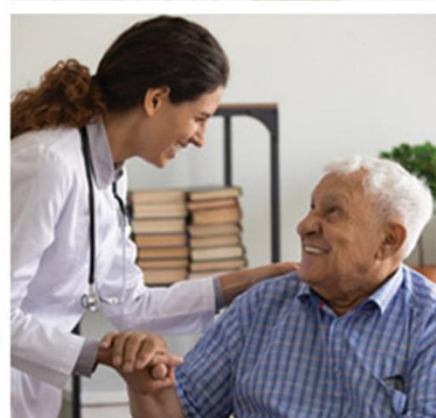
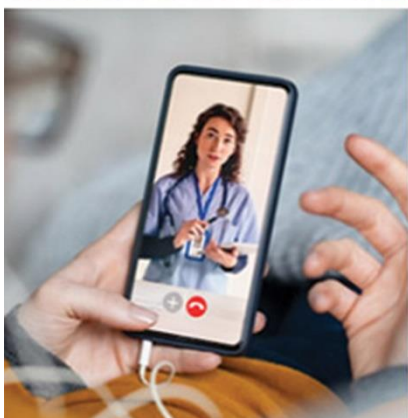


GUIDE TO HEALTH LITERACY

CONTRIBUTING TO TRUST BUILDING AND EQUITABLE ACCESS TO HEALTHCARE



Steering Committee for Human Rights
in the fields of Biomedicine
and Health (CDBIO)

***GUIDE TO HEALTH LITERACY
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EQUITABLE ACCESS TO HEALTHCARE***

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ESSENTIAL ELEMENTS

Health literacy makes a fundamentally important contribution to safeguarding the human rights principle of equitable access to healthcare, especially when existing healthcare resources are less accessible to certain populations due to their circumstances.

Improving the health literacy of people and systems has the potential to improve the safety and quality of health care, reduce disparities in health outcomes thereby promoting more prosperous and equitable societies. It is an asset for healthcare, disease prevention and health promotion. It generates a return on social and economic investments which helps to save time, costs, and lives.

The Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO) invites member states to strengthen and develop their health literacy efforts - with a view to securing equity in accessing healthcare and decreasing health disparities - in particular by:

- ▶ **supporting users of health systems, including their caregivers and representatives of associations, to access valid health information and appropriate care, as well as to actively participate in shared decision making with health professionals and health authorities regarding treatment and care;**
- ▶ **promoting access to digital spaces to understand and thereby to use health services, so that individuals may fully benefit from them;**
- ▶ **mobilising policy makers and health authorities to advance health literacy in collaboration with non-state stakeholders, such as academia, industry, and NGOs;**
- ▶ **conducting health literacy needs assessments at various levels. Decision-makers and health providers are encouraged to deploy an evidence-based approach to health literacy;**
- ▶ **increasing health literacy capacity, such as in the design of health systems, workforce and leadership training and education, awareness raising of health literacy as a job opportunity and requirement, and the development of health literacy as a professional skill.**

FOREWORD

In the framework of its Strategic Action Plan on Human Rights and Technologies in Biomedicine (2020-2025), the CDBIO committed to preparing a Guide to health literacy for equitable access to health care in order to empower all people, including those in vulnerable situations, to be more effective advocates in accessing healthcare services and in making appropriate decisions regarding their health. It is essential that they understand health information and know what healthcare services are available and how best to access them.

The coordination of this work was entrusted to CDBIO member, Assunta Morresi (Italy), chair of the drafting group to prepare the guide. The drafting group was composed of the following members, Lucie Bozec (France), Siobhan O'Sullivan (Ireland), Rodica Gramma (Moldova), Jorge Soares (Portugal), Iuliia Davydova (Ukraine), and by the following consultant experts, Kristine Sørensen (Denmark), Leena Paakkari (Finland).

From 16 February to 18 March 2022, an expert consultation was organised by the drafting group. The consultation collected comments, suggestions, and examples from representatives of various sectors, including the Office of the Special Representative for migration and refugees as the guide is an activity foreseen in the Council of Europe Action Plan on Protecting Vulnerable Persons in the Context of Migration and Asylum in Europe (2021-2025). The drafting group took into account these comments in revising the guide which was presented to the CDBIO at its first meeting, held on 2-4 June 2022, and later approved by the CDBIO at its second meeting, held on 2-4 November 2022.



INTRODUCTION

The efficiency of health systems relies to a large extent on the way they are perceived, understood, and trusted, as well as on the accessibility of the services they offer, whilst ensuring respect for human rights. Those elements are greatly affected by people's health literacy. Limited health literacy is closely related to adverse health outcomes whereby health literacy becomes a critical social determinant of health. This has an impact on the use of health services, health costs and the ways in which people engage with the health system. Despite investments in health services, many people are often not supported in accessing, understanding, appraising, and applying information to navigate complex health systems and environments.

European health systems face a range of challenges, including reductions in funding, ageing populations, increased immigration, cultural diversity, personnel shortages, waiting lists for patients, managed care, home care, long-term care, the growing use of technology and digital health services and tools, and health threats. The Covid-19 pandemic has clearly shown that health literacy is a matter of public concern. Health literacy is highly content- and context-related and it relates to low-income, medium-income and high-income countries alike.

PURPOSE

This guide is intended for decision-makers, health professionals and health providers to help them identify the needs of individuals in accessing healthcare, and to undertake the corresponding responsibilities this entails, namely to:

- ▶ support the development of more accessible and inclusive health systems in which health literacy serves as a profound pillar in relation to good governance.
- ▶ policymakers and health providers play a central role in prioritising and implementing health literacy through a whole-of-governance and whole-of-society approach, in ways that enhance the health literacy of populations as well as the responsiveness of organisations providing health and social services.
- ▶ improve health literacy policy, research, and practice in their countries as part of the human rights agenda, identifying national needs and developing targeted health literacy solutions, such as for people in vulnerable situations, and collaborating with and developing health literacy communities within and beyond the member states of the Council of Europe.

The guide is intended to be:

- ▶ an informative and actionable online resource;
- ▶ illustrative by using good practices;
- ▶ ready and easy to use.

In addressing health literacy, the guide explains why it is important in relation to saving time, costs, and lives. It provides examples of health literacy barriers and enablers for equitable access to health care. The guide focuses on the challenges and opportunities in implementing health literacy in policy and practice. It also suggests ways in which decision-makers and health providers can implement health literacy at various individual, organisational, and political levels to help monitor progress based on strategy, targets, and measurements.

SCOPE

The guide focuses on health literacy in relation to individuals and health systems, including healthcare, disease prevention and health promotion.

FOR THE PURPOSE OF THIS GUIDE:

Health literacy is linked to literacy and entails people's knowledge, motivation, and competencies to access, understand, appraise, and apply health information in order to make judgments and make decisions in everyday life concerning healthcare, disease prevention and health promotion for themselves and those around them.

On the one hand, health literacy reflects people's skills to meet the complex demands of health systems. On the other hand, health literacy concerns the capacity of health systems to meet the complex needs and demands of people they serve. Health literacy is a multidimensional concept based on the interaction and match between health systems and individuals, families, and communities. Many countries are most likely already actively engaged in health literacy matters without adding the health literacy label to their actions.

HEALTH LITERACY KNOWLEDGE AND COMPETENCIES REFER TO:

- ▶ health knowledge, such as information related to health, disease, and patients' rights;
- ▶ practical skills, such as basic digital skills, communication skills and abilities to seek health information and to navigate health care settings;
- ▶ critical thinking and self-reflective skills, such as the abilities to compare and assess the credibility of health information, to reflect on the usefulness of information from a personal perspective, and to be aware of and identify the symptoms of various diseases;
- ▶ ethical responsibility, such as the knowledge of one's rights as a patient, the ability to go beyond a personal perspective by thinking about the consequences of one's actions on others.



HEALTH LITERACY - AN INTEGRAL FOUNDATION OF AN EFFICIENT AND TRUSTWORTHY HEALTH SYSTEM

Being closely linked to literacy, health literacy is one of several types of literacy, such as data literacy and civic literacy, which are needed to make sense of the world. Apart from general health literacy, it is often described in relation to specific content or context, for instance digital health literacy, vaccine literacy and diabetes literacy.

WHAT IS HEALTH LITERACY AND WHY IS IT IMPORTANT?

The comprehensive conceptual model of health literacy (see figure below) focuses on how people access, understand, appraise, and apply information concerning healthcare, disease prevention and health promotion. It explains how health literacy develops across the life span and illustrates the influence of personal, situational, and contextual factors, such as social and environmental determinants. The model also demonstrates how health literacy can impact health system use and costs, health behaviour and health outcomes, participation and empowerment, equity, and sustainability. While it is highly relevant for individuals and populations' ability to act on health matters, health literacy also depends on the support provided by health systems, such as services being easy to access and navigate, clear communication, and informed decision-making.

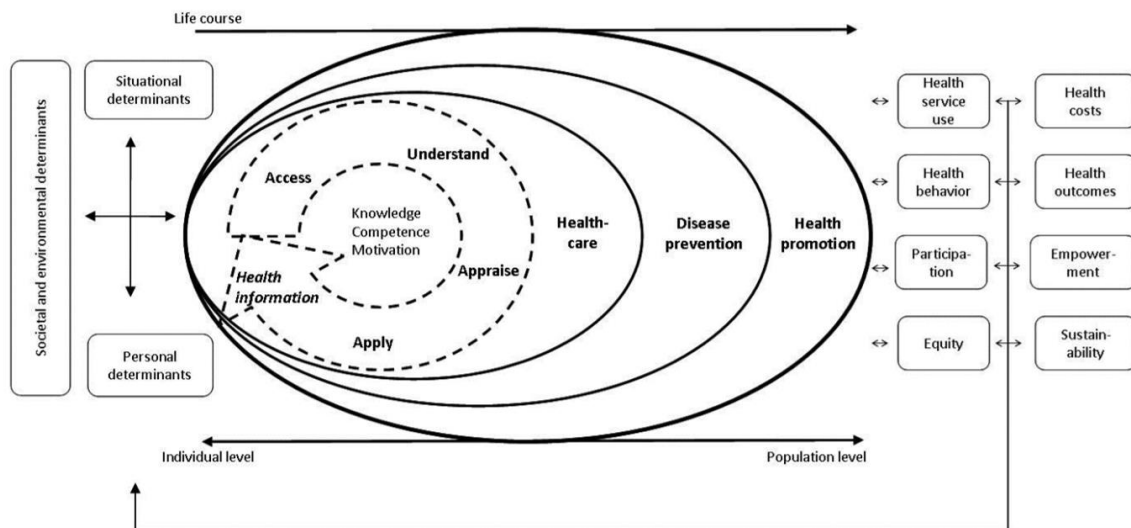


Figure: Health literacy conceptual model¹

Health literacy is critical to efficient and trustworthy health systems. It enables people to continually learn new information and to ‘unlearn’ outdated information to maintain good health and act as informed users of health services.

Developing the health literacy of both people and systems, and building the reciprocal responsibility between them, strengthens the equality of opportunities in accessing healthcare. Importantly, the vulnerability of people is determined and impacted by their competencies and needs, as well as the organisation of the health services. The development of health literacy should therefore be guaranteed to all, including people in vulnerable situations facing health literacy challenges.

HEALTH LITERACY, HEALTH INEQUITIES AND ECONOMIC IMPACT

Health literacy is an important determinant of health and a constituent of avoidable and unfair health inequalities. A strong socio-economic gradient has been identified which indicates how low socio-economic status, low education, adverse health behaviours, poor self-reported health, and increased use of services correlates with limited levels of health literacy. Health literacy gaps can lead to inequities between countries and between different population groups within countries.

Poor health literacy is a drain on human and financial resources and an obstacle for sustainable development. The economic research on health literacy in Europe is scarce. Estimating the costs of poor health literacy is a complex area which requires some assumptions to be made. US research suggests that the annual cost of poor health literacy is 3–5% of the health budget². Based on these estimates, the cost of poor health literacy in England could be £2.95–4.92bn (based on the NHS England budget for 2014-15 being £98.4bn)³. However, it is difficult to accurately transfer US cost implication findings to health systems in Europe. A recent study conducted in the US among Medicare beneficiaries

¹ Sørensen, K. *et al.* Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health* **12**, (2012).

² Vernon *et al.* 2007.

³ Lamb P, Berry J. Health Literacy – the agenda we cannot afford to ignore: Community Health & Learning Foundation (2014).

estimated that improving health literacy could prevent nearly one million hospital visits and save over \$25 billion a year⁴.

HUMAN RIGHTS RELATING TO HEALTH LITERACY

Together with the European Convention on Human Rights and the European Social Charter, the Convention on human rights and biomedicine (Oviedo Convention) provides a human rights framework relevant in the field of health laying down principles which respect, and implementation may be substantially impacted by, health literacy. For example, the principle of informed consent to undergo a health intervention (Article 5, Oviedo Convention) involves being able to access and understand appropriate information to consent to it. In other words, health literacy (understanding and access to information, critical thinking) enables individuals to assess the benefit and risks of an intervention so that fully informed decisions can be reached.

Health literacy makes an important contribution to attaining goal 3 “Ensuring healthy lives and the promotion of well-being for all at all ages” of the United Nations Sustainable Development Goals. Health literacy can be considered a tool to empower people, using various forms of communication and action taken through health systems and other policies, to gain access, understand and use information in ways which promote and maintain good health. Furthermore, health literacy provides a strategic approach to achieving the highest attainable standard of health for everyone, based on four essential elements: 1) **Availability**: the need for public health and health care facilities, goods, and services, as well as programmes for all; 2) **Accessibility**: health facilities, goods and services must be accessible to everyone and exercise non-discrimination, be affordable, provide access to information and be within (physical) reach; 3) **Acceptability**: all health facilities, goods and services must be respectful of medical ethics and culturally appropriate; 4) **Quality**: health facilities, goods and services must also be scientifically and medically appropriate and of good quality, including engagement of skilled health care personnel.

HEALTH LITERACY TO BUILD TRUST IN HEALTH SYSTEMS

Health systems and their operators and providers are critically important in enabling people to make free and informed choices about their health. Health literacy empowers patients to face the complexities of these systems, to become familiar with their knowledge and methods, to enable them to assess information, and to decide on treatment and care.

Health literacy is important in the broader context of health prevention. It concerns the understanding of different scientific and clinical information to promote health outcomes (health prevention measures are taken to avoid illness and so they may not be personally experienced, unlike treatments and therapies which have a tangible effect on people during illness).

⁴ United Health Group, 2020.

Consider the following examples:

- ▶ The Covid-19 pandemic prompted the largest vaccination campaign in human history. Among the many challenges faced by individuals was the assessment of risk vs benefit of vaccination (arguably requiring a deep conceptual comprehension of statistical data, such as percentage, probability, predictive models, and different scenarios). In this regard, health literacy can help people to perceive, understand and assess associated risks.
- ▶ Eating a healthy diet contributes to a healthy life, including lower risks of cardiovascular disease. Diet is strongly dependant on the cultural and geographical dimensions of people and groups in society. In this regard, health literacy contributes to the skills, sensibilities and empathy needed towards different people and groups in order to be more effective in encouraging changes in their daily diets.

Consequently, health literacy can be considered as a determinant of both personal and public health. It contributes to the health of individual persons and to the health of communities or other collectives of individuals with a shared health knowledge. In other words, health literacy is essentially a relational activity which can facilitate improvements in general well-being, including for people in vulnerable situations.



HEALTH LITERACY TO ENABLE EQUITY AND TRUST IN HEALTH SYSTEMS

To ensure equitable access to healthcare, there are five challenges which can be taken into account: 1) access to valid health information; 2) access to appropriate care; 3) communication between individuals, health professionals and health authorities; 4) shared decision-making regarding treatments and care; and 5) access to digital spaces to understand and use health services.

Improving the health literacy of both people and systems strengthens the equity of opportunities in accessing healthcare. Vulnerability in terms of these challenges is determined and impacted by people's competencies and needs as well as the organisation of health services.



ACCESS TO VALID HEALTH INFORMATION

- ▶ **Assessing the credibility of health information is a major challenge. Health literacy and clear communications from trusted sources support access to valid information.**

CONTEXT

Health information should be accurate, relevant, timely, up to date, and transparent. All people should have equal opportunities to access and receive it. It should be easy to understand.

Access to valid health information includes the ability to extract, compare and analyse health information from different sources, to have genuine opportunities to comprehend and to use it. This contributes to the knowledge and awareness needed for individuals to decide on choices of care, to exercise self-management of health.

Digital health information complements information provided by health professionals. It can support peoples' understanding of, and ways to promote, their health. Access to valid health information is also an important protective measure, acting a means of prevention against disease panic.

CHALLENGES

In Europe, one in four adolescents has difficulties in assessing the credibility of health information as well as comparing information from different sources. One in five adolescents has difficulties in finding health related information that is easy for them to understand⁵. Between 25-72% of adult populations report difficulties in judging the reliability of health information⁶.

Finding offline information has become more difficult. As regards digital health information, one in four Europeans consider that their national authorities do not make it easy to find information without using the Internet, in contrast with one in every six Europeans able to find health information⁷.

The validity of information not only relates to its accuracy but to its applicability to one's life and current needs. Limited health literacy to find, understand, appraise, and use information hinders genuine access to trusted knowledge, depriving individuals from understanding their health, the ways to promote and sustain it, and when and how to seek help.

Access to valid health information is necessary when faced with the rapid spread of misinformation and disinformation via social media and other internet tools and services. This phenomenon known as 'infodemic', coupled with limited health literacy, makes it challenging for individuals to find reliable information from trusted sources, increasing the risks of non-compliance with protective measures and late access to relevant care. People with limited health literacy are more likely to trust information from social media and friends than from health authorities and medical professionals. Poverty-stricken communities suffer more from misinformation due to lower levels of trust in health authorities and health care service providers which, coupled with lower levels of immunisation against other prevalent illnesses, results in disease panic and a lack of access to medical services.

The ability to use and understand numbers (i.e., numeracy) plays an important role in how information is displayed and communicated. However, the complexity of numerical information about health risks and benefits may not always be easily understood. Consider, for example, numerical information on treatment risks and effectiveness, lifestyle benefits, and side effects from medication. In this regard, many people, including the less affluent, the less educated, and those suffering from cognitive impairments or language difficulties, are more likely to experience difficulties.

ACTIONS AND GOOD PRACTICE

Available information should be shared by trusted sources. Access to valid health information supports the ability of individuals to seek and develop a comprehensive understanding of their health. Abilities to assess the validity of health-related information can be developed from a young age through the school curriculum. Health literacy school education in all countries contributes to narrowing the disparities at regional and global level.

⁵ Health Behaviour in School-aged Children study 2017/18, unpublished findings.

⁶ The Health Literacy Population Survey Project (HLS19) Consortium of WHO Action Network M-POHL, 2021.

⁷ EU Fundamental Rights Agency: <https://fra.europa.eu/en/data-and-maps/2021/frs>

Actions

<p>Individuals need:</p> <ul style="list-style-type: none">• to seek and find health information from different sources;• to compare, synthesise and appraise health information from different sources;• to reflect on the usefulness and applicability of information from one's personal perspective.	<p>Systems have the responsibility to offer:</p> <ul style="list-style-type: none">• information in a manner that secures information access to people with differing needs, such as those with learning disabilities or hearing and seeing impairments;• easily available health information in all relevant languages, through different channels and in different formats;• information that is easy to understand, culturally sensitive and empathetic, by using different communication strategies;• updated and valid health information from trusted sources;• information that is relevant and adaptable to the daily lives of individuals with differing needs.
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Good practice

Teaching digital education and literacy via cross-cutting themes addressed across various subjects – Germany

Aim and objectives: Based on the German education sector's strategy, all schools should prepare pupils for digital transformation. On the state level, digital education and digital literacy strategies translates into the media literacy competence framework and curriculum.

Target group: School pupils

Method: Digital education and digital literacy serve as cross-cutting themes that should be addressed across subjects from grades 1-13. Along with learning using digital tools, communicating in digital spaces, data protection and ethics, pupils are taught to develop a critical stance, and to seek, compare and analyse information from various sources.

Outcome: Using health as a subject within a competence framework and curriculum makes it possible to address health literacy and at the same time saves resources.

Added value: Education in schools reaches all school-aged children. Health literacy as part of the school curricula, including media and digital literacy, is a promising strategy to support all young people in acquiring the knowledge and skills needed to access valid health information, relevant for their health and wellbeing.



Good practice

Teaching health literacy as a mandatory school subject – Finland

Aim and objectives: Health literacy, including critical thinking, is taught through an independent and mandatory school subject called “health education”.

Target group: Pupils in primary and secondary schools.

Method: In grades 1–6, health education is taught as an independent component in a cluster of subjects called ‘environmental studies’. In grades 7–9, and general upper secondary school, health education is a stand-alone subject. Already in lower grades, pupils are taught to assess information and to select valid information sources. Then in higher grades they are taught to assess information using several criteria. Later, they are also taught about the reliability of information as well as differences between lay information and scientific information. Health-related competencies, as well as media literacy and digital skills, are taught via crosscutting themes running through all school subjects.

Outcome: The curriculum improves the ability of children and adolescents to access valid health information.

Added value: Teaching health literacy as a mandatory subject has the potential to reduce health literacy disparities within schools.



Good practice

Health literacy for caregivers of older persons with different levels of dependency – Italy

Aim and objectives: Nowadays, many older persons with different levels of physical and/or mental challenges are assisted at home. They need help for a considerable part of their daily living, which is usually provided by a family member or by a person employed to do so. In both cases, the health literacy for the caregiver is of crucial importance in guaranteeing older persons access to appropriate information and care, which includes the administration of medication, preparing and eating food, help with personal hygiene, and support when accessing and navigating the health system (e.g. programming visits with health professionals, physical examinations, etc.).

Many family and paid caregivers do not have the requisite levels of health literacy (cognitive, social abilities) to access, understand, and act upon the information needed to take care of dependent older persons.

Method:

- ▶ measuring caregivers’ health literacy levels in different settings, including at home and in contacts with the health system;
- ▶ assessing caregivers’ health literacy levels in relation to the level of complexity of care needed to assist older persons;

- ▶ targeting training for health care professionals assisting older persons with disabilities, to help them assess the health literacy levels needed for caregivers during different phases of the care pathway for older persons;
- ▶ reviewing the health literacy skills and competencies for caregivers to advise and train them accordingly.

Outcome: Being able to assess the health literacy skills and competencies needed for caregivers helps to decide whether a given caregiver has the capability to take care of older persons with comorbidities and/or a high level of care complexity. This assessment plays a key role in reflecting and reviewing the relationships between healthcare professionals to ensure continuity in the care offered, so that the family remains supported.

Added value: The health literacy for caregivers helps to provide appropriate continuous care - formal, managerial and relational care - for older persons with different levels of dependency.



Good practice

Health literacy for children to promote healthy lifestyles – Romania

Obesity is one of the most serious public health challenges. Obesity, as well as associated diseases, are largely preventable if acted upon from childhood. Preventing childhood obesity is therefore a priority.

Aim and objectives: The “Granny’s Health Bag. Healthy traditions for healthy children” initiative was launched in Iasi (Romania) in 2012. It is a community-based program to encourage healthy behaviours via the promotion of cultural traditions, this includes campaigns in kindergartens and schools to encourage healthy behaviours in children and original educational resources based on scientific evidence.

The main learning tool is the “Health Bag”. Children learn about the elements of a healthy lifestyle helped by a magic bag, namely “Granny’s Health Bag”. Illustrated with folk tale characters (the goat, the three kids, the bad wolf, etc.); children learn to recognise what is good and what is bad for their health.

Method:

- ▶ training courses for teachers to teach the 2020-2021 optional course "Granny’s Health Bag";
- ▶ information campaigns - for example, the campaign “Body rhythms: traditions and health”, in which 20,000 children from Iasi County participated;
- ▶ workshops for children, parents and teachers;
- ▶ introducing in schools the optional discipline of healthy lifestyle training which, in September 2020, led to the enrolment of 4,000 children aged between 5 and 10 years;
- ▶ development of teaching materials for the training of healthy behaviours in children;
- ▶ the conference "Prevention of childhood obesity", which is organised annually in Iasi, was last held in June 2021, and focused on "Childhood obesity during Covid-19 -

the evolution of family habits". The conference took place online and had speakers from 10 countries.

Added value / Outcome:

The initiative targets children from 3-11 years and their families and has benefitted 100,000 children. In 2021, the prevalence of childhood obesity has decreased from 11% to 7% in the city of Iași.

There has been considerable international recognition of the initiative, notably:

- ▶ it is part of the international networks for the prevention of obesity among children – EPODE (*Ensemble Prévenons l'Obésité Des Enfants*) International Network and Youth Health Community;
- ▶ at the Global Obesity Forum (New York, 2012), it was awarded the first prize for the best childhood obesity prevention activity;
- ▶ it was awarded by the European Community with the first prize – the 2020 EU Health Award- category Healthy Lifestyle Cities for the best initiative at the level of community (Iași city) to promote healthy lifestyles.



ACCESS TO APPROPRIATE CARE

- ▶ **A lack of awareness of available health services and how to find and use them is a major challenge which affects the ability of people to find the health care they need.**
- ▶ **Healthcare provision, systems and environments have become increasing complex which can make it challenging for individuals to access services. There is a responsibility to organise these services so that they provide coherent pathways and options for care which people can understand, access and navigate.**
- ▶ **Health literacy research and practice indicates the need to engage mediators as well as community and patient advocates to foster information and communication between hard-to-reach individuals and groups.**

CONTEXT

As a precondition, health services should be easily accessible and available to citizens. The ability to find the appropriate primary care serves as an important gateway to the health care system, especially when this concerns interventions regarding severe diseases. Seeking and accessing appropriate care is a matter of responsible behaviour towards others, especially in managing the spread of and in treating communicable diseases.

Access to appropriate care is a central factor in health disparities and health outcomes. In determining what is appropriate care depends on the consideration of a number of factors: 1) care is based on clear evidence of effectiveness to improve health, and is delivered by health system professionals with the expertise to work in a culturally sensitive manner; 2) care takes into account the use of resources according to the needs of regions and population groups, mindful of the principle of cost-effectiveness; 3) care is offered in a way that secures equity in care delivery; 4) care is patient-centred and therefore sensitive to the context, culture, autonomy, needs and preferences of patients, which includes their involvement in care and empowerment in seeking care and self-management.

CHALLENGE

A key component in accessing appropriate care is the awareness of one's rights as a patient. This includes knowing about the existence of health services and how to use them. Not knowing about them may hinder timely access to care. In this regard, those with limited health literacy are more likely to experience difficulties, resulting in delays in receiving care.

Limited health literacy is also linked with the unnecessary and improper use of health services and resources. This is a significant problem in Europe as one in six people report having difficulties in finding out where to get professional help when they are ill⁸.

Health literacy should not be assumed, especially not among those having special needs or who are otherwise limited in their ability to find and receive care, to navigate the health system environment. For example, people with long-term mental health conditions, older persons, and those with socioeconomic deprivation are more likely to miss appointments. This is of particular concern when they relate to healthcare and disease prevention measures, such as screening and monitoring of chronic disease.

Ensuring individual access to appropriate care for all parts of the population can be a challenge for health systems, especially when they are complex and fragmented. Consider, for example, the challenges of providing care to migrants with language and communication barriers. It should however be noted that the health literacy of migrants varies in different European countries; in some countries, such as Austria, some migrants are reported as having high levels of health literacy, whereas in others, such as Denmark, it is the opposite. In this regard, cultural mediators as well as knowledge-brokers might be considered in order to "translate" between health system actors and patients.

⁸ The Health Literacy Population Survey Project (HLS19) Consortium of the WHO Action Network M-POHL, 2021.

ACTIONS, TOOLS AND GOOD PRACTICE

Improving individuals' health literacy means finding the health care one needs and adopting responsible 'help-seeking' behaviour. Health systems have a responsibility to develop appropriate care which is made easily available.

Actions

<p>Individuals need:</p> <ul style="list-style-type: none"> • information about one's rights as patients, including available and options for health care, and be able to demand appropriate care; • relevant information about one's health condition; • to be able to identify and interpret the symptoms of various diseases; • to know when and where to seek help; • to be able to think through the consequences of one's actions on others (e.g., how to seek health care in relation to communicable diseases). 	<p>Systems have a responsibility to:</p> <ul style="list-style-type: none"> • promote cultural sensitivity and understanding of care, to use intercultural mediators if needed to adapt health services to the cultural characteristics of migrants and others in similar situations, offering options for various types of care; • make available easy access information on various options for care, in all relevant languages; • develop coherent and simple health system environments for people to navigate; • involve people in developing user- and health literacy friendly systems.
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Tools

Health literacy and patient journeys

Aim and objectives: The focus on health literate organisations highlights the need for them to facilitate a coherent and smooth journey for users of the health system. Patient journey mapping (see example below) is a way to visualise and obtain an overview of patient experience during their entire care journey.

Method: A patient journey map (also known as health system customer journey map) is an outline of all the touchpoints a patient goes through in their care journey in a health system facility. This includes all the touchpoints pre-, during, and post-visit.

Outcome: This method provides insights into patient experiences during their care journey in a health system facility and the patient flow in general to create strategies to improve the quality of care, increase efficiency, and improve patient satisfaction.

Added value: Patient journey mapping is an increasingly valuable tool for health organisations and companies of all types and sizes, for many applications. The benefits include highlighting the obstacles patients face in accessing care; define how to deliver a better patient experience during treatment; and identify ways to support patients after treatment ends.

	PRE	DURING				POST		
MOMENTS	General cancer prevention	GP appointment	Oncologist appointment	Treatment	Trial		Recovery	Palliative
EMOTION	Little to no worries	Concerned	Worried / Depressed / Scared	Worried / Scared / Hopeful	Concerned / Optimistic / Hopeful		Concerned / Hopeful	Concerned / coming to terms
NOTES	Living life as usual	Becoming a patient	Cancer patient	Cancer patient	Cancer patient		Cancer survivor	Terminal cancer patient

Figure: Example of health system customer journey map



Good practice

Facilitating Syrian refugee access to medical services – Türkiye

Türkiye hosts millions of refugees whose access to health care is hindered by cultural and linguistic barriers. Reinforcing the trust of migrants in health systems and health professionals is a key component in facilitating their access to health systems.

Aim and objectives: The objective of the joint Türkiye, EU and WHO initiative is to familiarise Syrian refugees with the Turkish health care system so that they may practice medicine in Türkiye and provide health services directly to Syrian refugees. In doing so, the initiative fosters the integration of Syrian refugees in Turkish society and empowers them to serve the community. The initiative also helps to alleviate the burden on the Turkish health system.

Target group: The initiative targets Syrian health care workers who form part of the 3.7 million Syrian migrants displaced in Türkiye. In particular, the initiative is designed for doctors, nurses, midwives and other medical specialists.

Method: Syrian health care workers are identified and undergo theoretical and practical training in one of the seven training centres established across the country (Ankara, Gazantep, Sanliurfa, Izmir and Mersin), under the supervision of Turkish medical professionals. There, they undertake an adaptation course designed by the WHO country office in Türkiye. During the Covid-19 pandemic, training was dispensed digitally through a specifically developed distance learning platform. The course contents include modules on mental health, non-communicable diseases, early childhood development, psychosocial support training in disasters, medical record systems, and occupational health and safety. The centres also train translators to serve as cultural mediators in medical facilities. Eventually, Syrian health professionals receive authorisation to work in the Turkish health system.

Outcome: Thousands of health professionals have undergone the program since it began. Teaching materials have been developed as part of the program that have also been used to train Turkish professionals on mental health.

Added value: The employment of Syrian health professionals in Türkiye is instrumental in suppressing language and cultural barriers in access to health care. Their empowerment and integration in Türkiye provide an occupational opportunity for refugees and a chance to gain additional knowledge. This improved the cultural sensitivity of the health system and has helped to build resilience at the local level. More generally, it has improved the health literacy of Syrian refugees.



Good practice

MILSA: A Support Platform for Migration and Health – Sweden

Aim and objectives: Receiving information about the society in which you are living in and gaining knowledge of how to take care of your health is a key component for successful integration in society. This is the guiding principle for civic and health communicators working all over Sweden.

MILSA is a knowledge-based support platform for migration and health which is devoted to producing and supporting methodological development conducive to a health-promoting and inclusive reception of newly arrived migrants in Swedish society.

The MILSA educational platform is a national initiative for civic and health communicators with a focus on education, exchange of experiences and networking. The project is supported by the European Social Fund and the Ministry of Health and Social Affairs of Sweden. The project collaborates with universities and experts in various fields, county administrative boards, regions, municipalities, and civil society organisations at both national and international levels.

The research within MILSA is oriented towards the integration system and needs of newly arrived migrants, and it is carried out by way of broad collaboration between different universities and multi-level agencies that work with newly arrived migrants. The work is based on a broad approach to health, including themes such as societal participation and empowerment, mental health and well-being, housing issues, economic stress, confidence, and trust.

Target group: Approximately 200 communicators provide civic orientation and health communication in different languages throughout the country. MILSA's educational programme covers 22 essential topics concerning different aspects of life and takes approximately 18 months to complete.

Teachers from several universities, together with experts, have been responsible for shaping the content of the education which is carried out mostly at a distance, supplemented with practical training sessions and physical meetings.

Method: In addition to providing a unified education for civic and health communicators, MILSA is producing textbooks on civic and health communication and a manual of methods for communicators. The textbooks are based on the national civic orientation regulation and aim at providing a deeper understanding of the subject areas. The manual of methods is to provide practical hands-on support for the communicators in the classrooms. For example, it deals with how to create a safe environment in the classroom, how to ensure that the participants receive and understand the information

that is communicated, how to approach and discuss sensitive topics and what are the limitations of the communicator's role.

Outcome: The MILSA educational platform creates a framework for networking, collaboration and exchange of experiences between communicators and other professionals working on migration, health and integration.

Added value: The work in the MILSA educational platform is built on civic orientation of unique potential for newly arrived migrants and opportunities for integration, employment and health.



Good practice

Health care professionals working in nursing homes – Italy

Aim and objectives: Health care professionals working in nursing homes, in direct contact with fragile and dependent older persons, are essential for access to appropriate care for those with comorbidities and insufficient family support. Staff working in these settings have specific roles and responsibilities in guaranteeing the best quality of life for these older persons. Measuring the health literacy skills and competencies of these health care professionals is a necessary first step in understanding how and when to build targeted health literacy programs for them.

Method:

- ▶ by promoting the concept of health literacy in nursing homes;
- ▶ by promoting also specific efforts and programs devoted to the development of the health literacy of health professionals in nursing homes;
- ▶ by involving the directors and personnel of nursing homes in health literacy programs;
- ▶ by developing an 'organisational health literacy' approach within nursing homes.

Outcome: Nursing homes - via the education of their directors and staff - adopt an 'organisational health literacy' approach as a principle of management, aimed at guaranteeing the best access to appropriate care for older persons, especially those who are fragile and dependent.

As a secondary objective, the development of health literacy skills for these health care professionals also helps them at home with their own families.

Added value: The health literacy skills and competencies of staff and professionals in nursing homes, in the framework of an 'organisational health literacy' approach, supports the right care pathways for older persons in institutionalised settings. This provides health care professionals with an opportunity to apply health literacy skills and competencies in their everyday working lives.



Good practice

Literacy Audit for Healthcare Settings – Ireland

Aim and objectives: This audit, prepared by the National Adult Literacy Agency, seeks to make the Irish health service literacy friendly where both the skills of individuals and the literacy demands of the health service are analysed. It envisions a health service where literacy is not a barrier to treatment. It works to support the health service in every context: promotion, protection, prevention, access to care and maintenance.

Target group: The responsibility for making health activities less burdensome and services more accessible rests with those providing the services. Organisations have a responsibility to make their environment easy to access and navigate. While literacy skills are often viewed as the responsibility of the individual, it is important to examine the skills of health professionals as well.

Method: The health literacy audit promotes an understanding of how literacy friendly a health setting is. This audit helps to identify possible barriers for adults with literacy difficulties. Healthcare workers need a way to measure how literacy friendly their writing material, websites and general communication are to the public. The audit is designed to help analyse and record how patients and service users might encounter difficulties in accessing health services and in understanding health and administrative messages, and pinpoint areas that can be improved.

Outcome: Each organisation can devise its own specific literacy plan based on the results of the audit. The summary sheet is helpful as a record of what work is needed.

Added value: The audit tool helps to inform and qualify the work of health service organisations to become health literacy friendly. The approach can be tailored to suit local needs.



COMMUNICATION BETWEEN INDIVIDUALS, HEALTH PROFESSIONALS AND HEALTH AUTHORITIES

- ▶ **The lack of adequate communication between patients and health professionals may hamper patient-centred care and shared decision-making. This requires attention to promoting understandable two-way health dialogue and efforts by health professionals and health authorities to find better ways to reach all people.**

CONTEXT

Improving communication between individuals, health professionals and health authorities is likely to improve equity. It can help build trust in public institutions and save lives (e.g., during public health crises, well-developed health communication which is clear and transparent can, for instance, encourage compliance with public health measures).

The creation of spaces for equal communication and genuine dialogue between patients and health professionals is key to ensuring that both options for available care and the care provided are understood, relevant and applicable to patients' lives. The communication should be open and honest in what is known and unknown, and be consistent, simple, and understandable, as well as empathetic.

Clear and participatory (two-way) communication empowers people (groups and communities) to make choices. This requires a shared language, including the use of words, concepts, opportunities to ask clarifying questions and to obtain responses at the same level.

The communication style of the care provider is linked with better patient self-management and empowerment. Patients' understanding of care and confidence in self-care abilities can enhance the impact of the provider's communication.

Health authorities should find the best ways to reach all people, especially those in vulnerable situations and those who are difficult to reach, such as homeless persons and the digitally disadvantaged with mobility restrictions.

CHALLENGE

On average in Europe, 15% of adults report difficulties in understanding what the doctor is saying, 18 % of adults report difficulties in reflecting and assessing if the information provided by the doctor is applicable to one's life, and 28 % of adults report difficulties in understanding the leaflets that come with prescribed medicine⁹. These difficulties echo a clear mismatch between an individuals' competencies and the communication styles of health system providers and health authorities. Doctors may be overestimating their communication skills. However, the challenges of increasing workloads for healthcare professionals and shortages in doctors across Europe, may also be impacting on the effectiveness of communication between individuals, health system providers and health authorities.

The complexity of communication and the lack of common language, either due to different spoken languages or the use of words not commonly understood, are obstacles to effective patient-provider communication.

Communication challenges are especially evident when a patient has complex communication needs that should be considered carefully. Planning different ways to communicate, in addition to oral communication, are of paramount importance.

Medical terms, such as the concept of risk, and medical jargon used either by health professionals or expressed in printed materials offered to patients are likely to result in the misunderstanding of information by patients. Also, limited time allocated for appointments may lead to an instruction that does not allow space for questions and dialogue which is an integral part of the process of care. This is a particular concern in situations when extra time would be necessary due to complex communication needs, such as those associated with developmental or acquired disabilities, or when people lack sufficient skills in communicating with health professionals, in general.

ACTIONS, GOOD PRACTICE AND TOOLS

Clear communication is the basis for people to understand and act on health information. Regardless of the level of health literacy, it is important that staff ensure that patients understand the information they have been given.

For communication to be effective and appropriate between individuals, health professionals and health authorities, people need sufficient knowledge about their health conditions and the ability to link information to their daily lives. Health systems should ensure that their communication is clear and transparent, meeting the needs of different people, including those with cognitive impairments or language difficulties. Common tools to improve interaction and

⁹ Comparative Report on Health Literacy in Eight EU Member States: The European Health Literacy Survey HLS-EU. (2012).

communication include Communicate for All, Ask Me 3®, Teach-Back and use of Plain Language principles (below).

Actions

<p>Individuals need:</p> <ul style="list-style-type: none"> • to be informed that they have the right to communication, in a manner that is appropriate to one's capacity for understanding; • 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; • an ability to communicate clearly (also on online) and to seek clarifications; • an ability to assess the appropriateness of care and the applicability of instructions from a personal perspective, to apply the instructions and decisions in practice, in daily life. 	<p>Systems have the responsibility to:</p> <ul style="list-style-type: none"> • adapt transparent and open ways of communicating, also on uncertainties related to health risks; • create spaces for communication that consider the special communication needs and cultural background of patients, providing professional translators or consider using cultural mediators if needed; • develop the availability of digital eHealth sites and services for people with different communication needs, and to complement face-to-face appointments; • avoid medical jargon and difficult words (shared language) in their communications; • offer training for health professionals about various ways of communicating with patients with or without complex communication needs and their caregivers, and to communicate in digital environments in a way that supports shared decision-making.
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Good practice

Informing patients diagnosed with an illness (Cancer Plan) – France

Aim and objectives: The system to inform patients diagnosed with an illness was a measure introduced in the early 2000s, as part of the first cancer plan. The aim of this system (which responds to a request made by patients in the context of general meetings with them) is to provide patients (and their families) with better conditions when being informed of the diagnosis of their disease and the proposed treatment. This system encourages adherence to the proposed treatment and the strategies for adapting to the disease. It is based on the provision of clear and appropriate information that respects patients and their wishes, leading to real support.

Target group: All cancer patients are targeted by the system, starting from the initial diagnosis of a histologically confirmed cancer to relapse of the disease.

Method: The system is centred on the hospital and is composed of four phases:

- ▶ informing a patient of the diagnosis and proposed treatment of an illness;
- ▶ accompanying the patient, identify his/her needs;

- ▶ referral/access to support care (notably in the event of preserving fertility);
- ▶ coordination between the town of residence and the hospital.

Various documents are provided to the patient to help him/her navigate the health system, such as the possibilities for personalised care and its pathway, which sets out the stages of treatment, the corresponding timetable, and information on supportive care as well as a list of useful contacts.

The system is based on multidisciplinary care, primarily involving doctors and paramedical staff. The National Cancer Institute has published recommendations and guidelines to help health establishments and professionals set up the system. The professionals concerned (both hospital and private practitioners) receive ad hoc continuing education.

The system has evolved with successive cancer plans, taking into account the diversification of care (increasing the role of so-called "town" medicine) and the situations of certain groups, such as children and people with intellectual disabilities.

Outcome: The system to inform patients diagnosed with an illness is implemented in all health establishments authorised to provide cancer treatment. Its organisation is described in the National Cancer Institute's guidelines and is identical throughout the country. The implementation of the system is one of the transversal quality conditions that all establishments concerned with cancer treatment must apply.

Added value: The added value of the system lies in the provision of clear and appropriate information that respects patients and their wishes, leading to real multidisciplinary support. The fact that it has been developed throughout the country, in accordance with a reference system, is a major asset.



Good practice

Improving literacy in the use of prescription medication – Türkiye

The establishment of the “Unit of Patient Education for Medicine Use” is an example of a local health literacy project in Şanlıurfa Training and Research Hospital, which is located in the province of Ş.Urfa in the southeastern Anatolian region of Türkiye.

Aim and objectives: To ensure correct drug use and effective treatment results for hospital in-patients who are prescribed medication.

Target group: All patients, including children (and their parents) undergoing treatment.

Method: After being examined, a physician may prescribe medication which must be followed by the patient. Patients are therefore directed to the “Unit of Patient Education for Medicine Use” where nurses work under the supervision of a pharmacist. The Unit, which is located in the centre of the hospital for easy access, teaches patients how to use their medicines. Patients with chronic illnesses are incentivised to visit the Unit because they may be issued with a ‘medication report’ by a specialist physician which allows for medicines to be prescribed by a family doctor, thereby helping to reduce the number of hospital visits.

Outcome:

- ▶ improved patient health outcomes;
- ▶ reduced possible side effects due to incorrect drug use;
- ▶ reduced emergency service admissions, hospitalisations and repeated applications.

Added value: The correct use of medication reduces health costs and improves patient outcomes.



Good practice

Professional interpreting in health for liberal doctors (all specialties) and liberal midwives in the North-East territory - France

Aim and objectives: the lack of knowledge of the French language by patients during medical consultations is an obstacle to quality care. Promoting understanding during exchanges between health professionals and patients thus allows:

- ▶ improving access to prevention, screening and medical care;
- ▶ the reduction of irrelevant, unnecessary and costly examinations;
- ▶ the reinforcement of the person's autonomy and the respect of his or her rights (information, confidentiality, free and informed consent).

The aim is therefore to give health professionals the opportunity to use health interpreting services.

Target group: All non-native speakers in the North-East region are concerned, as well as all private doctors and midwives who may be consulted by them.

Method: Private practitioners and midwives in the North-East region can request telephone (and/or face-to-face) interpreting services from a service provider chosen and financed by the *Agence Régionale de Santé* via a call for tenders. To do so, they must first register for the scheme, which offers 185 languages. Professionals are provided with a user guide, which invites them to prepare consultations in advance and in writing, in order to optimise the interpreter's contribution. This interpreting service is free of charge for both the professional and the patient. Interpreters are bound by professional secrecy.

Outcome: An interpreter who speaks the patient's language is available within 5 minutes of the request by the health professional, even without a scheduled appointment.

Added value: As mentioned above, access to professional health interpreting helps to promote quality access to care for non-native speakers and thus their integration into the health system. Telephone interpreting also helps to reduce territorial disparities in access to this service.



Tools

“Communicate For All: a guide to accessible communication” – France

Aim and objectives: “Communicate for all: a guide to accessible communication” is a guide developed by a French health agency (*Santé Publique France*) based on the concept of literacy.

Target group: The guide is intended for all actors involved in designing and sharing information accessible to all, regardless of their audiences and literacy skills: general population, migrants, people in illiteracy situations, older persons, people with disabilities. This reference framework has, among other actors, been designated for health and medico-social facilities and services, to help these organisations become pro-literacy organisations. It is of relevance to health professionals and health promotion professionals.

Method: This guide is a very practical tool, illustrated with many examples, as an aid to conceive written, oral, digital, pictorial communication, whatever the patient’s level of health literacy. The guide also identifies pitfalls to avoid and share good practices.

Outcome: The guide meets the needs of actors, depending on whether they want to design printed documents, design and/or use images, design web sites or other digital media, design oral communication. It also proposes ways to better consider differences in literacy skills within an organisation.

Added value: The guide has been designed in such a way that the actors who consult it are guided, accompanied step by step in the design of their communication, with the ultimate objective of being understood by all.



Tools

Health Literacy Tool Shed – United States

Aim and objectives: The Health Literacy Tool Shed is hosted by Boston University. It is an online database of more than 200 health literacy measures. The site contains information about measures, including their psychometric properties, based on a review of peer-reviewed literature.

Target group: It is a database for researchers, decision-makers, and health providers. It helps them identify the most relevant measurements to use in health literacy research, needs assessments, evaluations, etc.

Method: It is an open-source database, freely available to all users.

Outcome: It enhances the opportunities for choosing the most relevant tool for a certain research purpose.

Added value: The Health Literacy Tool Shed makes it possible to gain access to cutting-edge measurement tools. Previously, the review of such tools was published in scientific

journals. The Health Literacy Tool Shed democratised accessibility to these measurements and accelerated the speed of knowledge-sharing and use of appropriate measurement tools.



Tools

Ask me 3: Good Questions for Your Good Health® – United States

Aim and objectives: Ask Me 3® is an educational program developed by the Institute for Healthcare Improvement that encourages patients and families to ask three specific questions of their providers to better understand their health conditions and what they need to do to stay healthy.

Target group: Designed by health literacy experts, Ask Me 3® is a quick, effective tool designed to improve health communications between patients, families, and health providers and help patients become more active members of their health care team.

Method: 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:

- ▶ *what is my main problem?*
- ▶ *what do I need to do?*
- ▶ *why is it important for me to do this?*

Outcome: Ask Me 3® is simple to use, inexpensive to implement and facilitates simple communication.

Added value: Active participation empowers patients and makes the conversation easier for the health provider. Questions prompted by patients give health providers clues to the level of understanding, acceptance, and insight of the condition which in turn may guide the health professional to deliver timely and appropriate information.



Tools

Quick Start Guide to Teach-Back – United States

Aim and objectives: Teach-Back is an activity in which learners teach each other what they have learned, for instance, by using verbal explanations, demonstrations, and skits.

Target group: According to the US Agency for Healthcare Research and Quality, Teach-back is a technique for health care providers to ensure that they have explained medical information clearly so that patients and their families understand what is communicated to them. This intervention includes several materials to support adoption.

Method: The 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.

Outcome: The resources needed for Teach-back are modest. Health providers can implement Teach-back as part of their regular duties. The time of implementation using this practice is minimal in the short run and can save much time in the long run.

Added value: Using Teach-back systematically will help remove barriers and challenges to improve communication and processes.



Tools

Toolkit for Making Written Material Clear and Effective – United States

Aim and objectives: Most text-based health information continues to be too hard for most adults to read. While plain language is only one of many broad-based solutions needed to address limited health literacy, the benefits to everyone call for increased use by health organisations.

Target group: Given that clinical research communications can be very technical and complex, using plain language can help clearly explain information so that the target audience has a better chance of understanding. The target group can be patients, caregivers, other actors in the health eco-system involved in solving health challenges.

Method: Plain language helps the reader to:

- ▶ find what they need;
- ▶ understand what they find;
- ▶ use what they find to meet their needs.

Outcome: Applying plain-language principles facilitates relevant health information for the audience, keeping it simple, making sure its readable, and making it timely and actionable.

Added value: Plain language supports access to information, equity, and participation in society. It also improves efficiency and builds brand trust.



Tools

Mapping linguistic landscapes

Aim and objectives: Mapping linguistic landscapes is used to gain insights in how people navigate health systems and to improve health system environments.

Target group: It is a tool for health providers, managers, and decision-makers to enhance service design and user journeys.

Method: Using linguistic landscape analysis as a diagnostic, relevant questions may include:

- ▶ how many and what languages occur on signs in a specific public space?
- ▶ are the signs monolingual, bilingual, multilingual and in what ways, i.e. what combinations of languages occur?

- ▶ are different languages used for different contents and in different domains?
- ▶ in what forms do signs occur (notice boards, traffic signs, billboards, shop windows, posters, flags, banners, graffiti, menus, T-shirts, Facebook, Twitter, Instagram, Blogs, Websites)?
- ▶ what about the language in terms of normativity: orthography, handwriting conventions, lexicon, syntax, literacy level?

A next step would include a more in-depth analysis and interpretation of the signs. Looking at deeper layers of meaning connected to the signs that can explain what they refer to in addition to their referential meaning is also called the indexicality. Examples include to study the past (e.g., the conditions of production), the future (e.g., the conditions for uptake), and the present (e.g., at the specific placement of the sign among other signs).

Outcome: Mapping linguistic landscapes is a way to study visible semiotic signs in public spaces and to study how language includes or excludes people from communication and full participation in social and societal contexts.



Figure : Example of linguistic landscapes - signposting in hospitals



Tools

Open-Source tools for Data Visualisation

Aim and objectives: 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.

Target group: Applying visual elements and plain language help bring an individual with limited health literacy and numeracy skills to an outcome that equates to better health behaviours and practices.

Method: 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. Data dashboards may be effective visualisation tools for tracking and visualising data from multiple sources (e.g., tables, pie charts and stacked bar charts, line graphs and area graphs, histograms, scatter plots, heat maps and tree maps). It might also be combined with infographics, including icons and minor text to show a visual narrative.

Outcome: Storytelling with data through simple graphs, comparative charts and representational icons often helps to make the implicit explicit to enhance individual and population health.

Added value: Data visualisation can improve understanding and analyses, as well as enabling better and faster decision making.



SHARED DECISION-MAKING REGARDING TREATMENTS AND CARE

- ▶ **Hierarchical health systems and barriers to active participation of people and health providers may hamper shared decision-making. Health literacy facilitates active participation, sharing of power and knowledge to make decisions with informed consent.**

CONTEXT

Shared decision making - whereby health professionals and patients discuss possible options for care and make decisions together using best available information - is central to patient empowerment and autonomy. This fosters genuine possibilities for patients to freely choose and make informed decisions about medical alternatives and self-care management.

Associated with improvements in the quality of decisions, better patient knowledge and risk perception, shared decision-making regarding treatment and care has the potential to reduce health disparities between less and more disadvantaged patients in terms of their health literacy skills. Patients who are informed and express preferences contribute to improved health outcomes, which are safer, cost-effective, and efficient.

CHALLENGE

Hierarchical health systems and a lack of awareness of the possibility for individuals to be co-opted in decision-making processes are a challenge.

European research reveals challenges when people engage with health providers. For instance, in the UK 23 % report concerns with a health system provider, 35 % report difficulties in making sure that the health system provider understands them properly, 25 % report difficulties in discussing with the provider until they understand all they need to know, and 23 % experience difficulties in asking questions to providers to obtain health information¹⁰. Though some of these difficulties are rooted in patients' limited health literacy, this may also relate to the difficulties of health authorities to redistribute power and agency.

Limited health literacy has been linked with greater decision conflict between patients and health care professionals, which may be due to its association with difficulties in comprehending risk estimates of suggested care. Considering that European research shows that 43% of adults perceive difficulties in assessing the advantages and disadvantages of different treatment options¹¹, the regional challenges for genuine shared decision-making are evident.

In a patient-centred process for informed consent, information about various options for treatments and their risks, benefits and costs, should be communicated in a clear, transparent and unbiased manner. Based on their individual preferences and experiences, patients should be able to weigh the benefits of treatment against probable risks and to avoid decisions that would not have been made if patients were well informed and involved.

Furthermore, to improve shared decision-making and treatment adherence, different approaches are needed for people with limited levels of health literacy and for people with high levels of health literacy (i.e. non-adherence can, on the one hand, be unintentional for patients with limited levels of health literacy while, on the other hand, be intentional for patients with high health literacy).

ACTIONS, GOOD PRACTICE AND TOOLS

Health literacy empowers people to genuinely participate in shared decision making. Health systems have the responsibility to secure opportunities for shared decision-making by adapting their procedures to the needs of individuals, to give them a voice, to acknowledge their social situations, and to collaborate with them equally. In this connection, the use of intercultural mediators in health could help to bridge socio-cultural gaps, to build trust in health care providers, and to facilitate shared decision-making relationships.

¹⁰ Kashaf, M. S., McGill, E. T., & Berger, 2017.

¹¹ The Health Literacy Population Survey Project (HLS19) Consortium of the WHO Action Network M-POHL, 2021.

Actions

<p>Individuals need:</p> <ul style="list-style-type: none">• relevant information about their health conditions and available options for care;• information about their right to be heard and to participate in making decisions that influence their health and health care;• to identify and describe their expectations, preferences, wishes and needs;• to reflect on information from their personal perspective and to assess what fits with their own lives (opportunities, preferences);• to ask for clarifications when necessary;• to participate in making care plans, to discuss alternative options and to make joint decisions.	<p>Systems have the responsibility to:</p> <ul style="list-style-type: none">• provide sufficient amounts of information for patients, in needed formats;• facilitate patient's reflective thinking and question-making;• value patients (their knowledge, experiences etc.);• distribute power, creating mutual understanding and trust, respect patients' views, expectations and values, by using, if needed, intercultural health mediators;• be aware of patient diversity and their unique needs.
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Good practice

Integration of patients' and health care professionals' different domains of knowledge for shared decision making in treatment discussion – Finland

Aim and objectives: Integrating the knowledge pools of professionals' medical knowledge and patients' experiential knowledge when negotiating treatment in health care encounters.

The domains of knowledge or "knowledge pools" into which patients and health care professionals are entitled to have access to are asymmetric: professionals have access to medical information, whereas patients have access to information concerning their own experiences and life world, such as their symptoms, their preferences and values.

Target group: Health care professionals.

Method:

- ▶ inquiring about the patient's perspective, such as expectations concerning treatment and its integration in the treatment suggestion;
- ▶ presenting options rather than just one possible alternative;
- ▶ if needed, recommending a specific option by drawing upon the patient's disclosed perspective and explaining why this option is recommended.

Outcome: Patients can match the suggested treatment to their possible expected treatment solutions and to understand the grounds for treatment recommendation.

Added value: Expected improvements in patient experience of possibilities to influence their own treatment and better adherence to treatment.



Good practice

Shared decision-making tools and guidelines – UK

Aim and objectives: Shared decision-making is a joint process in which a healthcare professional works together with a person to reach a decision about care. It involves choosing tests and treatments based both on evidence and on the person's individual preferences, beliefs and values.

Target group: The key audiences for decision aids of the National Institute for Care and Excellence (NICE) are people facing those decisions (and their carers, guardians and relatives as appropriate) and the practitioners involved in their care. Secondary audiences are organisations commissioning or providing care (which may include decision aids in policies and pathways), and voluntary and community sector organisations (which may promote them to the people with whom they work).

Method: Preference-sensitive decision points are points where the person's values and preferences are particularly important. They occur when either:

- ▶ There are two or more options for investigation, treatment or care that deliver similar outcomes but:
 - they have different types of harms and benefits which people may value differently, or
 - the likelihood of the harms or benefits may differ, or
 - the practicalities of the options are different (for example, the choice is between medicine and surgery, or the requirements for monitoring differ), or
 - people may consider the overall risks of harms for any of the options outweigh the overall benefits compared with no treatment.

or

- ▶ The choice between an investigation, treatment or care option and the option of 'no treatment' is finely balanced.

The NICE decision aids are developed for various treatments and care options which helps to:

- ▶ summarise the best available evidence relating to the effectiveness, safety and practical factors relating to the treatment or care options, and
- ▶ present that information in a way that is easy for people facing the decision (and their carers, as appropriate) to understand, with support from their health or care practitioner, so that they can weigh up the options pros, cons and trade-offs.

Outcome: Decision-making aids allow people to discuss and share information. This makes sure people have a good understanding of the benefits, harms and possible outcomes of different options. Shared decision-making empowers people to make decisions about the treatment and care that is right for them at that time, including choosing to continue with their current treatment or choosing no treatment at all.

Added value: Shared decision-making tools allow people the opportunity to choose to what degree they want to engage in decision making. Although, at times, some people prefer not to take an active role in making decisions with their healthcare professionals.



Tools

Health Literacy Pathway Model – United States

Aim and objectives: The Health Literacy Pathway Model 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 actively involved in health system consultations and informed decision-making.

Target group: Patients with a long-term condition can develop health literacy skills over time and put their skills into practice in becoming more active in health system consultations.

Method: The method entails development of knowledge, health literacy skills and practices, health literacy actions, abilities in seeking options and informed and shared decision-making opportunities.

Outcome: Applying the health literacy pathway in practice, helps to identify the motivations and barriers to developing and practising health literacy skills while also taking into account the characteristics of the individuals as well as the health professionals.

Added value: Developing the health literacy pathway supports people to become more involved in health system processes, including informed and shared decision-making.

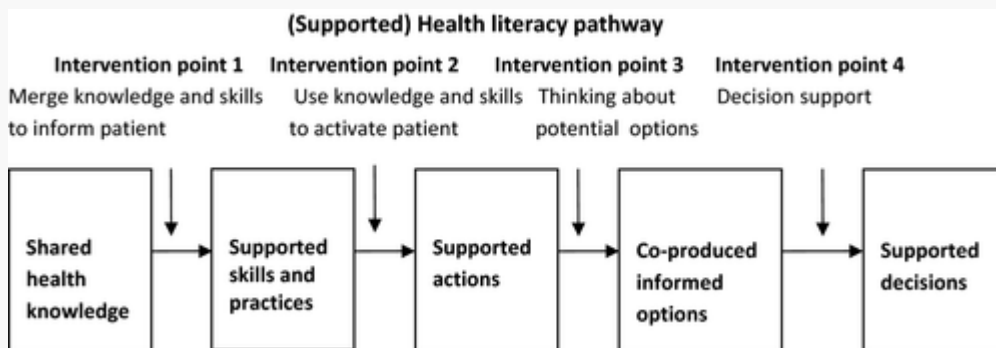


Figure : The supported health literacy pathway¹².

¹² The development of health literacy in patients with a long-term health condition: the health literacy pathway model | BMC Public Health | Full Text (biomedcentral.com)



ACCESS TO DIGITAL SPACES TO UNDERSTAND AND USE HEALTH SERVICES

- ▶ **Despite progress in the global digital transformation of health and health care, there remains disparities in skills and resources when accessing online health systems. Overcoming these disparities requires efforts to ensure access for all to the equipment needed and the acquisition of skills to use online sites and services. Digital health communication and health care services should be easy to use and adapted to individual needs.**

CONTEXT

'Digital' is part of all spheres of life. Online spaces have become a central environment for communication and engagement, learning and work, but also for health promotion, disease prevention, health system interventions, self-care, and self-management.

Health 4.0 is a term used to describe the digital transformation of health and medical care, and digital health can be considered knowledge and practice linked with the development and use of digital technologies to improve health. Digital health literacy (i.e., e-health literacy) is one form of health literacy which covers the skills needed to access and navigate digital sources of health information and tools.

Having relevant digital competencies, equipment and internet access are determinants of health which should be secured for all.

Access to digital spaces is particularly important when mobility is restricted or when people live in rural or remote areas. As compared to traditional communication strategies, digital spaces support accessibility and the widening of access to health information for different people and groups, irrespective of personally identifiable characteristics such as age, geographical situation, ethnicity, age, education, or race.

Telehealth and digital technologies make it possible for people to manage their care with remote support from health professionals. Wearable devices and smart phones create a constant connection between patients and clinicians, to be able to raise the alarm in the event of an emergency.

CHALLENGES

While 91% of European households have internet access, some still do not. Access differs between urban and rural areas and between countries in general¹³. Hence, there is a need for the constant development of both online and offline health information and services.

Although the digital transformation of health and medical care may bring many benefits it may also reproduce and reinforce existing inequalities related to restricted mobility due to disparities in skills and resources and the lack of preparedness of health providers to consider digital health inequity and individuals' experiences about online health technologies.

Many new online health services and technologies may only be available for those with relevant knowledge, skills, and financial resources. However, for people suffering from vision or cognitive impairments or rare diseases, or for migrants and the homeless, online health services might be lacking or otherwise inaccessible.

Covid-19

In Europe, before the Covid-19 pandemic, nearly 40 % of people lacked the basic digital skills needed to access digital spaces and services¹⁴. Such a divide increases vulnerability in reaching timely and appropriate health care. It also increases exposure to various unfavourable health indicators, such as depression and loneliness. During the Covid-19 pandemic, this vulnerability increased, especially among older persons, resulting in inequities in vaccine access across countries.

The Covid-19 pandemic demonstrated the importance of being able to access digital platforms on an equal basis. Digital technologies, such as mobile phones, made it possible to organise rapid contact tracing, symptom checking, advice seeking and receiving online health care (e.g., tele-medicine, online prescriptions), and to advance public communication and education. With billions of people in self-isolation, digital environments enabled access to valid and updated information, including self-care guidelines and health-care services. They provided a vital means for people to connect with each other while minimising their exposure to infectious disease.

¹³ Statista Research Department, 2021.

¹⁴ Statista Research Department, 2021.

Digital access for older persons

During the Covid-19 pandemic, many older adults used traditional media, such as television and newspapers, as sources of information about the virus and protective measures. These were accessible to nearly everyone, whereas electronic information was accessible to less than half. It is important to secure access to appropriate offline information along with the access to online information.

Those with limited levels of education, who live alone or lack social support or have impaired cognitive functioning are often more challenged when accessing digital spaces. Significantly older persons (i.e. persons over the age of 85) are less likely to use digital devices and to access digital information.

Mediation for Roma - Latvia

The Covid-19 pandemic significantly increased the challenges facing Roma parents and children alike, and communication and dialogue between Roma families and municipality institutions.

In March 2020, the Ministry of Culture updated its Guidelines for Roma mediators to provide Roma mediation services at the municipal level. The Guidelines include the provision of regular information to Roma families on prevention measures regarding the Covid-19 virus. In February 2021, additional financial support for Roma mediation services was provided to cope with the constraints and precautionary measures related to the Covid-19 pandemic.

Access to online learning for Roma children - Greece

Following a ministerial decision to suspend all school services during periods of lockdown, it was decided to support Roma students attending primary and secondary education. In cooperation with the Ministry of Education and Religious Affairs, equal access and distance learning for Roma students was ensured by offering them a 200 euros voucher to purchase equipment (tablet, laptop, desktop). The voucher was awarded based on low family income (up to 6,000 euros) and social criteria which resulted in support given to 325,000 families with 560,000 dependent children and young people aged 4 to 24 years.

ACTIONS, GOOD PRACTICE AND TOOLS

The development of digital health services and tools, and individuals' competencies to access and to use them, have the potential to increase equity in accessing health care of appropriate quality and to decrease health disparities.

Actions

<p>Individuals need:</p> <ul style="list-style-type: none"> • general digital skills to use devices and applications; • knowledge on available digital health system services (sites and applications), and relevant health concepts, to find appropriate information in (online medical) records; • skills to find, navigate and use relevant digital health system sites and services; • skills to interpret and critically appraise the results of various health apps; • (online) communication skills with health personnel in eHealth. 	<p>Systems have the responsibility to:</p> <ul style="list-style-type: none"> • develop secure easily accessible internet access for all people (incl. homeless people, etc.); • offer support to use information technologies; • develop digital health communications and health system services (sites and applications) that are easy to use and adaptable for individuals with different needs; • develop health system providers competencies in using online health services; • develop health system providers' competencies that are sensitive to the different needs of individuals who are using digital technologies and services, for example digital health service-related mediators who help communities as well as people in vulnerable situations.
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Good practice

eHealth portal – Denmark

Aim and objectives: There is an urgent need to break down industry silos and increase collaboration to drive progress towards a patient-centric and cost-effective model. Denmark has been at the forefront of many IT initiatives within health services. The majority of these initiatives are based on a common infrastructure. The Danish National eHealth Portal, known as sundhed.dk ("sundhed" means "health") helps to promote the optimisation of the Danish healthcare sector.

Target group: Sundhed.dk is a public, Internet-based portal that collects and distributes healthcare information among citizens and healthcare professionals.

All Danish citizens have access to Sundhed.dk, enabling patients to communicate, and patients and their families to get an overview of correct and updated healthcare information, making the services appear close-by, open and familiar. Every citizen has his/her own personal page (available upon identification), which reflects the specific situation of this particular person.

Method: Sundhed.dk is a partnership established between all public health authorities in Denmark. The platform builds on a role-based and personalised, customizable portal environment. The portal provides information to a large range of user groups: physicians, GPs, pharmacists, dentists, chronically sick, frequent users, occasional users, etc. Every

user group has its own special requirements with regard to the information it needs and how it is presented. To handle all these user groups, almost 100 different applications are needed and updated every three months.

Outcome: Sundhed.dk has transformed the Danish health service from consisting of information islands of independent, individual solutions and databases, each with its own limited group of users, into a structure that is based on the joint use of standard solutions and sharing of data. In helping every user who logs on to the portal via personal identification, the portal has been built in such a way that it adapts the presentation to its user needs, integrating the several channels of technological information into one.

Added value: The portals range of information and services has proved that it is possible to work across sector borders and specialist fields to present the user with a single point of entry that provides a general view and guides the user to the relevant information and the relevant services. Thus, Sundhed.dk integrates systems that are specific to the Danish health service but other regional or national health services, or completely different sectors or industries, will be able to obtain similar benefits by making use of the experience gained from sundhed.dk of building transparency and sharing information and systems.



Good practice

My Health Space: making patients real players in the management of their health data – France

Aim and objectives: The aim is to make a single digital portal available to all persons affiliated to the social security system. The portal is fed input directly by health professionals thanks to a system of interoperability with the software they use. My Health Space enables users to better monitor and manage their health. The overall objective is to improve medical care by centralising documents (avoiding loss and omission), improving coordination between health professionals (authorised to access patients' care history), and raising digital awareness among all users (via an ad hoc support system).

Target group: My Health Space is aimed at all people affiliated to the social security system, and all they need is a *carte vitale* to benefit from it. This represents a target of more than 60 million users, for whom the creation of an account is automatic, with the possibility of opposition left to the user.

Method: My Health Space is the result of a dialogue between the Ministry of Health, the *Assurance Maladie*, health professionals, software publishers, patient associations and users of the health system.

My Health Space is built around four main components: 1) a shared medical file supplied by healthcare professionals and the patient; 2) a secure messaging system for confidential exchanges with healthcare professionals; 3) a diary listing medical appointments; and 4) a catalogue of services referencing several applications. Access to the documents contained in My Health Space is entirely at the patient's discretion, and the patient can choose to hide a document or "block" a health professional, if necessary.

Following the roll out of My Health Space in February 2022, a support strategy for all users has been put in place, with a focus on those who are furthest from the digital environment (awareness-raising and training of digital mediation players, funding of posts dedicated to the digital mediation strategy in the regions).

Numerous partnerships have been formed with associations and companies, and training has been provided to all administrative assistance offices.

Outcome: The deployment of My Health Space is progressive. All French people have been notified of the creation of their account with a six-week withdrawal period. The automatic creations will be completed in July 2022. My Health Space is already used by many French people, and the software used by health professionals is currently being made compatible with their product by sector (pharmacies, medical laboratories, radiology, etc.).

Added value: My Health Space is a unique tool, used by all the players in the healthcare chain but which remains in the hands of the patient. It has been co-constructed with citizens (setting up of a citizen committee), health professionals, software publishers and users of the health system, who also benefit from support in learning how to use it. This is the first time that a State digital product has been proposed in conjunction with a digital inclusion strategy. Finally, the tool meets high ethical and legal requirements.



Good practice

Digital health system – Estonia

Aim and objectives: Estonia's health service has been digital for 12 years. More than 99% of the data generated by hospitals and doctors is digitised.

Target group: Citizens can access their own medical records via a super-secure online portal and choose who gets to look at those records.

Method: Many health services happen online — from video consultations to e-prescriptions. Services are intersectoral, also including notifications of death. For example, once a death is registered online, notifications are automatically sent to that person's workplace, the tax office, and the population registry.

Outcome: The system is highly transparent and health professionals can communicate easily with patients. Moreover, patients are empowered to 'lock' and 'unlock' their own data thereby deciding who has access to their data. Moreover, being highly people-centred, citizens are also involved in key decisions about the system.

Added value: Trustworthiness is built into the system's design. Every time someone accesses a patient's information, it is logged. No one can check the medical records just for curiosity. The system is designed to integrate citizen science to inform and qualify digital services.



European Ethical Principles For Digital Health – European Union

In January 2022, the European Union set out a framework for digital health. Approved by the eHealth Network, composed of EU Member State representatives responsible for digital health, and proposed by the French Presidency of the Council of the European Union, 16 European principles for ethics in digital health were established to improve mutual understanding and to facilitate discussions on the future European regulation on the European health data space. They directly address the EU citizen and incorporate four ethical dimensions: “placing digital health within a framework of humanist values”, “enabling people to manage their own health data digitally”, “developing inclusive digital health”, and “implementing eco-friendly digital health”.

Base Digital Health on humanistic values

1. Digital Health complements and optimises face-to-face healthcare
2. Individuals are informed about the benefits and limits of Digital Health
3. Individuals are informed about the functioning of Digital Health services and can easily customise interactions with them
4. When artificial intelligence is used, all reasonable efforts are made to make it explainable and without discriminatory bias

Enable individuals to manage their Digital Health and data

5. Individuals are actively involved in shaping the European and national frameworks of Digital Health and data
6. Individuals can easily and reliably retrieve their health data in a commonly used format
7. Individuals can easily get information on how their health data have been or may be accessed and for which purpose
8. Individuals can easily and reliably grant access to their health data and exercise their rights, including objection when applicable

Make Digital Health inclusive

9. Digital Health services are accessible by all, including by people with disabilities or low levels of literacy
10. Digital Health services are intuitive and easy to use
11. Individuals have access to Digital Health training
12. Digital Health services include support through human communication when needed

Implement eco-responsible Digital Health

13. Environmental impacts of Digital Health are identified and measured
14. Digital Health services are developed in compliance with eco-design best practices
15. Re-use and recycling of Digital Health equipment is ensured
16. Digital Health stakeholders are committed to reducing their ecological footprint



HEALTH LITERACY POLICY, MOBILISATION AND CAPACITY BUILDING

At all levels, greater efforts are needed to promote a culture of health literacy in order to foster equitable access to healthcare for all, including people in vulnerable situations. In practice, this means the development of public policy at the local, regional, national and international levels. This also requires cross-sectoral collaboration with other stakeholders (interest groups, coalitions, alliances, networks etc.) and capacity building in health authorities and systems to strengthen the capacity and skills of the workforce.

HEALTH LITERACY PUBLIC POLICY

Health literacy public policy is increasing. Governments across Europe are mobilising forces to increase health literacy in collaboration with non-state stakeholders, such as academia, industry and NGOs. For instance, several European countries have adopted nationwide health literacy actions plans, such as Austria, Norway, Portugal and the UK (Scotland), which are driving interventions and programmes nationwide to enhance population health literacy.



Good practice

Health literacy as a national health goal – Austria

Aim and objectives: In 2012, the Austrian Council of Ministers approved ten comprehensive targets to improve determinants of health in the sense of Health in All Policies. Health target number 3 aimed to enhance health literacy in the population.

Method: A working group consisting of 30 experts from public administration, social security, research institutions and civic society developed specific sub-targets and indicators including:

- ▶ to make the health system more health literate through involving stakeholders and those affected (for example, by developing health literate organisations);
- ▶ to strengthen individual health literacy with consideration for people in vulnerable situations (for example, by collaborating with the education system);
- ▶ to embed health literacy in the service and production sectors (the economic system).

Outcome: The national healthcare reform process was an entry point for change towards a more health literate system. The steps included establishing the Austrian Health Literacy Platform as a steering body for health literacy initiatives, participation on European and national health literacy surveys, implementation of interventions focusing on health literacy-sensitive information and communication as well as the development of health literate organisations. Moreover, health literacy is promoted as a professional competency of health providers.

Added value: Since the agreement of health target 3 on health literacy, health literacy has become part of the mainstream public discourse in Austria and is included in the government's programme. It is an emerging topic in curricula of health professionals and the health literacy evidence has put in motion multiple new initiatives to improve practice. More can still be achieved with regards to shared decision-making and activities beyond the healthcare sector.



Good practice

Strategy to improve health literacy in the population 2019-2023 – Norway

Aim and objectives: The aim of the strategy is to increase the health literacy of the population in Norway. It is targeted at health and social professionals, decision-makers, and managers as well as patient organisations and other relevant stakeholders. It pursues a cross-sectoral approach, in particular the involvement of the health and educational sector.

Method: The methods include:

- ▶ promoting the concept of health literacy in the Norwegian context;
- ▶ setting- up targeted efforts to improve population health literacy;
- ▶ highlighting the importance of health literacy among health providers for the patients' engagement in services;
- ▶ developing health and social services with respect to the health literacy responsiveness of staff;
- ▶ identifying the state of the art of health literacy in the population;
- ▶ describing different initiatives that can enhance health literacy in various population groups and showcasing examples of ongoing activities that support health literacy without being labelled as such;
- ▶ conducting health literacy research;
- ▶ describing how health authorities will work to improve health literacy in populations and sub-groups of the population.

Outcome: Health authorities are required to facilitate patients journeys that engage patients in shared and informed decisions, such as asking "what is important to you?". Health literacy is regarded as a precondition for realising patient-centered health services.

Added value: The strategy on health literacy supports the vision of a patient-centered health system. It implies that patients and users have the knowledge, competencies and opportunities to manage health in the best possible way.



Good practice

Improving health literacy – Portugal

Aim and objectives: In Portugal, the national action plan on health literacy aims to reach different parts of the population, including, for example, immigrant populations and temporary residents. The national action plan was launched after a survey revealed that up to 40% of the population had difficulties in accessing adequate and reliable information on health care. For young people, health information is often obtained via social media platforms which can be both a challenge and an opportunity to tailor and better direct health literacy towards their lifestyles.

Target group: The success and development of the Action Plan will depend on the close coordination and work with the following strategic partners: Public, Social and Private Sectors; Ministries, General-Directorates and Inter-ministerial Committees; National Health Plan Health Programmes; other structures belonging to the Ministry of Health Academy, Professional Bodies, Scientific Societies, Private Institutions for Social Solidarity (IPSS), NGOs, Media, Social Media, Digital Media, Civil Society Patient Associations.

Method: The action plan focuses on four priorities:

- ▶ adopting healthy lifestyles;
- ▶ training for proper use;
- ▶ promoting well-being;
- ▶ promoting knowledge and research.

Outcome: The Action Plan facilitates the provision of instruments and tools to health professionals to promote health literacy; campaigns and thematic interventions are carried out for the population that promote health literacy; the network of stakeholders to incorporate and strengthen health Literacy promotion interventions and their impact are increased; and a monitoring committee with the purpose of supporting the prioritisation of actions and measures, and as a resource of excellence for the development of strategic information.

Added value: Whilst keeping a person-centred approach to interventions, the Action Plan intends to improve the health literacy levels of the Portuguese population continuously and consciously in a sustainable way. Deploying a life cycle approach is in line with other policy initiatives related to “Health Citizenship”, “Equity and Access to Healthcare”, “Quality in Health”, “Healthy Policies” and their respective objectives and goals.



Good practice

Health literacy Action Plan 2022-2026 – Türkiye

Aim: To increase nationwide levels of health literacy by developing necessary cognitive and social skills to access, understand and use health-related information in order to improve their health and maintain good health.

Objectives:

- ▶ to develop and implement assessment scales which determine the current state of health literacy of the population;
- ▶ to develop and disseminate accurate, accessible and actionable health information;
- ▶ to develop and implement software applications related to health, such as in E-NABIZ and MHRS: MHRS is a Central Physician Appointment System; E-NABIZ is a personal health record system which manages personal health information and is used by public and health professionals to view diagnoses and treatments, tests and examination reports, diagnostic imaging records and reports, prescriptions, vaccinations, visits of healthcare services, past and future appointments of patients;
- ▶ to increase the health literacy of health care workers;
- ▶ to raise social awareness about disease and risk factors;
- ▶ to promote healthy lifestyle habits;
- ▶ to raise public awareness of appropriate uses of health services;
- ▶ to conduct monitoring and evaluation processes.

Target Group: The aim is to reach all segments of the public, including children, pregnant women, parents, persons with disabilities and older persons.

Method: The Action Plan is carried out in cooperation with relevant stakeholders such as universities, TÜİK (Turkish Statistical Institute), TRT (Turkish Radio Television), private TV and radio channels, other ministries and NGOs. Ministries and their regional organisations prepare projects related to health literacy falling within the scope of their duty and responsibilities (e.g. the Ministry of Family and Social Services, in collaboration with the Ministry of Health, carry out health literacy trainings for families). Cooperation is in planning with the following institutions:

- ▶ TÜİK in the implementation of the assessment scales which determine the current state of health literacy of the population;
- ▶ Universities for the evaluation of results of the abovementioned assessment scales and preparation of scientific publications;
- ▶ TRT, Private Radio/TV Channels, traditional and new media channels for the preparation of content aimed at increasing health literacy for adults;
- ▶ Union of Municipalities of Türkiye and relevant NGOs for the organisation and dissemination of activities throughout the country;
- ▶ The Turkish Green Crescent Society for raising awareness about addiction;
- ▶ World Health Organisation for studies on addiction and rational drug use.

For the efficacy and continuity of activities within the scope of the Action Plan:

- ▶ according to the mission, vision and field of work of each institution, a responsible institution is designated among the partner institutions, which is also responsible for submitting a report about the activities every 6 months;
- ▶ data regarding the activities carried out is input into the online monitoring platform for activities that are under the responsibility of stakeholder institutions;
- ▶ the General Directorate of Health Promotion of the Ministry of Health monitors the process and preparation of progress reports every six months to ensure efficacy and continuity of the activities in the scope of the Action Plan.

Outcome: Improvements in and continuity of healthy lifestyle behaviours.

Added Value: Low health literacy is the cause of various negative behaviours and outcomes, such as poor understanding of health-related messages, inappropriate use of drugs, increased hospitalisations resulting from the under-utilisation of preventive health services, and the overuse of emergency services. These situations challenge the efficient use of health services, they also lead to low productivity, increased morbidity and mortality, and an increase in the cost of medical expenses. On this basis, it is predicted that by increasing health literacy levels there will be an increase in general quality of life and a significant decrease in health costs.

Outcome: According to the “Health Literacy Level and Related Factors Survey of Türkiye (2018)”, in accordance with the Scale of Health Literacy of Türkiye-Türkiye Sağlık Okur Yazarlığı Ölçeği-TSOY-32, the health literacy levels of participants are reported as 30.9% (inadequate) and 38% (problematic-limited). Measuring the level of health literacy of all segments of society at regular intervals provides important guidance for actions and policies to improve health literacy.

The expected outcomes of the Action Plan are as follows:

- ▶ providing opportunities to access reliable and understandable information for every member of society;
- ▶ raising awareness among children and their families, by including health literacy as a subject in the basic education curriculum;
- ▶ positive changes in healthy lifestyle behaviours of individuals;
- ▶ individuals are involved in the decision-making process for their own treatment and care,
- ▶ individuals comply with instructions for treatment, helping to reduce errors in drug (medicine) administration and use;
- ▶ individuals have knowledge and take responsibility for their health and diseases they are faced with;
- ▶ increasing awareness of society about the fight against substance addiction;
- ▶ individuals have knowledge about reproductive health, occupational health and safety, health and care of older persons, patient care, environmental health, chronic diseases, such as hypertension, diabetes, asthma, infectious diseases, and comply with disease management programs;
- ▶ increasing participation in health-promotion practices, such as cancer screening, prevention of risky health behaviours, prevention of home accidents, family education programs;
- ▶ eliminating the lack of information on preventive health services and using these services effectively;
- ▶ reducing inappropriate use of emergency services and hospitalisations;
- ▶ reducing health expenditures.



Good practice

Making it Easier. Health Literacy Action Plan – UK (Scotland)

Aim and objectives: “Making it easier”, which is Scotland’s second action plan on health literacy developed by the NHS, sets out an action plan for improving health literacy in Scotland 2017-2025. The first plan was titled “Making it easy”. The action plan aims to remove barriers and prevent them being put there in the first place.

Target group: The action plan is aimed at health providers, patient organisations and decision-makers.

Method: The action plan focuses on four areas:

- ▶ share the learning from “Making it Easy” across Scotland;
- ▶ embed ways to improve health literacy in policy and practice;
- ▶ develop more health literacy responsive organisations and communities;
- ▶ design support and services to better meet people’s health literacy levels.

Outcome: The health literacy action plan helps to improve how to design and deliver services in the future based on supporting people’s needs through shared decision-making.

Added value: The health literacy action plan sets out the ambition for Scotland to be a health literate society that enables the population to have the confidence, knowledge, understanding and skills to maintain good health.



Good practice

National Action Plan on Health Literacy – Germany

Aim and objectives: The development of the National Action Plan on Health Literacy was triggered by results of the first German study on health literacy which showed that more than half of the German population perceive great problems in processing health information. In response, a group of 15 experts from academia, practice and policy worked together to publish the first version in 2018.

Target group: The Action Plan is aimed at health providers, patient organisations and decision-makers.

Method: The Plan focuses on four areas of action presenting 15 specific recommendations to strengthen health literacy in Germany following five key principles.

Outcome: The National Action Plan on Health Literacy was accompanied by an implementation strategy co-designed with relevant stakeholders to enhance the impact.

Added value: The National Action Plan on Health Literacy has enhanced health literacy on the health agenda in the German policy landscape.



MOBILISING HEALTH LITERACY COMMUNITIES AND ‘CHAMPIONS’

Fostering health literacy communities is a key component in the promotion of health equity. This is because 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. Formal and informal interest groups, coalitions, alliances, networks, platforms as well as institutes, organisations, and associations help to discuss, assess and strengthen health literacy capacities at various levels in society (some examples below).

To implement health literacy, change-agents are needed to develop and drive impact. These change-agents, often called ‘health literacy champions’, may come from policy, academia, practice or civic society. The presence of advocates for organisational change is critical, however, their impact depends highly on support from leadership. A management structure and culture that supports health literacy innovation and quality improvement is essential for a successful implementation (example far below).



Tools

Health Literacy Champion Toolkit – United States

Aim and objectives: The Horowitz Center partnered with the Nebraska Association of Local Health Directors to offer the Health Literacy Champion Toolkit.

Target group: The Toolkit is for local health department staff to assess health literacy capacity, develop an action plan, and commit to implementing the plan. State health departments and other organisations may also find the toolkit a valuable assessment and planning tool, although some of their organisational functions may differ.

Method: The Health Literacy Champion Process has 5 steps:

- ▶ Review the Toolkit background document;
- ▶ Health Literacy Check-Up: assess health literate policies and procedures in the department;
- ▶ Health Literacy Action Plan: develop SMART goals and an action plan;
- ▶ Health Literacy Pledge: commit to implementing the plan;
- ▶ Action Plan Implementation: implement the plan.

Outcome: The Partnership supports health literacy training that aligns with national standards and the development of a database of evidence-based health literacy training resources to aid in program development.

Added value: The initiative supports the engagement of multiple local health counties in the development of health literacy strategic plans, including discussing county-specific strengths, gaps, and opportunities, accreditation opportunities, education and professional development, guidelines for Maryland to become a health literate state.



Tools

The International Health Literacy Association (IHLA) 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 organisation are the interest groups which develop and implement health literacy within a wide range of topics.

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.

Asian Health Literacy Association was launched in 2013. It hosts the Asian Health Literacy Conferences and supports the development of health literacy in Asia.

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 oversees 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.

Francophone health literacy network is the first French-language interdisciplinary network of researchers dedicated to health literacy, including digital health literacy. Its website gathers works carried out in France, Switzerland and Belgium.

UK Health Literacy Network is a multi-disciplinary group. The aim of the network is to advance research, theory, education, and practice on health literacy with special attention to personal, social, economic, and political implications.

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 the health literacy of citizens and supports health professionals in recognising and addressing health literacy issues. The Alliance also promotes clear communication and plain language.

Portuguese Health Literacy Society was inaugurated in 2022. It seeks to develop and influence the impact of health literacy in Portugal and beyond.

German Alliance for Health Literacy

The Ministry of Health launched the "Alliance for Health Literacy" in 2017 together with the heads of the self-administration of the German health care system. The common goal was to strengthen and further promote health literacy among the population in Germany. The Alliance for Health Literacy includes 14 different organisations.

Covid-HL network is an interdisciplinary network established as an open science and research community to foster research in the field of health literacy, health information, and digital health. Since its launch in February 2020, more than 100 researchers from more than 50 countries joined the network, both early career and experienced researchers. Together they explore health literacy in individuals and systems to better understand how the Covid-19 pandemic has changed society, health, and information management.



CAPACITY BUILDING IN HEALTH AUTHORITIES AND SYSTEMS

Health literacy authorities and systems become more 'people-centred' when they integrate health literacy as a cross-cutting and transversal value and strategy in all parts of their work. Resources include the Ten attributes of health literate organisations, the Vienna model for health literate hospitals, and the Ophelia Toolkit, which are examples of how to optimise health literacy in organisations and communities. The Health Literacy Survey Tool (HLS) supports the measuring and monitoring of health literacy progress across populations and organisations.



Tools

Ten Attributes of Health Literate Health Care Organizations – United States

Aim and objectives: The Brach model highlights ten attributes of health literate organisations.

Target group: The Brach model can be used for strategic planning by health professionals, providers and decision-makers.

Method: The model describes ten action areas for health providers and managers to develop and improve to become a health literate organisation:

- ▶ leadership that makes health literacy integral to its mission, structure, and operations;
- ▶ integration of health literacy into planning, evaluation measures, patient safety, and quality improvement;
- ▶ training of workforce to be health literate and monitor progress;
- ▶ involvement of populations served in the design, implementation, and evaluation of health information and services;
- ▶ meeting the needs of populations with a range of health literacy skills while avoiding stigmatisation;
- ▶ applying health literacy strategies in interpersonal communications and confirm understanding at all points of contact;
- ▶ provision of easy access to health information and services and navigation assistance;
- ▶ designing and distributing print, audio-visual, and social media content that is easy to understand and act upon;
- ▶ addressing health literacy in high-risk situations, including care transitions and communication about medicines;
- ▶ clear communication of what health plans cover and what individuals will have to pay for services.

Outcome: The Brach model has been influential in the agenda-setting for structural efforts to improve health literacy.

Added value: Applying a strategic approach in the implementation of health literacy strengthens the impact of health literacy across the organisation and beyond.



Tools

Vienna model for health literate hospitals – Austria

Aim and objectives: The Vienna model has the dual aim of fostering material conditions and creating a work culture inside health care organisations to make it easier for people to use information.

Target group: The Vienna Health Literate Organisation (V-HLO) self-assessment tool is a questionnaire for quality managers of health care organisations. Its objective is to determine the strengths and weaknesses of the organisation in terms of health literacy.

Method: The Vienna Health Literate Organisation self-assessment tool focuses on nine standards and 22 sub-standards.

9 standards and the 22 sub-standards of the Vienna Health Literate Organisation

The organisation should:	The organisation:
1. Establish management policy and organisational structures for health literacy	1.1 Understands health literacy as an organisational responsibility 1.2 Ensures quality assurance in the field of health literacy
2. Develop materials and services in participation with relevant stakeholders	2.1 Involves patient representatives in the development of materials and services 2.2 Involves staff in the development of materials and services
3. Quality staff for health-literate communication with patients	3.1 Ensures that staff are trained for health literate communication in diagnosis, therapy, treatment and care, and discharge preparation 3.2 Ensures that staff are trained for health literate communication in disease prevention and health promotion
4. Provide a supportive environment – health literate navigation and access	4.1 Ensures barrier-free contact by internet and telephone 4.2 Provides all information needed for accessing the organisation 4.3 Ensures sufficient orientation support in the entrance area for patients and visitors to easily find their way 4.4 Has an easy-to-follow navigation system and signage 4.5 Ensures that patients and visitors have access to free health information
5. Apply health literacy principles in routine communication with patients	5.1 Face-to-face communication with patients follows health literacy principles 5.2 Written and audio-visual material are designed according to health literacy principles 5.3 The organisation provides resources to guarantee translation support when needed 5.4 Communication in high-risk situations follows health literacy principles
6. Improve the health literacy of patients and their entourage	6.1 Patients (and their entourage) are supported to improve health literacy for disease-related self-management 6.2 Patients (and their entourage) are supported to improve health literacy for healthy lifestyles
7. Improve the health literacy of staff	7.1 Staff are supported to improve the health literacy they need for managing job-related health risks 7.2 Staff are supported to improve health literacy for healthy lifestyles
8. Contribute to health literacy in the region	8.1 Supports health literacy in continuous and integrated care 8.2 Contributes to the development of health literacy in the regional population
9. Share experiences and be a role model	9.1 Supports the dissemination and further development of concepts and practice of health-literate healthcare

Outcome: The tool is suitable for conducting needs assessment to help hospitals raise awareness and formulate targeted actions to further strengthen their health literacy responsiveness.

Added value: Strengthening the capacity of hospitals to consider the level of health literacy of the population is needed to improve the quality of care. One way to develop adequate health literacy responsive policy and strategies in hospitals is the use of self-assessment tools to raise awareness, help prioritise action and mobilise stakeholders.



Tools

Ophelia Toolkit – Australia

Aim and objectives: Each Ophelia (OPTimising HEalth Literacy and Access) project seeks to improve health and equity by increasing the availability and accessibility of health information and services in locally appropriate ways.

Target group: The Ophelia Approach involves the collaboration of a wide range of community members, community leaders, and workers to develop health literacy interventions that are based on needs identified within a community.

Method: The method focuses on the development of interventions in local communities. It draws on intervention mapping, quality improvement collaboratives, and realist synthesis. The intervention protocol is outcomes-oriented and focuses on two key questions: 'What are the health literacy strengths and weaknesses of clients of participating sites?', and 'How do sites interpret and respond to these to achieve positive health and equity outcomes for their clients?'.

The first phase is a needs assessment that uses the Health Literacy Questionnaire (HLQ), a multi-dimensional measure of health literacy, to identify common health literacy needs among clients. The second phase involves front-line staff and management within each service organisation in co-creating intervention plans to strategically respond to the identified local needs. The third phase will trial the interventions within each site to determine if the site can improve identified limitations to service access and/or health outcomes.

Outcome: Improving health literacy outcomes and responsiveness locally.



Tools

Measuring health literacy in populations and organizations (M-POHL) – Europe and beyond

Aim and objectives: The European health literacy survey is a tool to measure health literacy in populations.

Target group: The European Health Literacy Survey is currently being used widely across the European region and beyond. It has been translated into multiple languages and has been applied in low, middle-income and high-income countries.

Method: The questionnaire is available in various versions and can be retrieved from the International Coordination Center for the Action Network on Measuring Population and Organisational Health Literacy (M-POHL).

Outcome: The Health Literacy Survey helps to benchmark health literacy developments and monitor progress. The analytical insights can inform and qualify health literacy related policy-development, research and practice.

Added value: Establishing the evidence-based on health literacy is driving action across the European region and beyond. The Action Network involves governmental stakeholders as well as researchers to ensure a strong implementation and impact of the data generated from the health literacy surveys.



HEALTH LITERACY AS A PROFESSIONAL SKILL – INCREASING THE HEALTH LITERACY CAPACITY OF THE WORKFORCE

Health literacy is creating job opportunities and requirements to enhance the workforce with the development of health literacy as a professional skill. Considering the general growth in health literacy research and policymaking, health literacy is becoming a skill and competency demanded by health authorities and systems.

This requires the inclusion of health literacy in the educational curricula of higher education and post-graduate training within a wide range of disciplines. In practice, this means attention to the knowledge, skills, and attitudes of health professionals, especially when dealing with people in vulnerable situations and those with limited levels of health literacy. In this regard, sensitivity towards culturally different people and groups in society is important. The integration of user-experience and testimonials as well as focus on the co-production of health services is also useful to develop.



Good practice

Health Literacy Handbook – Australia

Aim and objectives: Key health service quality frameworks, including the National Quality and Safety Health Service Standards (NQS) and the Royal Australian College of General Practitioner’s Standards for General Practice, require action to address health literacy.

Target group: A handbook was written for health professionals across Northern NSW for all staff working in health, at all levels.

Method: Under the accreditation standards, there is an obligation to consumers to provide safe, quality care. This means recognising a consumer’s right to be a partner in their health care. The handbook guides health professionals to enable consumers to make their best health decisions.

Outcome: Access to learning material supports the professional development of staff working in healthcare and increases the quality of their work to accommodate the needs of people they serve, in particular people in vulnerable situations.

Added value: The Handbook is an easy and cost-effective way to upgrade the knowledge, motivation and competency of the health workforce.