- The **Dutch Health Literacy Alliance** was created in 2010, as a spin-off of the European Health Literacy Project, to establish a more inclusive society by improving health literacy competencies for health and self-management of the population. The Alliance promotes health literacy of citizens and supports health professionals in

recognizing and addressing health literacy issues. The Alliance also promotes clear communication and plain language [https://www.gezondheidsvaardigheden.nl/].

At an institutional level, partnerships and knowledge-sharing regarding health literacy is being developed in various forms. This includes the German Interdisciplinary Centre for Health Literacy Research at Bielefeld University focuses on research and policy development; the UK's Health Literacy Place which is the primary health literacy resource for the NHS, and the US Health Literacy Tool Shed which is hosted by Boston University.

- The **Interdisciplinary Centre for Health Literacy Research at Bielefeld University** [ICHL] is a cross-faculty research unit aiming to streamline all research activities concerning health literacy at Bielefeld University. The focus is on both basic research and applied research. As a health literacy hub, it focuses on health literacy research, practice and policy as well as providing a home for early career researchers, post docs and senior researchers from Germany and abroad [https://www.uni-bielefeld.de/(en)/erziehungswissenschaft/izgk/].
- The **Health Literacy Place** is the main resource platform for the UK's NHS. The NHS has launched two national health literacy action plans. The platform supports knowledge exchange and tools and best practices [http://www.healthliteracyplace.org.uk/]
- **Health Literacy Tool Shed** is hosted by Boston University. It is an online database of health literacy measures. The site contains information about measures, including their psychometric properties, based on a review of peer-reviewed literature [https://healthliteracy.bu.edu/].

Health literacy is highly cross-sectoral and inter-disciplinary. Increased collaboration across sectors and disciplines can enhance the knowledge transfer and outcome of health literacy partnerships and programmes.

CONCLUDING REMARKS

This technical report aims to inform decision-makers on the mitigating role of health literacy in the provision of equitable access to healthcare in order to guide policy, strategy and service design. It introduces the concept of health literacy and argues its importance for the development of sustainable healthcare systems. Moreover, it lists a range of challenges which needs to be considered when developing user-centred solutions that can help lower barriers related to accessibility. Finally, a toolbox provides a way how to implement health literacy in practice as part of policy, strategy and service design.

Improving the health literacy of people and organisations has the potential to improve the safety and quality of health care, reduce disparities in health outcomes and to promote more prosperous and equitable societies[102]. Social justice is at the heart of the work of

Council of Europe. Inequities in health systematically put groups of people who are already socially disadvantaged (for example, by virtue of being poor, female, and/or members of a disenfranchised racial, ethnic, or religious group) at further disadvantage with respect to their health. Recognising that health is essential to wellbeing and to overcoming other effects of social disadvantage, health literacy as a means to enhance access to healthcare can be a lever to increase equal opportunities to be healthy for all population groups. Equity in health implies that resources are distributed and processes are designed in ways most likely to move toward equalising the health outcomes of disadvantaged social groups with the outcomes of their more advantaged counterparts. This includes the distribution and design not only of health care resources and programmes but of all resources, policies and programmes that play an important part in shaping health, many of which are outside the immediate control of the health sector.

The pandemic demonstrates how important health literacy is for the prevention of communicable and non-communicable diseases[36] and how essential it is to develop health literate populations and organisations that can respond adequately to needs and demands[36]. In many countries, health literacy is an untapped resource which is not yet fully developed. Health literacy is an asset for healthcare, disease prevention and health promotion[103]. An investment in health literacy generates a return on economic and social investments[104] because it can help save time, costs and lives[105]. Enhancing equal access to healthcare is, therefore, an important aspect to prioritise.

REFERENCES

1. Sørensen, K. *et al.* Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *Eur. J. Public Health* **25**, 1053–8 (2015).

2. Sørensen, K., Trezona, A., Levin-Zamir, D., Kosir, U. & Nutbeam, D. *Transforming health systems and societies by investing in health literacy policy and strategy*. (2019).

3. Council of Europe. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. (1997). Available at: https://www.coe.int/en/web/conventions/full-list/-/conventions/rms/090000168007cf98. (Accessed: 30th April 2021)

4. Nutbeam, D. & Lloyd, J. E. Understanding and Responding to Health Literacy as a Social Determinant of Health. *Annu. Rev. Public Health* **42**, (2021).

5. Nutbeam, D. & Muscat, D. M. Health Promotion Glossary 2021. *Health Promot. Int.* (2021). doi:10.1093/heapro/daaa157

6. Kickbusch, I. Health and citizenship: the characteristics of 21st century health. *World Hosp Heal. Serv.* **40**, 12–4 (2004).

7. Sørensen, K. *et al.* Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health* **12**, (2012).

8. McIntyre, D., Thiede, M. & Birch, S. Access as a policy-relevant concept in low- and middle-income countries. *Heal. Econ. Policy Law* **4**, 179–193 (2009).

9. Abatemarco, A., Beraldo, S. & Stroffolini, F. Equality of opportunity in health care: access and equal access revisited. *Int. Rev. Econ.* **67**, 13–29 (2020).

10. Dixon-Woods, M. *et al.* Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology* **6**, 35 (2006).

11. Marmot, M., Friel, S., Bell, R., Houweling, T. A. & Taylor, S. Closing the gap in a generation: health equity through action on the social determinants of health. *Lancet* **372**, 1661–1669 (2008).

12. Trezona, A., Dodson, S. & Osborne, R. H. Development of the organisational health literacy responsiveness (Org-HLR) framework in collaboration with health and social services professionals. *BMC Health Serv. Res.* **17**, 513 (2017).

13. World Helalth Organization. *Global Strategy on Digital Health 2020–2025*. (2020).

14. A Europe fit for the digital age | European Commission. Available at: https://ec.europa.eu/info/strategy/priorities-2019-2024/europe-fit-digital-age_en. (Accessed: 30th April 2021)

15. Kickbusch, I., Agrawal, A., Jack, A., Lee, N. & Horton, R. Governing health futures 2030: growing up in a digital world”a joint The Lancet and Financial Times Commission. *Lancet* **394**, 1309 (2019).

16. Beaunoyer, E., Dupéré, S. & Guitton, M. J. COVID-19 and digital inequalities: Reciprocal impacts and mitigation strategies. *Comput. Human Behav.* **111**, 106424 (2020).

17. Crawford, A. & Serhal, E. Digital health equity and COVID-19: The innovation curve cannot reinforce the social gradient of health. *Journal of Medical Internet Research* **22**, e19361 (2020).

18. Blandford, A., Wesson, J., Amalberti, R., AlHazme, R. & Allwihan, R. Opportunities and challenges for telehealth within, and beyond, a pandemic. *The Lancet Global Health* **8**, e1364–e1365 (2020).

19. Moorhead, S. A. *et al.* A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for health communication. *Journal of Medical Internet Research* **15**, e1933 (2013).

20. Statista Research Department. Share of households with internet access in the European Union (EU) from 2007 to 2020. (2021).

21. Council of Europe. *Strategic Action Plan on Human Rights and Technologies in Biomedicine (2020-2025)*. (2020).

22. Brall, C., Schröder-Bäck, P. & Maeckelberghe, E. Ethical aspects of digital health from a justice point of view. *Eur. J. Public Health* **29**, 18–22 (2019).

23. Ayalon, L. *et al.* Aging in Times of the COVID-19 Pandemic: Avoiding Ageism and Fostering Intergenerational Solidarity. *J. Gerontol. B. Psychol. Sci. Soc. Sci.* **76**, e49–e52 (2021).

24. Kaurin, D. *Space and imagination: rethinking refugees' digital access*. (2020).

25. The Lancet Healthy Longevity. Ageing in a post COVID world. *The Lancet Healthy Longevity* **2**, e53 (2021).

26. Chan, C. V & Kaufman, D. R. A Framework for Characterizing eHealth Literacy Demands and Barriers. *J. Med. Internet Res.* **13**, e94 (2011).

27. *Health at a Glance: Europe 2018*. (OECD, 2018). doi:10.1787/health_glance_eur-2018-en

28. European Patients Forum. *The Patients' Charter on Patient Empowerment*. (2015).

29. Thiede, M. Information and access to health care: Is there a role for trust? in *Social Science and Medicine* **61**, 1452–1462 (2005).

30. The Lancet. COVID-19: fighting panic with information. *The Lancet* **395**, 537 (2020).

31. Inoue, Y., Sato, M. & Filo, K. Transformative Sport Service Research: Linking Sport Services With Well-Being. *J. Sport Manag.* **34**, 285–290 (2020).

32. Gilmour, J. A. Reducing disparities in the access and use of Internet health information. A discussion paper. *International Journal of Nursing Studies* **44**, 1270–1278 (2007).

33. Poureslami, I. *et al.* Development and pretesting of a new functional-based health literacy measurement tool for chronic obstructive pulmonary disease (COPD) and asthma management. *Int. J. COPD* **15**, 613–625 (2020).

34. Abdel-Latif, M. M. M. The enigma of health literacy and COVID-19 pandemic. *Public Health* **185**, 95–96 (2020).

35. Chen, X. *et al.* Health Literacy and Use and Trust in Health Information. *J. Health Commun.* **23**, 724–734 (2018).

36. Paakkari, L. & Okan, O. COVID-19: health literacy is an underestimated problem. *Lancet Public Heal.* **5**, e249–e250 (2020).

37. Suka, M. *et al.* Relationship between health literacy, health information access, health behavior, and health status in Japanese people. *Patient Educ. Couns.* **98**, 660–668 (2015).

38. Robertson-Preidler, J., Biller-Andorno, N. & Johnson, T. J. What is appropriate care? An integrative review of emerging themes in the literature. *BMC Health Serv. Res.* **17**, 452 (2017).

39. World Health Organization. *A declaration on the promotion of patients´ rights in Europe*. (1994).

40. Gulliford, M. Access to primary care and public health. *Lancet Public Heal.* **2**, e532–e533 (2017).

41. Levy, H. & Janke, A. Health Literacy and Access to Care. *J. Health Commun.* **21**, 43–50 (2016).

42. Baskaradoss, J. K. The association between oral health literacy and missed dental appointments. *J. Am. Dent. Assoc.* **147**, 867–874 (2016).

43. Cronin, R. M. *et al.* Modifying factors of the health belief model associated with missed clinic appointments among individuals with sickle cell disease. *Hematology* **23**, 683–691 (2018).

44. McQueenie, R., Ellis, D. A., McConnachie, A., Wilson, P. & Williamson, A. E. Morbidity, mortality and missed appointments in healthcare: A national retrospective data linkage study. *BMC Med.* **17**, 2 (2019).

45. Ellis, D. A., McQueenie, R., McConnachie, A., Wilson, P. & Williamson, A. E. Demographic and practice factors predicting repeated non-attendance in primary care: a national retrospective cohort analysis. *Lancet Public Heal.* **2**, e551–e559 (2017).

46. Palumbo, R., Annarumma, C., Adinolfi, P., Musella, M. & Piscopo, G. The Italian Health Literacy Project: Insights from the assessment of health literacy skills in Italy. *Health Policy (New. York).* **120**, 1087–1094 (2016).

47. Sørensen, K. *et al.* Health literacy in Europe: Comparative results of the European health literacy survey (HLS-EU). *Eur. J. Public Health* **25**, 1053–1058 (2015).

48. Comparative Report on Health Literacy in Eight EU Member States: The European Health Literacy Survey HLS-EU. (2012).

49. Schaeffer, D., Berens, E.-M. & Vogt, D. Health Literacy in the German Population Results of a Representative Survey. **144**, (2017).

50. Hasnain-Wynia, R. & Wolf, M. S. Promoting health care equity: is health literacy a missing link? *Health Serv. Res.* **45**, 897–903 (2010).

51. Palumbo, R. Designing health-literate health care organization: A literature review. *Heal. Serv. Manag. Res.* **29**, 79–87 (2016).

52. Dougherty, L., Lloyd, J., Harris, E., Caffrey, P., & Harris, M. Access to appropriate health care for non-English speaking migrant families with a newborn/young child: a systematic scoping literature review. *BMC Health Serv. Res.* **20**, 1–12 (2020).

53. Singh Ospina, N. *et al.* Educational programs to teach shared decision making to medical trainees: A systematic review. *Patient Education and Counseling* **103**, 1082–1094 (2020).

54. Thiede, M. & McIntyre, D. Information, communication and equitable access to health care: A conceptual note. *Cadernos de Saude Publica* **24**, 1168–1173 (2008).

55. Heisler, M., Bouknight, R. R., Hayward, R. A., Smith, D. M. & Kerr, E. A. The relative importance of physician communication, participatory decision making, and patient understanding in diabetes self-management. *J. Gen. Intern. Med.* **17**, 243–252 (2002).

56. Finset, A. *et al.* Effective health communication – a key factor in fighting the COVID-19 pandemic. *Patient Education and Counseling* **103**, 873–876 (2020).

57. Ha, J. F. & Longnecker, N. Doctor-patient communication: A review. *Ochsner Journal* **10**, 38–43 (2010).

58. Finke, E. H., Light, J., & Kitko, L. A systematic review of the effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication. *J. Clin. Nurs.* **17**, 2102–2115 (2008).

59. Stiggelbout, A. M. *et al.* Shared decision making: Really putting patients at the centre of healthcare. *BMJ (Online)* **344**, (2012).

60. Spatz, E. S., Krumholz, H. M. & Moulton, B. W. The new era of informed consent getting to a reasonable-patient standard through shared decision making. *JAMA - Journal of the American Medical Association* **315**, 2063–2064 (2016).

61. Kashaf, M. S., McGill, E. T., & Berger, Z. D. Shared decision-making and outcomes in type 2 diabetes: a systematic review and meta-analysis. *Patient Educ. Couns.* **100**, 2159–2171 (2017).

62. Durand, M. A. *et al.* Do interventions designed to support shared decision- making reduce health inequalities? A systematic review and meta-analysis. *PLoS One* **9**, e94670 (2014).

63. Elwyn, G., Frosch, D. L. & Kobrin, S. Implementing shared decision-making: Consider all the consequences. *Implement. Sci.* **11**, 114 (2016).

64. Bo, A., Friis, K., Osborne, R. H. & Maindal, H. T. National indicators of health literacy: ability to understand health information and to engage actively with healthcare providers - a population-based survey among Danish adults. *BMC Public Health* **14**, 1095 (2014).

65. Halvorsen, K., Dihle, A., Hansen, C., Nordhaug, M., Jerpseth, H., Tveiten, S., ... & Knutsen, I. R. Empowerment in healthcare: A thematic synthesis and critical discussion of concept analyses of empowerment. *Patient Educ. Couns.* **103**, 1263–1271 (2020).

66. Samerski, S. Health literacy as a social practice: Social and empirical dimensions of knowledge on health and healthcare. *Soc. Sci. Med.* **226**, 1–8 (2019).

67. Krumholz, H. M. Informed consent to promote patient-centered care. *JAMA - Journal of the American Medical Association* **303**, 1190–1191 (2010).

68. WHO | What are integrated people-centred health services? *WHO* (2017).

69. Kyle, M. A. *et al.* Toward a Corporate Culture of Health: Results of a National Survey. *Milbank Q.* (2019). doi:10.1111/1468-0009.12418

70. Koh, H. K., Baur, C., Brach, C., Harris, L. M. & Rowden, J. N. Toward a Systems Approach to Health Literacy Research. *J. Health Commun.* **18**, 1–5 (2013).

71. World Health Organization. *Shanghai Declaration on Health Promotion in the 2030 Agenda for Sustainable Development*. (2016).

72. Australian Commission on Safety and Quality in Health Care. *Health literacy: Taking action to improve safety and quality*. (ACSQHC, 2014).

73. Trezona, A. *et al.* Progress in Implementing National Policies and Strategies for Health Literacy—What Have We Learned so Far? *Int. J. Environ. Res. Public Health* **15**, 1554 (2018).

74. Direção-Geral da Saúde. *Plano de ação para a literacia em saúde health literacy action plan portugal 2019-2021*. (2018).

75. Hawe, P., Noort, M., King, L. & Jordens, C. Multiplying health gains: the critical role of capacity-building within public health programs. *Health Policy (New. York).* **39:**, 29-42. (1997).

76. Aluttis, C. *et al. Review of Public Health Capacity in the EU*. *x* (European Commission Directorate General for Health and Consumers, 2013).

77. Sørensen, K. Professionalizing health literacy: a new public health capacity. *Eur. J. Public Health* **24**, (2014).

78. Schyve, P. M. Language differences as a barrier to quality and safety in health care: the Joint Commission perspective. *J. Gen. Intern. Med.* **22 Suppl 2**, 360–1 (2007).

79. Karuranga, S., Sørensen, K., Coleman, C. & Mahmud, A. J. Health Literacy Competencies for European Health Care Personnel. *HLRP Heal. Lit. Res. Pract.* **1**, e247–e256 (2017).

80. Coleman, C. A., Hudson, S. & Maine, L. L. Health literacy practices and educational competencies for health professionals: a consensus study. *J. Health Commun.* **18 Suppl 1**, 82–102 (2013).

81. Nielsen-Bohlman, L. T., Panzer, A. M. & Kindig, D. A. *Health Literacy: A Prescription to End Confusion*. (The National Academies Press, 2004).

82. Brach, C. *et al.* Attributes of a Health Literate Organization. *Inst. Med.* (2012).

83. Batterham, R. W. *et al.* The OPtimising HEalth LIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform. *BMC Public Health* **14**, 694 (2014).

84. Agency for Healthcare Research and Quality. *AHRQ Health Literacy Universal Precautions Toolkit*. (2017).

85. Pelikan, J. & Professor. The Vienna model for health literate hospitals: engaging patients and caregivers 1. in 23 (HARC, 2016).

86. Paakkari, L. & Paakkari, O. Health literacy as a learning outcome in schools. *Health Education* **112**, 133–152 (2012).

87. Sørensen, K. & Okan, O. *Health literacy. Health literacy of children and adolescents in school settings.* (2020).

88. Hochmut, N. & Sørensen, K. Health literate companies - a systematic literature review. *J. Heal. Lit. Res. Pract.* **In print**, (2021).

89. Okan, O., Paakkari, L., & Dadaczynski, K. *Health literacy in schools. State of the Art.* (2021).

90. Paakkari, L., Inchley, J., Schulz, A., Weber, M. W., & Okan, O. Addressing health literacy in schools in the WHO European Region. **5**, 2–3 (2019).

91. Volandes, A. E. & Paasche-Orlow, M. K. Health literacy, health inequality and a just healthcare system. *Am. J. Bioeth.* **7**, 5–10 (2007).

92. Paasche-Orlow, M. K., Parker, R. M., Gazmararian, J. A., Nielsen-Bohlman, L. T. & Rudd, R. R. The prevalence of limited health literacy. *J. Gen. Intern. Med.* **20**, 175–184 (2005).

93. Wångdahl, J., Lytsy, P., Mårtensson, L. & Westerling, R. Health literacy among refugees in Sweden - a cross-sectional study. *BMC Public Health* **14**, 1030 (2014).

94. Tille, F., Weishaar, H., Gibis, B. & Schnitzer, S. Patients' understanding of health information in Germany. *Patient Prefer. Adherence* **13**, 805–817 (2019).

95. Health Quality & Safety Commission New Zealand. *Three steps to better health literacy – a guide for health professionals*.

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

97. Patient journey mapping: What you need to know. Available at: https://www.qmatic.com/blog/patient-journey-mapping. (Accessed: 1st May 2021)

98. Rudd, R. R. & Anderson, J. E. *The health literacy environment of hospitals and health centers*. (Harvard School of Public Health, 2006).

99. Health Literacy Innovations. *The Health Literacy & Plain Language Resource Guide*. (2008).

100. Arcia, A. *et al.* Method for the development of data visualizations for community members with varying levels of health literacy. *AMIA Annu. Symp. Proc.* **2013**, 51–60 (2013).

101. Sørensen, K., Karuranga, S., Denysiuk, E. & McLernon, L. Health literacy and social change: exploring networks and interests groups shaping the rising global health literacy movement. *Glob. Health Promot.* **25**, 89–92 (2018).

102. Sørensen, K., Trezona, A., Levin-Zamir, D., Kosir, U. & Nutbeam, D. Transforming health systems and societies by investing in health literacy policy and strategy. *Public Heal. Panor.* **5**, 123–329 (2019).

103. Nutbeam, D. & Muscat, D. M. Advancing Health Literacy Interventions. in *Studies in Health Technology and Informatics* **269**, 115–127 (IOS Press, 2020).

104. Stielke, A., Dyakova, M., Ashton, K. & van Dam, T. The social and economic benefit of health literacy interventions in the WHO EURO region. *Eur. J. Public Health* **29**, (2019).

105. Koh, H. K. *et al.* New Federal Policy Initiatives To Boost Health Literacy Can Help The Nation Move Beyond The Cycle Of Costly 'Crisis Care'. *Health Aff.* **31**, 434–443 (2012).