

# **Improving health literacy at individual and organisational levels - Creating a solid alliance between stakeholders to promote human rights**

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## AIM

The aim of the report is to explore the setting up of a broad coalition of European and international stakeholders tasked with promoting best practice and initiatives in the field of health literacy and human rights.

## SCOPE/INTRO

Since health is a human right, all the measures and interventions aimed at increasing (promoting, preventing, safeguarding) health thereby contribute to protection of this right.

In the modern understanding of health, that is the ability to adapt and self-manage in the face of social, physical, and emotional challenges (Huber, 2011), health can gain many favorable perspectives and features from the development of Health Literacy (HL): giving people powerful tools to navigate societies and, more specifically, health and social care systems and services, put them on the right way to reach their “possible” welfare.

The right to the protection of health possesses three characteristics or principles: universality, inalienability, non-negotiability.

*Universality* means that that the protection of health is universal and applies to all people, everywhere, regardless of nationality, ethnicity, gender, religion, or any other status. All human beings possess the same fundamental right to health simply by virtue of being human. This right is inherent to all individuals and not granted by any authority, nor can it be taken away based on any characteristics or circumstances.

*Inalienability* refers to the fact that the right cannot be surrendered, transferred, or renounced. It ensures that any human right remains with the individual regardless of actions, laws, or situations that might otherwise attempt to undermine or infringe upon it. For example, even in cases of imprisonment and any other forms of confinement, an individual still retains the right to health and human treatment.

*Non-negotiability* means that human rights are not subject to compromise or trade-offs: health is inherent to each individual and cannot be taken away, even if the individual wishes to give it up.

Together, these principles form the foundation of the right to the protection of health for everyone as referred in international law and practice. They highlight the intrinsic, unconditional, and uncompromising nature of health and human rights, ensuring that all individuals are treated with

equal dignity and respect. Health must not be adjusted or negotiated away based on convenience, political agreements, or cultural differences.

However, these characteristics should not be taken for granted considering the many threats - economic, social, political, and commercial - which call into question what, for many years and in most European countries, has been considered an achieved goal.

Nowadays, *Health for All* risks remaining a mere beautiful slogan if we are not able to safeguard it. The transitions in act, both demographic and epidemiological, necessitate greater attention towards people and groups in vulnerable situations, characterized by different health risks and needing a higher level of assistance. The care of these people and groups can be neglected due to ageism, racism, discrimination, etc. These cultural phenomena are often underestimated and even “tolerated” by parts of the community, sometimes impacting also professionals who work in health and social settings with limited knowledge when not absolute ignorance of social and health dynamics.

Moreover, the progressive development of innovative treatments and technologies and sometimes the limited access to it, calls for reflection on what is health today and how we can do *more with less*: in this specific timeframe, many societies and countries are in crisis and have less money, less infrastructures, fewer and less support for professionals in public services; these “hard” prerequisites for the protection of health could be partially compensated by more self-support and/or more support by the social and family networks, should we be open to communication, education and empowerment.

Finally, individuals’ health (but also individuals’ power of choices, indirectly linked to their rights as humans) is also threatened by the so called commercial determinants of health, that is the systems, practices, and pathways through which commercial actors drive health and equity: just four industry sectors (ie, tobacco, ultra-processed food, fossil fuel, and alcohol) already account for at least a third of global deaths (Gilmore, 2023).

Based on these premises, HL presents a way forward for the right to the protection of health and combat discriminations and inequalities: contributing to people and groups health, well-being, autonomy (independent choices and knowledge of one’s own health status) at every stage of life with a view to possibly preventing or stopping health being lost. Consequently, HL can act as a lever for the emancipation of people and groups in the field of health and social services, derived from their right to be respected as human beings with human rights.

As affirmed in the European Social Charter (1996), everyone has the right to benefit from any measures enabling him or her to enjoy the highest possible standard of health attainable. This is only possible with access to relevant information, to understanding the information, and therein being able to process and use. In summary, this right is frustrated without HL, which contributes to the preservation of human dignity through equitable and appropriate use of healthcare, educational and social services.

In recent times (2023), the Council of Europe published the “Guide to health literacy. Contributing to trust building and equitable access to healthcare”, in which the main principles of HL have been revised in the light of human rights: it affirms that HL can give important contribution to safeguarding equitable access to healthcare. This document represents an effort 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.

In such perspective, HL is a means to promote the achieving of an effective process of humanization in healthcare and in health-related settings, enabling action to be taken at multiple levels to address inequities and inequalities in health.

This perspective of humanization includes also the right to be appropriately informed, comprising the ability to give informed consent to health interventions: this refers and is strictly linked to any intervention regarding health and illness which is really “informed” and well understood. This aligns with what is affirmed in the Convention on human rights and biomedicine (The Oviedo Convention, 1997), refuting the paternalist approach of “old” medicine which ignores the preferences of patients. In curtailing any authoritative role of healthcare professionals, it becomes necessary to promote the autonomy of patients and individuals using HL, both from an individual and an organisational perspective.

## Health literacy, determinants of health and human rights

The role of social and commercial determinants in affecting individual, community and population health is well-documented, as well as their impact in generating health inequities/inequalities. The World Health Organisation defined health inequalities as systematic differences in the health status among different social groups. Some experts consider individual low HL itself as a social determinant of health (Pelikan, 2018), while others view it as crucial for improving control over modifiable social determinants such as education level or income (Rowlands, 2017, Lastrucci, 2019). In both perspectives, individual HL can be viewed as an individual characteristic that could affect health. In addition, it is crucial to consider that, like other determinants of health, an individual's level of HL depends on the ability of his/her living environment to support the development of an increasingly higher level of HL. In particular, the characteristics of these environments affect how people learn about and understand health, and make decisions about it.

For this reason, when considering the health determinants related to contextual factors, it is essential to refer to the concepts of health literacy environment (that is, the way information and services regarding health are provided by the various information sources) and organisational health literacy (that is the degree to which any kind of organisations enable individuals to find, understand, and use information and services in order to inform health-related decisions and actions both for themselves and others). Finally, individual health and HL are strongly related with the HL of social networks and communities. It can be said that HL development is influenced by social practices that start from early infant experiences, and, in turn, the HL of the community and of the social networks could affect individual health-related behaviours. Moreover, some authors affirm that a health-literate community is able to gather information on social determinants of health, to mobilise the collective resources to act upon these determinants, and to advocate efficiently for structural changes in order to improve the daily living conditions of its members. From this perspective, the HL of the community is fundamental to its own empowerment, which implies community ownership and actions that explicitly target social and political change, and therefore contrasting discrimination. In the figure below by Guo (2020), we can see why and how HL is linked with personal and social determinants and influenced by different environments and individual characteristics through the entire course of life.

In summary, in conceptualising the relationship between HL, health inequalities and human rights with regard to the determinants of health, **three different levels** should be taken into

account: the *individual* level, the *community* level, and the *organisational/institutional* level, throughout the entire course of life.

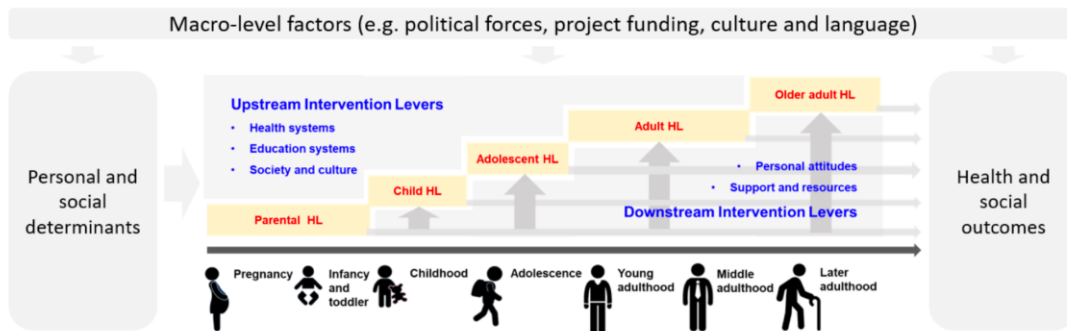


Figure 1: Health literacy and equity (Source: Guo S et al, *Moving Health Literacy Research and Practice towards a Vision of Equity, Precision and Transparency, Int. J. Environ. Res. Public Health*, 2020).

Regarding the commercial determinants of health, the situation is quite different. Only a few international “players” influence the greater part of the behavioural choices that individuals can make apparently on their own willingness, especially in specific sectors as tobacco, food, drinks, (West and Marteau, 2013; Gilmore, 2023). The pressure exerted through channels of information and publicity leaves little space to individual choices, especially among people and groups in vulnerable situations, that is those persons with the lowest level of HL. Ilona Kickbush (2016) identifies four private sector action channels which play a great role on individuals’ health and healthcare: marketing; lobbying activities; the implementation of corporate social responsibility policies; and the massive and progressive extension of distribution chains. The World Health Organisation stated that commercial determinants drive inequities (WHO, 2023).



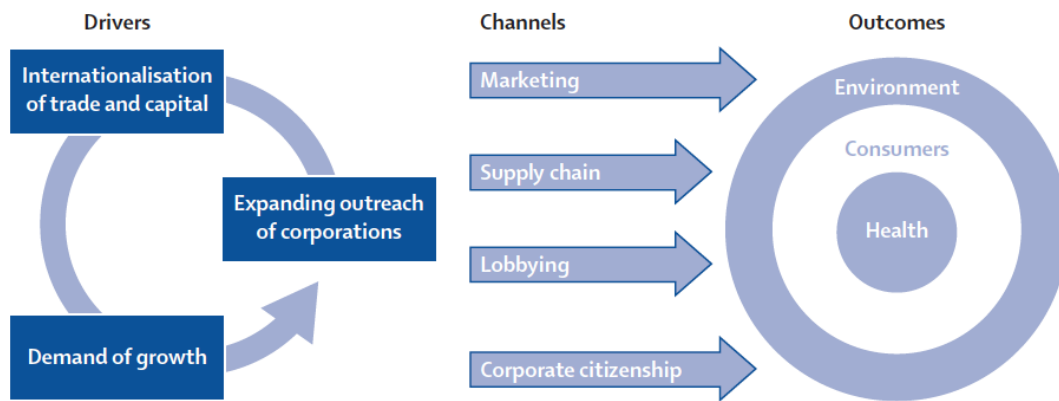


Figure 2: Dynamics that constitute the commercial determinants of health (Source: Kickbusch, Ilona et al., *The commercial determinants of health. The Lancet Global Health, 2016; 4(12): e895 - e896*).

By combining the potential harmful effects of both social and commercial determinants of health we can conclude that HL is a resource and a value for life and well-being, and therefore must be protected, implemented and warranted across the whole life course, in the same way as human rights. In this sense, HL can become a powerful tool to exercise and safeguard human rights for all.

## PRIORITIES

HL development is crucial in order to reduce inequality and combat discrimination. It involves how health professionals, services, systems, organisations, and policymakers (across various government sectors and through cross-sectoral public policies) empower individuals, families, groups, and communities by creating supportive environments (Osborne, 2021). In fact, these environments help people access, comprehend, evaluate, recall, and apply health-related information through verbal, written, digital, and other communication channels, as well as social resources, to support their health and well-being and of those around them, within the context of their daily lives. Numerous stakeholders can contribute to enhancing HL in various settings, as they contribute to generating or disseminating information and knowledge. They should also be key elements in guaranteeing the goal of universal access to reliable health and healthcare information.

In particular, the most important settings in creating a health literate environment are: healthcare; education; community; workplace; media and communication; market and private sector. The following figure provides a detailed overview of the various stakeholders in the diverse settings.



*Figure 3: Major stakeholders involved in health literacy (Source: Kickbusch I et al. "Health Literacy: The Solid Facts–World Health Organisation." (2013). Adapted from: Mitic W, Rootman I. An intersectoral approach for improving health literacy for Canada; a discussion paper. Vancouver, Public Health Association of British Columbia, 2012.)*

### Health literacy in healthcare, and beyond

Universal access to reliable healthcare information is implicit in the World Health Organisation’s (WHO) Constitution. However, there is still a lack of high-level political and financial commitment to this goal: lack of availability and use of reliable healthcare information is arguably a neglected global health issue and a major cause of avoidable death and suffering. According to Coleman (2023), the lack of clear communication practices in healthcare can act as a form of systemic racism, as it disproportionately disadvantages those with lower HL. This structural inequity is not widely acknowledged, yet has significant implications for access to care and outcomes among racial minorities. Enhancing organisational HL could be an effective strategy to lessen the effects of discrimination (Bather, 2024).

HL can help find the way to counteract against odds in access to, as well as in the continuity of, care. To realise this, some key directions to follow are identifiable:

- the **relational dimension**: by training professionals in the different areas of health - physical, mental, social, but also educational and (partly) political/regulatory – especially in empathetic listening, caregiving relationships, promoting the empowerment of patients/caregivers, cultural diversity, and end-of-life care. That said, training in relational skills

cannot overlook the need to allocate adequate time for communication with patients/citizens/caregivers;

- the **structural dimension**: by creating care environments that meet and protect the social and healthcare needs of people and patients (e.g., physical accessibility, comfort, privacy, presence of family members/caregivers);
- the **organisational dimension**: by implementing solutions that tailor care processes to the demands of people, considered as individuals with specific needs, values, and expectations related to gender, age, and cultural background;
- and on **investing in Human Resources' HL**: by training healthcare and social professionals, we can also protect their physical and mental health so that they can better support people and reduce working stress.

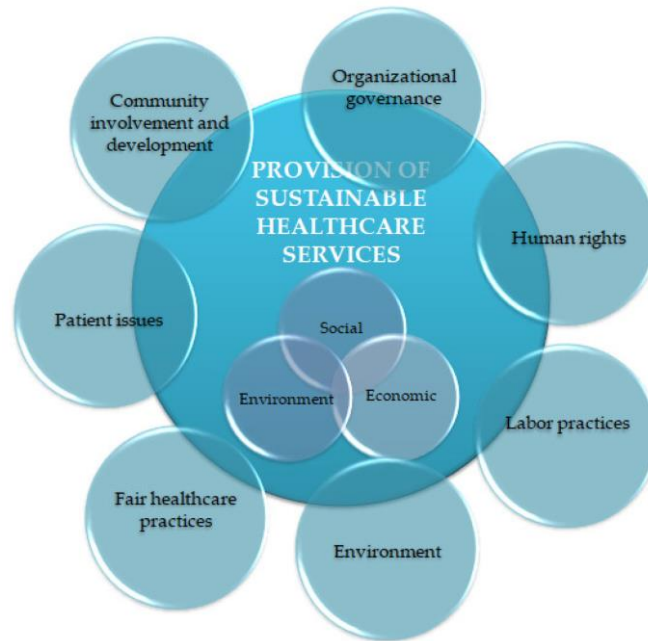
These directions represent trust in institutions at national, local and European levels. In the last few years, various crises (social, economic and political) have eroded public trust. This necessitates efforts to regain this trust in public authorities as democratic guardians to safeguard the protection of health which includes the defense of more fragile people and groups in vulnerable situations.

Recent crises (war, pandemic, etc) have provoked many misconceptions about health, notably by way of fake news, which raises many open questions:

- Health is not just about services and monitoring, and it is fundamental to act according to evidence-based solutions and risk stratification. The failure of periodic individual check-ups, and the rise of public health screenings testifies to the importance of a collective, community approach towards health. In this perspective, a fruitful strategy could include public health management developed in a co-creative perspective, involving each people and feeling him/herself co-responsible of the solutions adopted by the society;
- Health is dynamic which requires staying up-to-date with advancements in health and welfare, and defining new objectives driven by changes which are verified;
- Health is a question of public and private organisations, of political willingness, and the willingness and consciousness of every individual: promoting well-being, informing decision-making, developing/promoting awareness of one's health status at every life stage (and, if necessary, awareness of declining health), all of which is tied very closely to the exercise of human rights.

In the figure below, taken by Moldovan F et al, 2022, as an adaptation of the seven core subjects of the standard *ISO26000 - Social responsibility guidelines*, governance, human rights, labor,

environment, business practices, consumer and community interact altogether in a unique environment. In this context, HL can become the common “language” through which the different sectors can communicate on a common ground established by the right to health for all.



*Figure 4: Sustainable development in healthcare (Source: Moldovan F et al, An Innovative Framework for Sustainable Development in Healthcare: The Human Rights Assessment, Int. J. Environ. Res. Public Health 2022, 19, 2222).*

## Educational settings

Educational settings and entities play a crucial role in promoting human rights by improving HL, ensuring that individuals are equipped to make informed health decisions, advocate for their rights, and contribute to healthier, more equitable societies. In fact, at schools and universities, students can develop life skills, acquire knowledge and competence on health issues and human rights, including the right to health. Educational institutions can foster an understanding of how health is intertwined with dignity, equity, and justice. Educational entities can ensure that health education is inclusive, addressing the needs of all students, regardless of their background, ability, or socioeconomic status. This promotes equity and ensures that all students have the opportunity to achieve their right to health. Additionally, educational institutions can partner with healthcare providers, NGOs, and government agencies to bring health education and services to students and their communities. This extends the impact of health literacy beyond the classroom and into the wider community.

Transferring the concept of a health literate healthcare organization, a health-literate school optimizes processes, structures and frameworks in such a way that health literacy can be developed, practiced and enhanced within and through its setting. A health-literate school enables everyone involved in the school—students, school principals, teachers and non-teaching staff, parents and caregivers as well as persons in the extended school environment—to deal with and manage health information and to improve and reinforce health-literate behaviour (Kirchhoff S, 2022).

Finally, since HL should be developed throughout the life course, life-long learning is crucial in order to continually realign knowledge and skills with the demands and needs of a rapidly changing world. In this perspective, it is important to stress the role of public libraries as secure and trusted places for developing and promoting HL to different groups (Vassilakaki, 2023).

### The community level

The community is defined as a group of individuals who are linked by social ties, share common perspectives, and engage in joint action within a specific geographical area or within shared virtual spaces. In this context, a community serves as a critical unit for implementing health interventions and strategies aimed at improving public health outcomes. From the perspective of health promotion, a community setting focuses on leveraging the collective resources, knowledge, and strengths of community members to address health challenges. This approach emphasises community participation, empowerment, and the creation of supportive environments that foster healthy behaviours. In fact, people make daily health-related decisions in their homes and communities.

Community HL, refers to the collective ability of a community to obtain, process, and understand basic health information and services (Osborne, 2022). It includes: the knowledge that is held by people in the community; the extent to which knowledge is trusted, circulated and adapted freely in a community; health promoting customs embedded in cultural beliefs and norms, as well as in traditional or emerging practices of daily life; the relationships that the community has with outside sources of information. The way HL functions within a community context can influence the overall health outcomes, access to care, and the treatment of individuals within that community, thus significantly affecting human rights which can either reduce or – in case of lack - exacerbate discrimination.

Considering HL in a social context is important to building community-level HL in a sustainable way, including networks of organisations working together and the engagement of community

leaders to share trusted, community relevant health information in their professional and personal social networks (Sentell, 2023).

## The workplace

The workplace is a powerful setting for promoting HL, respecting human rights, and reducing discrimination. In particular, the development of workplace health programs and of health information strategies to provide access to information helps to generate a supportive environment for HL development. Workplaces are a strategic setting to promote human rights, reduce discrimination, and support a culture of inclusion. In this perspective, working leaders' commitment is essential.

## Media and communication

Since HL deals with health information, media and communication settings are strategic to the HL development, helping to promote human rights and avoiding discrimination.

HL and media literacy are not the same but are strictly correlated and interdependent. Within media literacy, digital media literacy has acquired a central role in information. As the role of digital media in disseminating information continues to grow, the balance between the complexity of digital information (e.g., content complexity, accessibility of reliable sources) and people's digital HL skills becomes increasingly crucial. From this perspective, it is expected that in the future the so-called digital divide could be reduced, as more individuals born in the era of the Internet and social networks come of age. However, this also risks creating "pockets" of disadvantaged people and groups in vulnerable situations, especially if advanced and powerful technologies become unaffordable or overly complex, particularly for older adults, who represent the fastest-growing segment of the population by age.

Finally, some private communication companies have recognized the importance of HL for commercial and marketing purposes and are specializing in creating effective, engaging, and evidence-based materials and programs.

## Market and private sector

The market and the private sector affect people's healthy choices because they influence the accessibility of products and the information about which types of behaviour or which products are healthy.

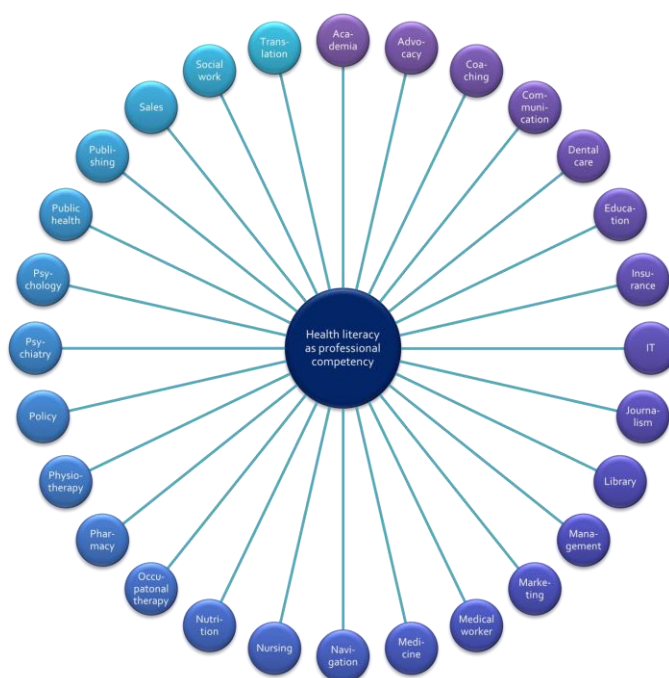
The involvement of the private sector in the development of individual and public HL is a sort of two-faced Janus. On the one side, it can help reach people in different settings thanks to its knowledge and abilities to persuade them and, following the rules of marketing, to effectively communicate specific contents of potentially great social value. On the other side, there is risk due to the fact that private companies do not have as their primary mission to pursue the interest of all the citizens, but - first and foremost - of their owners and stockholders. In this case, we are referring to the “pure”, for-profit, private sector, rather than the world of cooperation and NGOs, considered a sort of “leg” for the public authorities. In the past, such companies have not always demonstrated positive behaviour in the market sector regarding people’s health: paradigmatic is the pressure exerted by some food companies promoting junk food consumption, especially by leveraging specific communication channels devoted to fragile subgroups, such as children and people on low incomes, or the images and advertisements to symbolise success, wealth and desire (for example in acquiring and consuming alcoholic beverages). Market dynamics and industry targets are more aligned with profit than health goals, thus being able to engender health inequities by means of commercial determinants.

Conversely, companies also can make positive contributions to public health by promoting HL. For instance, they enhance access to essential medicines and health technologies, support the availability of safe, effective, high-quality, and affordable medical products, and reformulate products to reduce harm and risks. Examples include the introduction of seat belts, reducing salt content in foods, and working to eliminate trans fats from the global food supply. Additionally, some companies choose to divest from products and services detrimental to health (WHO, 2023).

Concluding, it is therefore necessary to establish a clear and transparent alliance to positively involve the private sector in advancing the public interest by means of promoting health via “good” communication strategies, namely the ones that positively impact on the health interests of citizens through health appropriate information.

## ACTIONS

HL can support people, (healthcare) organisations and political decisions in many ways. Nowadays HL can be considered a specific professional competency and resource in different working and living sectors (Sorensen, 2014). In the figure below, we can see how HL can be “spent” as a skill for capacity in different disciplines and job positions. HL has proven to be of relevance in many sectors, also beyond the healthcare sector which makes it relevant for many actors to get involved.



*Figure 5: Health literacy is a professional skill in a wide range of disciplines (Source: Sorensen K, Professionalizing health literacy: a new public health capacity: European Journal of Public Health, 2014, suppl\_2, October 2014, available at <https://doi.org/10.1093/eurpub/cku166.103>).*

In this perspective, different actions should be implemented, with different objectives.

A first objective concerns **how scientific communication can be understood and used by laypersons** to support self-care and prevention, promoting, therapeutic and rehab pathways. There are two main challenges in this regard: the first one, is that science must tell the truth every time, even when this truth is uncomfortable and difficult for people to tolerate; the second is how to communicate scientific evidence clearly and understandably. In practice, information must be reliable (Global Healthcare Information Network CIC, 2024). This is a practical, already existing, ground for HL.



In this perspective, it is important to promote effective and easy channels of communication between science, services, policies and people, which is “enlightened” by HL.

Therefore, key is to develop tools and strategies of *generative communication*: that is, a generative organisational process of communication between the “Top” (political as well as scientific or healthcare professionals) and the “Base” (individuals, community, patients), and also vice versa. The 'grammar' of such generative communication is founded in technical messages where the act of 'caring' and the pathway to do this should be consistently interpreted and understood by all the stakeholders - including citizens, patients, social or healthcare workers, as well as political representatives responsible for the design and the management of the health systems. Generative communication recognises that errors exist, not only in technical (preventive, diagnostic, or clinical) procedures but also in situations related to bureaucratic, financial and discrimination circumstances, accepts the errors and communicates how to overcome them.

For this reason, a society or an organisation which seeks to combat health inequities and promote human rights must adopt an organisational and communicative strategy that makes HL systematic allowing it to permeate decisions, actions, and relationships at all levels, across various fields, like a vital lifeblood that nourishes the essence of the organisation itself.

Another objective is linked to **how people can effectively navigate healthcare organisations and, more generally, all the services they need, when they need**. This is the basis of organisational HL, which should become a powerful competence of any professional who works in the field of public health. This requires deep reflection to see how to transfer this competence to health and social professionals. Themes like highlighting the pros and cons of every health-related decision, empowering individuals in the decision-making process, fostering the positive attitudes of individuals to take care of him/herself represent another fundamental (and practical, once more) ground for HL.

In this perspective, HL should be included in the study curriculum of any health and communication professional, and, more in general, as a matter of civil education in schools of any degree, with course rating the complexity of teaching on the basis of the age of learners. In this perspective, the training of the teachers is essential.

A third objective is **how people can surpass the barriers that prevent their access to services when they need**. People and groups are not always equal and can be subject to profound injustices in health.

In this perspective, the production of specific written guidelines, produced in co-creation with representatives of communities and co-managed by health authorities and citizens' organisations can explain how to access health and social services, navigating barriers that might exist. In realising the right to the protection of health and universal health care in a community, everyone belonging to that community must be informed, and be able to exercise this right.

## STAKEHOLDERS' COMPOSITION

Addressing HL requires diverse competencies at multiple levels of impact. The composition and active participation of the panel of stakeholders to be involved in HL refers to many different bodies, organisations and institutions. A preliminary, non-exhaustive list of stakeholders in the promotion of HL actions might be represented as follows:

- Healthcare and (public) Services Organisations:
  - representatives from some of the main hospital and territorial national facilities;
  - representatives from the main Scientific Societies involved in the management of healthcare services;
- Experts in communication (health communication, but not only);
- Representatives from the civil society (included patient associations);
- Representatives from voluntary organisations;
- Institutional/policy-makers representatives from different settings: Ministries (Health, Family, Equal Opportunities), regions, municipalities;
- Experts in Law, particularly in human rights protection;
- Representatives from Education and Higher Learning: National representatives (Ministry of Education and Universities); representatives from universities;
- Representatives from minorities: associations dedicated to protecting people and groups in vulnerable situations and/or fragile groups (i.e., minors, older persons, migrants, prisoners); CoE; UNAR (National Office Against Racial Discrimination);
- Journalists, representatives of the media (new and traditional).

In the following table, the stakeholders have been classified according to the settings they belong to, where they can exercise a major impact.

*Table 1: Health literacy relevance and representation regarding stakeholders and settings.*

<b>Stakeholders</b>	<b>Settings</b>
Healthcare and (public) Services Organisations	Healthcare, workplace
Experts in communication	Media and communication, healthcare
Representatives from the civil society	Community
Representatives from voluntary organisations	Community
Political representatives	Community
Experts in laws	Workplace, community
Representatives from Education and Higher Learning	Education, workplace
Representatives from minorities	Community
Journalists, representatives of the media	Media and communication

This core representation can guide processes and actions at more local levels, leading co-creation and co-management initiatives tailored to local contexts. It can support and empower local leaders by providing them with the appropriate guidance to realise initiatives within specific communities.

## TASKS

Exploring the relationship between HL and human rights can open up several meaningful pathways for discussion and action. The major directions to define the framework of the activities of a HL coalition are described as follows.

### Major directions

- Guarantee universal health information: since health information significantly influences our lives, achieving universal access to health information is a key element in safeguarding human rights. This includes disseminating information through appropriate channels (The Lancet Global Health, 2024).
- Combat any form of manipulation of information, including those for political consensus.
- Effectively communicate how to access health and social services based on what is needed and by whom.

- Explain which access barriers are partially removable (e.g., waiting lists) and which can be removed with proper access to necessary information.
- Diverse and Emerging Needs: as users' demographic characteristics diversify, new needs arise, such as those related to different forms of discrimination.
- Develop a monitoring and reporting system which warrants that all the above cited directions can be pursued and to analyse the potential deviations from the established objective.

The specific themes and tasks to be addressed by the core group of stakeholders to promote HL are described below. Of course, this is a tentative and not exhaustive list.

### Specific themes and tasks

#### 1. Health Literacy as a Fundamental Human Right/Human Rights concern

- Promoting HL as a human right (or, as a fundamental component to realise the right to health for all): advocate for the recognition of HL as a fundamental human right. The ability to access, understand, and use health information empowers individuals to make informed decisions about their health, which is essential to claim and warrant the right to health itself.
- Integration HL into legal frameworks: encouraging the incorporation of HL into national and international human rights frameworks, emphasizing that governments have the duty to ensure that all citizens can achieve a basic level of health literacy.

#### 2. Empowerment through HL

- Informed Decision-Making: HL enables individuals to make informed choices about their health, which is a core aspect of personal autonomy and freedom—a key principle in human rights. Educating people about their rights within healthcare systems (and other systems) can empower them to demand better services and avoid exploitation or neglect.
- Access to Information: emphasising that access to clear, accurate, and culturally appropriate health information is a human right *per se*. This ensures that all people, regardless of their background or education level, can make decisions that align with their values and needs.

### 3. Equity and HL

- **Addressing Disparities:** focus on how disparities in HL contribute to broader health inequities. Populations with lower HL often experience worse health outcomes, which can exacerbate social and economic inequalities. Framing HL as a human rights issue highlights the need for equitable access to education and resources.
- **People and groups in vulnerable situations:** Prioritize HL initiatives that target certain populations and marginalized communities. These groups often face barriers to health information and services, making the promotion of HL an essential tool for safeguarding their rights.

### 4. HL in Public Health Policy

- **Policy Development:** advocating for HL as a cornerstone of public health policy development. Governments should ensure that health communication is designed to be accessible to all citizens, regardless of their literacy levels or cultural background.
- **Human Rights-Based Approach to Health Communication:** this encourages a human rights-based approach to health communication, where policies are designed to respect, protect, and fulfill the right to health by making health information accessible and understandable.

### 5. Global HL Initiatives

- **International Collaboration:** promote global cooperation to improve HL, particularly in low- and middle-income countries. International organisations can play a crucial role in supporting countries to build HL as part of their broader human rights obligations.
- **Universal Health Coverage (UHC):** tie HL to the achievement of UHC by ensuring that individuals can understand and navigate healthcare systems. This is crucial to realising the human right to health, as outlined in various international human rights treaties. Universal access to health information is essential to achieving universal health coverage and the other health-related targets.

### 6. Legal Recourse and Health Literacy

- **Legal Protections:** explore the role of legal protections to ensure HL. For example, laws that require healthcare providers to communicate in plain language or offer interpretation services can help bridge the gap between HL and human rights.

- **Accountability Mechanisms:** develop accountability mechanisms that hold governments and institutions accountable for failing to provide adequate health literacy resources. This can include the right to redress when health information is not made accessible.

## 7. Cultural Sensitivity and HL

- **Respect for Cultural Diversity:** highlight the importance of cultural sensitivity in health communication. Ensuring that health information respects and reflects cultural differences is not only a matter of health literacy but also a fundamental aspect of respecting human rights.

## 8. HL in Crises Situations

- **Humanitarian Crises:** focus on the critical role of HL in humanitarian crises, where access to accurate health information can be a matter of life and death. Ensure that emergency responses include strategies to provide clear and accessible health information to affected populations.
- **Pandemic Response:** discuss the importance of HL in responding to pandemics, where misinformation can spread rapidly. A human rights approach would require governments to prioritize accurate, understandable communication as part of their public health strategy.

These ideas can form the basis of a comprehensive exploration of how HL intersects with human rights, emphasising the importance of ensuring that all people have the knowledge and resources they need to live healthy lives.

## EXAMPLES OF ALLIANCE/COALITION IN THE FIELD OF HEALTH LITERACY

To take the HL agenda forward and to gather momentum, it is recommended to establishing multi-sector alliances or networks. As reported by EVPOP Guide (Health literacy policies – how can they be developed and implemented? A guide for policy and decision makers, M-POHL 2023), in a few countries, national HL platforms, alliances, networks, associations or working groups already exist, sometimes even networks and associations alongside each other. They can be governmental only or act as partnerships between public agencies and private organisations as well as NGOs. They can have a focus on research and/or policy and/or practice.

National alliances, platforms and networks exist, for example, in Austria, the Czech Republic, Denmark, Germany, the Netherlands, Norway, Portugal, Spain, Sweden, Switzerland and the UK.

The development of networks and alliances is an organic and individual process in each country, differing in scope and focus. However, these structures have an important part to play in terms of HL improvement as they often serve as a platform where insights from research and practice on health literacy improvement can result in joint ideas for projects and policy initiatives.

Herewith some examples of existing alliances.

***Austria: the Austria health literacy alliance***

In 2015, the Austrian Alliance for Health Literacy began its work, establishing a “core team” as its decision-making body. This team includes members from the federal government, federal states, social insurance institutions, and partners from the Health in All Policies (HiAP) initiative. It is chaired by a representative from the Austrian Federal Ministry of Social Affairs, Health, Care, and Consumer Protection. The Alliance’s Coordination Center supports the core team and serves as a knowledge hub. Members of the Alliance consist of organisations or individuals whose activities and projects support Health Target 3 of the SDGs, Good Health and Well-being. To advance the priorities of Health Target 3, the Alliance undertakes the following tasks:

- supporting sustainable development and the promotion of health literacy in Austria
- fostering networking, collaboration, and knowledge sharing
- coordinating measures across various political and social sectors
- promoting a common understanding of health literacy, disseminating knowledge, and facilitating innovation
- establishing monitoring and reporting processes to ensure transparency and quality
- areas of focus.

To improve the HL of the population, intersectoral working groups have been established to develop guidelines, tools, and activities. In this context, the Alliance has defined five areas of focus:

- high-quality health information
- quality communication in healthcare
- health-literate organisations
- empowerment of citizens and patients
- measuring HL.

Examples of tools and activities developed by these working groups include, but are not limited to: criteria for enhancing written and audio information; a national training program for healthcare providers; self-assessment tools for organisations; and adaptation of the “Ask Me 3”

program. Additionally, the working group on health literacy measurement conducted the Austrian Health Literacy Survey (HLS 19-AT) and developed recommendations for strengthening health literacy in Austria.

For more information: <https://oepgk.at/english-summary/>

### ***Czech Republic: Alliance for health literacy***

The Alliance for Health Literacy is a volunteer coalition of doctors, healthcare providers, educators, schools, researchers, media representatives, public administrators, patients, and other citizens, along with various organisations and institutions. The Alliance is coordinated by the Institute for Health Literacy, which serves as its administrative base. Established as a non-profit organisation in 2017 following the implementation of the National Strategy for Health Protection and Promotion, the Institute aims to enhance health literacy among the Czech population. Since 2018, the Institute has closely collaborated with the Ministry of Health and the Czech Medical Society. The Alliance's primary goal is to improve communication between citizens and public administrators, between patients and healthcare professionals, and among all stakeholders working together to identify key HL challenges and develop effective solutions. It focuses on spreading information about health literacy and reinforcing its importance in healthcare. The Alliance gathers and shares knowledge, showcases best practices, and evaluates outcomes at seminars and conferences. In research and evaluation, it highlights the positive impact of HL on both individual health and well-being, as well as the economic benefits of a healthy society.

For more information: [www.uzg.cz](http://www.uzg.cz)

### ***Colorado: Health literacy coalition***

The Colorado Health Literacy Coalition promotes HL by providing resources, training and best practices through collaboration with organisations across the state. It is formed by a group of experts that have come together to promote health literacy in the state of Colorado, with the primary goal to assist those in the community with health navigation, promote wellness, and achieve quality outcomes. Members are representatives from Science library, University and school, Healthcare setting (Children's hospital, Kaiser Permanente, UC Health), Mercy Housing Corporation.

For more information: <https://www.healthliteracycolorado.org/>



### ***Pennsylvania: Health literacy coalition***

In 2014, the Pennsylvania Department of Health funded the statewide coalition on health literacy (the Pennsylvania Health Literacy Coalition - PAHLC). The Health Care Improvement Foundation serves as the lead organisation for the PAHLC. Major PAHLC priorities to date include establishing strong cross-sector partnerships, empowering patients to access the health information they need to thrive, and influencing provider and system-level change to create a culture of health literacy. The ultimate goal of these activities is to improve health communication and ensure good health for all. Healthcare professionals, patients, and community groups are members of the coalition and, using a collaboration approach, build infrastructure for health literacy training and create a culture of health literacy in Pennsylvania

For more information: <https://healthliteracypa.org/>

### ***The Dutch Health Literacy Alliance***

In the Netherlands, the Dutch Health Literacy Alliance was established as a spin-off from the HLS-EU study to bridge the health literacy gaps identified in the results.

Financed by the Dutch Ministry of Health, it is organised in “Inspiration Groups”, each of them dealing with specific themes:

- Inclusiveness and participation
- Professional Training and Education
- Scientific Research
- Hospitals and clinics
- Language makes you healthier
- Digital healthcare applications
- Health Literate municipal health services.

For more information: <https://www.gezondheidsvaardigheden.nl/>

At international level, several networks and associations have been formed based on formal and non-formal collaboration.

### ***Health Literacy Europe***

Health Literacy Europe was launched during the European Health Forum Gastein in Austria, October 2010 as a sustainable platform for advancing HL in Europe through knowledge exchange and networking at national, regional and international levels. The network is a spin-off of the

European Health Literacy project, which took place from 2009-2012. It has hosted four European Health Literacy Conferences and has approximately 2500 members in the network.

<https://www.healthliteracyeurope.net/>

### ***Asian Health Literacy Association***

The Asian Health Literacy Association (AHLA), an independent multinational non-governmental organization, is established for pursuing and promoting best practices and research in HL in Asia. In AHLA, practitioners, researchers and policy makers work together to develop strenuous numerous strategies to promote HL, with the ultimate goal to reduce health disparities and enhance healthcare quality. Through public education and research, they jointly develop good practices in health literacy and support relevant policy development.

AHLA supports dialog at all levels in the communities, groups and nations, encouraging patients, clinicians, health administrators, health service providers and policy makers discuss the importance of health literacy in health care systems and work together to resolve problems and handle challenges in health care practices. AHLA also supports multi-national research and national specific investigations. Sharing experiences and research findings in HL is the key. The AHLA members advocate collaborations for HL among all stakeholders in Asian countries.

<https://www.ahla-asia.org/>

### ***International Health Literacy Association***

The International Health Literacy Association (IHLA) is a non-governmental, not-for-profit, member-based organization, passionate about HL. The members are dedicated to creating an international voice for HL and raising awareness world-wide. Representing a multi-dimensional international organization, the organizational structure of IHLA is designed to promote a decentralized balance of power, foster accountability as well as high-level academic and professional practice standards and reinforce initiative and peer interaction, and enhance the standing of the health literacy field. It represents members from more than 50 countries.

<https://www.i-hla.org>

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## References

Bather JR, Cuevas AG, Harris A, Kaphingst KA, Goodman MS. Associations between perceived discrimination over the life course, subjective social status, and health literacy: A racial/ethnic stratification analysis. *PEC Innov.* 2024 Aug 20;5:100334. doi: 10.1016/j.pecinn.2024.100334. PMID: 39257628; PMCID: PMC11384512.

Coleman C, Birk S, DeVoe J. Health Literacy and Systemic Racism-Using Clear Communication to Reduce Health Care Inequities. *JAMA Intern Med.* 2023 Aug 1;183(8):753-754. doi: 10.1001/jamainternmed.2023.2558. PMID: 37358860

Council of Europe, 2023, Guide to Health Literacy contributing to trust building and equitable access to healthcare, available at <https://rm.coe.int/inf-2022-17-guide-health-literacy/1680a9cb75>

Gilmore AB, Fabbri A, Baum F, Bertscher A, Bondy K, Chang HJ, Demaio S, Erzse A, Freudenberg N, Friel S, Hofman KJ, Johns P, Abdool Karim S, Lacy-Nichols J, de Carvalho CMP, Marten R, McKee M, Petticrew M, Robertson L, Tangcharoensathien V, Thow AM. Defining and conceptualising the commercial determinants of health. *Lancet.* 2023 Apr 8;401(10383):1194-1213. doi: 10.1016/S0140-6736(23)00013-2. Epub 2023 Mar 23. PMID: 36966782.

Global Healthcare Information Network CIC, A report for the World Health Organisation, Universal access to reliable healthcare information: A global consultation. 2024 (available at [https://www.hifa.org/sites/default/files/articles/HIFA-WHO\\_report\\_final.pdf](https://www.hifa.org/sites/default/files/articles/HIFA-WHO_report_final.pdf))

Godlee F., What is health? *BMJ.* 2011;343:d4817 doi: 10.1136/bmj.d4817

Gilmore AB, Fabbri A, Baum F, Bertscher A, Bondy K, Chang HJ, Demaio S, Erzse A, Freudenberg N, Friel S, Hofman KJ, Johns P, Abdool Karim S, Lacy-Nichols J, de Carvalho CMP, Marten R, McKee M, Petticrew M, Robertson L, Tangcharoensathien V, Thow AM. Defining and conceptualising the commercial determinants of health. *Lancet.* 2023 Apr 8;401(10383):1194-1213. doi: 10.1016/S0140-6736(23)00013-2. Epub 2023 Mar 23. PMID: 36966782.

Guo S, Yu X, Okan O. Moving Health Literacy Research and Practice towards a Vision of Equity, Precision and Transparency. *Int J Environ Res Public Health.* 2020 Oct 20;17(20):7650. doi: 10.3390/ijerph17207650. PMID: 33092206; PMCID: PMC7589069.

Huber M, Knottnerus JA, Green L, van der Horst H, Jadad AR, Kromhout D, Leonard B, Lorig K, Loureiro MI, van der Meer JW, Schnabel P, Smith R, van Weel C, Smid H. How should we define health? *BMJ.* 2011 Jul 26;343:d4163. doi: 10.1136/bmj.d4163. PMID: 21791490.

Kickbusch I et al. "Health Literacy: The Solid Facts–World Health Organisation." (2013). Adapted from: Mitic W, Rootman I. An intersectoral approach for improving health literacy for Canada; a discussion paper. Vancouver, Public Health Association of British Columbia, 2012.

Kickbusch I, Allen L, Franz C. The commercial determinants of health. *Lancet Glob Health*. 2016 Dec;4(12):e895-e896. doi: 10.1016/S2214-109X(16)30217-0. PMID: 27855860.

Kickbusch I, Pelikan JM, Apfel F, Tsouros AD, Health Literacy: The Solid Facts. 2013, World Health Organisation.

Kirchhoff S, Dadaczynski K, Pelikan JM, Zelinka-Roitner I, Dietscher C, Bittlingmayer UH, Okan O. Organisational Health Literacy in Schools: Concept Development for Health-Literate Schools. *Int J Environ Res Public Health*. 2022 Jul 20;19(14):8795. doi: 10.3390/ijerph19148795. PMID: 35886647; PMCID: PMC9316432.

Lastrucci V, Lorini C, Caini S; Florence Health Literacy Research Group; Bonaccorsi G. Health literacy as a mediator of the relationship between socioeconomic status and health: A cross-sectional study in a population-based sample in Florence. *PLoS One*. 2019 Dec 23;14(12):e0227007. doi: 10.1371/journal.pone.0227007. PMID: 31869381; PMCID: PMC6927637.

M-POHL (2023): Health literacy policies – how can they be developed and implemented? A guide for policy and decision makers. International Coordination Center of M-POHL at the Austrian National Public Health Institute, Vienna (available at <https://m-pohl.net/ResultsEVPOP>)

Mitic W, Rootman I. An intersectoral approach for improving health literacy for Canada; a discussion paper. Vancouver, Public Health Association of British Columbia, 2012.

Moldovan F, Blaga P, Moldovan L, Bataga T. An Innovative Framework for Sustainable Development in Healthcare: The Human Rights Assessment. *Int J Environ Res Public Health*. 2022 Feb 16;19(4):2222. doi: 10.3390/ijerph19042222. PMID: 35206410; PMCID: PMC8872572.

Osborne RH, Elmer S, Hawkins M, Cheng C (2021). The Ophelia Manual. The Optimising Health Literacy and Access (Ophelia) process to plan and implement National Health Literacy Demonstration Projects. Centre for Global Health and Equity, School of Health Sciences, Swinburne University of Technology, Melbourne, Australia.

Osborne RH, Elmer S, Hawkins M, Cheng CC, Batterham RW, Dias S, Good S, Monteiro MG, Mikkelsen B, Nadarajah RG, Fones G. Health literacy development is central to the prevention and control of non-communicable diseases. *BMJ Glob Health*. 2022 Dec;7(12):e010362. doi: 10.1136/bmjgh-2022-010362. PMID: 36460323; PMCID: PMC9723891.

Pelikan JM, Ganahl K, Roethlin F. Health literacy as a determinant, mediator and/or moderator of health: empirical models using the European Health Literacy Survey dataset. *Glob Health Promot.* 2018 Nov 14;1757975918788300. doi: 10.1177/1757975918788300. Epub ahead of print. PMID: 30427258.

Rowlands G, Shaw A, Jaswal S, Smith S, Harpham T. Health literacy and the social determinants of health: a qualitative model from adult learners. *Health Promot Int.* 2017 Feb 1;32(1):130-138. doi: 10.1093/heapro/dav093. PMID: 28180257.

Sentell T, Saiki K, Abrams MA, Jones A, Melendez K, Chevrolet J, Roman M, Barnes J, Patterson E. Building Community Health Literacy with a Social Network Perspective. *Eur J Public Health.* 2023 Oct 24;33(Suppl 2):ckad160.048. doi: 10.1093/eurpub/ckad160.048. PMCID: PMC10595466.

Sorensen K, Professionalizing health literacy: a new public health capacity: *European Journal of Public Health*, 2014, suppl\_2, October 2014, available at <https://doi.org/10.1093/eurpub/cku166.103>

The Lancet Global Health. Contemporary challenges to health information for all. *Lancet Glob Health.* 2024 Sep;12(9):e1370. doi: 10.1016/S2214-109X(24)00336-X. PMID: 39151961.

Vassilakaki, E., Moniarou-Papaconstaninou, V. Librarians' support in improving health literacy: A systematic literature review. *Journal of Librarianship and Information Science.* 2023; 55(2), 500-514.

West, R · Marteau, T, Commentary on Casswell: the commercial determinants of health, *Addiction.* 2013; 108:686-687

World Health Organisation, 2023. Commercial determinants of health. <https://www.who.int/news-room/fact-sheets/detail/commercial-determinants-of-health>.

Accessed 14/11/2024